Dear Commissioners

Thank you for the opportunity to participate in this Inquiry.

I am 81 years of age – my son is 53 years and I am his sole carer.

1. We both have a case manager from Anglicare, Penrith, NSW 2750

2. Respite is presently given by The House With No Steps which is funded by the Federal Government under the Older Carers Respite Package (as far as I know). This is 4 hours per fortnight. This respite is allocated on a yearly basis upon application to the Respite Intake Allocation Programme (RIAP). I have no idea how much money is allocated to him and how the money is being spent or if it isn't spent, what happens to it. I am unable to say with certainty which government, Federal or State is funding this project. The "cogs in the wheel" are not transparent. As my son doesn't participate in any activities with the respite worker the worker becomes a friendly visitor to the home. There is little else that can be done apart from giving me the opportunity to leave the house for that period of time. It doesn't always suit me to go out at that particular time. As for participation in the community it is a complete waste of government money but keep hoping for a breakthrough i.e. that he may one day want to leave the house.

3. My son is on ADHC's register for Supported Accommodation and has received the services of a Speech Pathologist during 2009 due to an eating disorder and accompanying low speech. I was contacted on 22nd March 2010 for the delivery of further speech and eating disorder therapy.

4. Because of my son's Agoraphobia, he is unable to leave the house thus the necessity for In Home Respite. With Self-Directed Funding the Respite Money could go towards his future Accommodation Needs when I'm no longer able to look after him.

5. **In "Planning for the Future" I would like Graham to have access to funding to purchase his appropriate level of care and support, preferably Individualised/ Direct Funding whether it is under the present funding system or the proposed National Disability Insurance Support Scheme or other manner of funding. Paid support could supplement any unpaid support via a homesharer or house mate or just someone to sleep over at night living rent free or at least pay low rent. This presents the problem of screening/monitoring/suitability/compatibility. Graham is a loner and is very family orientated. Rather than 24 hours paid hours he may only need 8 or 10 hours which would be a much cheaper option for Governments in the long run. This is an approach which could be considered by Governments. The main benefit is that by being person centred, a self directed approach can deliver more flexible and appropriately targeted services that make a difference in the lives of people with disability and their families. At the same time, it can lead to better utilisation and effectiveness of limited resources. All people must be given the authority and the support to direct the resources targeted to their assistance. Key strategies to enhance the opportunity for success of a self directed approach include: a spectrum of funding, planning and support options in which the person with disability can choose the level of responsibility and that level of responsibility can change over time; government funded mechanisms that can be accessed by the person with disability and their family to assist them to plan and implement supports; capacity building for people with**

disability and families to assist them to take advantage of the opportunities presented by a self directed approach; support for and commitment to, service transformation.

ATTACHMENTS

The data below is significant to the way in which my son could be supported in the future.

The following was in the Australian Government's Media Release in 2008. In spite of the $1.9 billion to provide more than 24,000 places in supported accommodation, the crisis in New South Wales still remains.

"In May, the State, Territory and Federal Disability Ministers agreed to a $1.9 billion package to provide more than 24,000 places in supported accommodation, respite and in home care.

This comprised $100 million for supported accommodation, $901 million for accommodation, respite and in home care from the Australian Government and $900 million from the States. This funding will be incorporated into the new National Disability Agreement.

COAG agreed to undertake further work on roles and responsibilities in community based care over the coming year."

National Disability Agreement

Continuing a strong commitment to people with disability

The National Disability Agreement between the Australian Government and State and Territory Governments will improve and increase services for people with disability, their families and carers.

The agreement reflects a strong commitment from both levels of government to provide more opportunities for people with disability to participate in and enjoy Australia's economic and social life.

The new agreement is designed specifically to assist people with disability to live as independently as possible, by helping them to establish stable and sustainable living arrangements, increasing their choices, and improving their health and wellbeing. At the same time, the agreement focuses on supporting families and carers in their caring roles.

The Parties have agreed to concentrate initial national efforts in several identified priority areas to underpin the policy directions and achieve reforms in the disability service system. They are:

1. Better Measurement of Need – Under this priority: a national model to estimate demand will be developed by mid 2010; there will be improvements in the data collected through the Survey of Disability, Ageing and Carers (SDAC), which will provide a stronger basis for demand estimates; and improvements in the quality of data reported under the National Minimum Data Set, and jurisdiction-level unmet demand data.

2. Population Benchmarking for Disability Services – A National Population Benchmarking Framework will be developed and initial population benchmarking of disability services, based on information available, will be achieved by mid 2010 and improve the evidence base to assist in policy, service and planning decisions.

3. Making Older Carers a Priority – The National Disability Priorities Framework will assist Governments to target services to more vulnerable population groups based on relative need (including older carers and Indigenous people with disability).

4. Quality Improvement Systems based on Disability Standards – A National Disability Quality Framework with a National Quality Assurance system for disability services will be developed to introduce a national approach to quality assurance and the continuous improvement of disability services by mid 2010.

5. Service Planning and Strategies to Simplify Access – The National Framework for Service Planning and Access will be developed, focussing on providing a person centred approach to service delivery and to simplify access to specialist disability services.

6. Early Intervention and Prevention, Lifelong Planning and Increasing Independence and Social Participation Strategies – An Early Intervention and Prevention Framework will be developed to increase Governments' ability to be effective with early intervention and prevention strategies and to ensure that clients receive the most appropriate and timely support by mid 2011.

7. Increased Workforce Capacity – A national workforce strategy will be developed to address qualifications, training and cross sector career mapping issues and establishing the disability sector as an 'industry of choice' by the end of 2010.

8. Increased Access for Indigenous Australians – A National Indigenous Access Framework will ensure that the needs of Indigenous Australians with disability are addressed through appropriate service delivery arrangements.

9. Access to Aids and Equipment – More consistent access to aids and equipment by end of 2012.

10. Improved Access to Disability Care – Systems that improve access to disability care and ensure people are referred to the most appropriate disability services and supports, including consideration of single access points and national consistent assessment processes in line with nationally agreed principles by end 2011.

Allocating record levels of Australian Government funding

On 29 November 2008, the Council of Australian Governments (COAG) met to discuss the new financial framework and specific purpose payment reforms. COAG agreed to a new National Disability Agreement to improve and expand services for people with disability, their families and carers.

Under the new Agreement, the Commonwealth will provide more than $5 billion in funding over five years to the States for specialist disability services. The Agreement means that in 2013 the Australian Government's contribution will exceed $1.2 billion, compared to $620 million in 2007.

Outside the agreement, the Australian Government in 2009-10, will provide a projected $11.6 billion for the Disability Support Pension and $3.9 billion in payments to carers of older people, children and people with a disability and more than $600 million for services for people with disability, including employment services.

Funding previously provided through the CSTDA by the Australian Government and state and territory governments

Starting the new agreement

The National Disability Agreement came into effect on 1 January 2009 and replaces the existing Commonwealth State Territory Disability Agreement.

Memorandum of Understanding for $100 Million Investment in Supported Disability Accommodation

On 4 May 2008 the Prime Minister and Minister for Families, Housing, Community and Indigenous Affairs jointly announced the investment of $100 million in capital funds for supported accommodation.

The funding has been distributed to State and Territory Governments on a potential population basis, with no requirement for matched funding.

This funding will be used to establish new supported accommodation facilities for people with disability.

Capital Works Funding Memorandum of Understanding

Transfer of Administrative Responsibilities of Disability Assistance Package $901 million, Targeted Support and Transition Support Services

On 30 May 2008, Disability Ministers agreed that the $901 million being offered by the Commonwealth to the States and Territories will be distributed on a disability potential population basis and will be matched by State and Territory Governments. All jurisdictions also agreed to continue to share information and work cooperatively in identifying opportunities to improve support services for people with disability with the $1.8 billion total in funding.

The Australian Government has signed individual agreements with each State and Territory Government. There are three separate elements to these Bilateral Agreements, they are:

1. the transfer of the $901 million component of the former Government's Disability Assistance Package;
2. the novation of funding agreements for respite capacity building; and
3. the transfer of administrative responsibility for the delivery of targeted support services.

Agreements have been reached as follows:

- Australian Government and Australian Capital Territory Government Bilateral Agreement
- Australian Government and New South Wales Government Bilateral Agreement
- Australian Government and Northern Territory Government Bilateral Agreement
- Australian Government and Queensland Government Bilateral Agreement
- Australian Government and South Australian Government Bilateral Agreement
- Australian Government and Tasmanian Government Bilateral Agreement
- Australian Government and Victorian Government Bilateral Agreement
- Australian Government and Western Australian Government Bilateral Agreement

Community and Disability Services Ministers' Advisory Council

The Community and Disability Services Ministers' Advisory Council (CDSMAC) is an official forum of senior Commonwealth, State and Territory Disability officials who discuss nationally significant disability policy issues that are relevant to the provision of specialist disability services. They advise Ministers on matters pertaining to the services covered by the National Disability Agreement.

Community and Disability Services' Ministers Conference

The Community and Disability Services' Conference provides a forum for the Australian Government, State and Territory Governments, and the Government of New Zealand, to discuss matters of mutual interest concerning community, families and disability services policy and programs. They consider matters reported to the Conference by CDSMAC and Disability Policy Research Working Group.

Research and development

Under the National Disability Agreement, the Australian, State and Territory Governments have agreed to contribute to a total of $10 million over 5 years for disability research, data and evaluation. The Disability Policy and Research Working Group will maintain overall responsibility for the research, data and evaluation agenda under the Agreement and will set the Research Agenda in line with the Agreement's reform priorities.

Quotes from many jurisdictions in support of Individualised Funding :

Moving to a self directed approach February 2010 1 (Family Advocacy)

Moving to a Self Directed Approach

Introduction

An individualised or self directed approach to providing services and supports to people with disability is being adopted by many jurisdictions, both within Australia and internationally. The main benefit is that by being person centred, a self directed approach can deliver more flexible and appropriately targeted services that make a difference in the lives of people with disability and their families. At the same time, it can lead to better utilisation and effectiveness of limited resources.

Family Advocacy believes that all people with disability and their families must have the choice to use a self directed approach. All people must be given the authority and the support to direct the resources targeted to their assistance.

Key strategies to enhance the opportunity for success of a self directed approach include:

a spectrum of funding, planning and support options in which the person with disability can choose the level of responsibility and that level of responsibility can change over time;

government funded mechanisms that can be accessed by the person with disability and their family to assist them to plan and implement supports;

capacity building for people with disability and families to assist them to take advantage of the opportunities presented by a self directed approach;

support for and commitment to, service transformation.

What is an individualised or self directed approach?

An individualised or self directed approach places the individual at the centre of decision making and treats family members as partners. The process focuses on discovering the person’s skills and capacities, and on identifying the priorities of the person in terms of their hopes, goals and lifestyle choices.

A self directed approach is underpinned by the values of independence, choice and social inclusion and is designed to enable people to direct their own services and supports rather than attempting to fit within pre-existing service systems.

Core elements of a self directed approach include:

self directed planning: planning that is personalised and directed by the person and their family/support network or in the case of children, is family centred;

self directed funding: funding that allocates resources to the individual and their family/support network early in the process to enable the design and identification of supports that are flexible and responsive to individual needs;

self directed support: support in which a combination of formal and informal, public and privately provided services and supports are coordinated to deliver the best outcomes in response to the individual’s circumstance.

Why we must move to a self directed approach

It is better for people with disability

For too long, the quality of life of people with disability and their families has been outside their control, seemingly dependant on the whim of politicians, bureaucrats and services providers. The support, when given, has come from a list of prescribed responses, often created in isolation from the people who would be the recipients of the support.

People with disability and their families know what they need to thrive. They need control over the ‘what, when, where and by whom’ of support so that they can use the resources effectively to reawaken a dream, ‘have a life’ and move toward a goal. A self directed approach places people in the driver’s seat of their own lives rather than sees them as recipients of care.

The current system is not sustainable

Australian society has a commitment to ensure that people in need are not left without support. The sustainability of the existing system is however, challenged by changing demographics and expectations.

Demographic changes mean that all people, including people with disability are living longer. Advances in medical knowledge and practice mean that people who may not have survived in the past are living, sometimes, with very high support needs. In response, the demand for services is increasing.

The ‘system’ has encouraged and then reinforced dependence on government, teaching the paradigm of relief of burden. A new generation of families however, has a different set of social values. They see their family member with disability as having the right to a full life included in their community. An informal network of support is an essential ingredient in implementing this changed vision. All too often, however, the existing system is out of step with the vision of families and does not live up to the expectations of those who depend on it. People with disability and their families want more choice and control over all areas of their lives, including over publicly funded services.

Evidence supports the efficacy of a self directed approach

There is a growing evidence base that self directed support is more effective and no more costly than support provided through the traditional service system.

The National Evaluation of Individual Budgets Pilot Program (Department of Health UK:2008) found that people receiving an individual budget were significantly more likely to report feeling in control of their daily lives compared to those receiving conventional social care services. In addition, these consumers were more likely to report approval for the way in which their supports were delivered. Very little difference was found between the costs of individual budgets and a comparison group receiving conventional social care support.

In their evaluation of the second phase of self directed support in the UK, Hatton and Waters (2008) found that the vast majority of people receiving direct payments experienced improvements in their quality of life as a result of having more control over the resources directed at their support. These improvements included general health, wellbeing and quality of life, being able to spend time with people they liked, taking part and contributing to the community, having choice and control over their lives, feeling safe and secure at home and experiencing increased personal dignity.

These results have been mirrored in NSW where the Social Policy Research Centre Evaluation of Direct Payments through the Attendant Care Program found that participants who moved onto the direct funding pilot experienced positive outcomes on all measures when compared to people receiving attendant care through traditional service delivery approaches. These improvements included enhanced sense of wellbeing, a return to a sense of control, maximizing independence, choice and activities, improved physical and mental health, increased satisfaction, improved family relationships and improved friendships due to greater flexibility.

NSW has already begun to increase opportunities for people to direct their own support

In the last few years NSW has provided increased opportunities for people with disability and their families to direct their own supports. This can be seen through the self managed options in the Community Participation, Life Choices and Active Ageing Programs, the trial of direct payments in the Attendant Care Program and the four DADHC pilot programs.

In summary, NSW is well placed to realign the disability service system in ways that will empower families and people with disability. Moves to a self directed approach will move the system from the paradigm of providers of ‘care’ to that of enablers of support and reaffirm the authority of the family to guide and support its members with disability.

What can we build upon?

All Australian jurisdictions are implementing reforms to make their disability service systems more person centred and self directed. This is seen in the implementation (to varying extents) of individualised funding, person centred approaches and direct funding models. Key NSW initiatives are outlined above.

Internationally, person centred approaches are a strong feature of disability service systems in the UK, USA and Canada where there have been strong moves towards individualised funding and direct payments to people with disability who choose and purchase their supports.

Contemporary practice in Australia and internationally has a strong emphasis on moving away from program driven service provision to a system based on people with disability accessing the range of general community supports that fit their needs and aspirations, and maximise the use of informal supports. Where disability supports are required, they are tailored to and directed by the individual. The central concept is that people should be able to identify, design and oversee the support and resources they require thereby increasing their self determination and independence, (KPMG:2009:13)

Victoria

The Victorian move toward a more individualised approach is characterised by grass roots approaches to innovation and partnerships between people with disability, families, services and the Victorian Government in systemic policy and planning processes.

Moving to a self directed approach February 2010 4

In July 2008, partnership work over many years culminated in significant changes that provided people with disability and their families with more control over the resources targeted for their support. Multiple programs were amalgamated into a single set of guidelines and one set of planning and approval processes. The net result for people is more choice and flexibility. People with disability and their families now have the option to decide how their funds are managed including choice to:

- continue to have their funds paid to their existing service provider or move to other service providers;
- use a financial intermediary, an organisation that holds the funds, makes payments at the direction of the person and keeps records of the funds for the person;
- receive the funds directly and manage the package themselves (or with the help of family or a support network). This is currently restricted but will be more widely available over time.

Two other features that have been important in the Victorian move to individualisation and self direction include active support from government to enhance the capacity of people with disability and families to take the opportunities provided through a self directed approach and government support for service transformation.

Western Australia

The Western Australian move toward self directed support is built upon the statewide Local Area Coordination Program, operating since 1992 with its strong community development approach to enable people with disability to be embedded in community.

Funding for people with disability is individualised in WA and Local Area Coordinators have provided important role, mentoring people who wished to manage their own supports.

There is a long history of partnership between Government, people with disability, families and services working together in joint exploration and problem solving in relation to issues confronting people with disability and the system. The footprint of these partnerships can be seen in the Accommodation Blueprint Report, the Accommodation Think Tank that led to innovative funding, the Sector Health Check Report that led to a review of government capacities and functions and led to the emergence of the Community Living Plan and the Community Living Support Funding.

The Western Australian Government has invested in capacity building for people with disability and families and implemented the Shared Management Model in 2006 as a framework for people to discuss and negotiate the degree of self direction and management of their support arrangements that they want.

Embedding an individualised approach has led to new planning pathways that build on people's strengths, relationships and resources to create the life they want. It is an approach to help people move from a 'scarcity framework' to an 'abundance framework' where a person's fundamental needs for opportunities for reciprocal relationships and contributions are paramount. (Disability Services Commission:2008)

Obstacles

The major obstacles to the successful implementation and hence extension of a self directed approach in NSW involve factors in Government, in services and in people with disability and their families.

Factors in government

Ageing, Disability and Home Care operate a series of siloed funding streams that purchase outputs from services following a process of competitive tendering. This current approach captures supports for people in a service delivery paradigm that inhibits rather than enables an individualised approach.

Factors in services

There is little knowledge, skills and experience in NSW in developing, implementing and sustaining self directed supports that embed a person with disability in their community. As a result, many services continue to deliver a top down approach to service provision. Many rely exclusively on paid staff without any attempt to support and encourage informal, un-paid supports and reflect a lack of experience in building typical roles for people with significant disability as opposed to filling a diary with activities.

Factors impacting on families and people with disability

The disability service system has taught people with disability and their families to be dependent users of services, discouraging initiative and rewarding crisis. The system has often destroyed their dreams for their sons and daughters and until recently, most families have been immobilised in their ability to plan and think about the future because so much of the picture seemed dependent on the whims and changing policies of government.

Experience in other jurisdictions however, shows that when families hear about and see more individualised approaches working for people they consider similar to themselves, they are quickly able to imagine something different for the person they care about. They do, however, need significant support, especially at the beginning to plan and develop more individualised supports.

Recommendations

In order to move NSW toward a self directed approach, it is recommended that:

1. Ageing Disability and Home Care (ADAHC) amalgamate all program areas into a single funding program similar to the approach adopted by the Victorian Government. This will result in a single set of guidelines and one set of planning and approval processes enabling people with disability and their families to have greater choice including choice to:

a. continue to have their funds paid to their existing service provider or move to other service providers;

b. continue to have their funds paid to the service provider who provides the support or move to another service provider;

c. use a financial intermediary, an organisation that holds funds, makes payments at the direction of the person and keeps records of the funds for the person;

d. receive the funds directly and manage the package themselves (or with the help of family or a support network).

2. ADAHC adopt multiple strategies to enhance the capacity of people with disability and families to take advantage of the opportunities provided by a self directed approach. Some of the strategies include:

a. building the knowledge and skills of people with disability and families to direct their own support. This may include information provision, workshops that help families build vision and help families to plan and imagine better, mentoring programs etc;

b. developing an independent, community based, statewide resource centre that supports people with disability and their families to manage their own supports;

c. developing a mechanisms that assists people with disability and families to plan, implement and change supports. Such mechanisms must be accountable to the person with disability and independent of government and service providers.

3. ADAHC work with services to develop multiple strategies to to transform services from a service centred and congregate approaches to people centred and individualised approaches.

4. ADAHC work to realign its processes with an individualised approach including understanding the implications for planning, commissioning, budgets, resource allocation and the purchase of service, infrastructure to support people to take a self directed approach, monitoring, accountability, quality assurance and whole of government considerations.

Bibliography

Dept of Health (2008) *National Evaluation of Individual Budgets Pilot Program* Ibsen UK at www.kcl.ac.uk/research/groups/healthsoc/scwru.html

Disability Services Commission (2008) *Community Living Concept Plan*

Hatton, C., Waters, J., Duffy, S., Senker, J., Crosby, N., Poll, C., Tyson, A., O'Brien, J., Towell, D.,(2008) *A Report on in Control's Second Phase, Evaluation and Learnings 2005-2007*

KPMG (2009) prepared for Victorian Department of Human Services, *The Contemporary Disability Service System*

Social Policy Research Centre (2008) *Attendant Care Program Direct Funding Pilot Evaluation, Final Report*

SYSTEMIC ISSUES

Men and women with disability have a right to a home of their own!

A Supported Living Fund is a stream of government funding that would enable men and women with disability to move into a home of their own in a planned and timely way.

Fund would be a proactive strategy that aims to:

support people with disability to have their own home and life in the community;

enable each individual with disability and their family to choose who provides the support and how it is provided;

break the cycle of crisis by supporting and rewarding the initiative of families;

build on the strengths and capacities of people with disability, their families/networks and local community partnerships;

increase and evaluate the range of innovative, flexible and self directed community support options, on a state wide basis and with regard to cultural background.

Benefits of a Supported Living Fund

People will feel able to plan, leading to new pathways that build on people's strengths, relationships and resources and reduce reliance on crisis pathways.

People will regain control of their lives with the concomitant improvement in health and wellbeing.

Families will be supported in their efforts leading to empowerment rather than passive dependence currently fostered by the system.

There will be a reduction in crisis as people see clear pathways that support their initiative.

People with disability will have a life of their own in a home of their own.

An increased range of supported living options will be generated.

Expertise in supported living will be developed to compliment existing expertise in group living. This will inform directions on building capacity.

Expertise will be developed in supporting families to use their own initiative, reducing reliance on the service system.

An evidence base around individualised support and supported living will be developed.

Funding will be being used in ways that facilitate and assist to build new relationships and increase community inclusion with a shift away from the more traditional fee for service approach provided in current Business Rules.

See the Family Advocacy web site for a more extensive paper about the proposed Supported Living Fund – www.family-advocacy.com

CHANGES AT FAMILY ADVOCACY – RESOURCING FAMILIES PROJECT

Resourcing Families Project

Family Advocacy recognises that little support and information is currently available to families in relation to maintaining and nurturing informal supports, identifying and creating support networks and the concept of self directed and self managed funding.

Family Advocacy has received funding from Ageing, Disability and Home Care (ADHC) to establish a project providing this information and support to families in NSW.

ADHC has agreed to a three year ‘demonstration’ which will add to the evidence base and information about how to capture the benefits of informal support networks and parent to parent supports for families with a child or young person with a disability.

The project targets families of children and young people with disability 0-18 years in NSW, including those who are considering and/or are using self managed options.

It is hoped that the Project will:

- assist families to have a positive vision of their family member with disability and to build an ‘ordinary’ life enriched by valued roles and relationships
- assist families to build individual networks of informal support
- provide targeted information that assists families to make decisions and use initiative
- build the knowledge, skills and experience of families of children and young people with disability in developing, implementing and sustaining individualised, self managed supports
- support a greater number of families of children and young people with disability to have the confidence to direct their own supports
- share emerging practice and successes thereby preventing people ‘reinventing the wheel’.

The Project will provide materials about building informal supports, individualised funding and self managed supports. This information will be shared via the phone, at face to face workshops and via mentoring support.

In addition, the Project will run workshops sharing material to support families of children and young people with disability to understand, secure, manage and sustain supports. This will include material about person centred planning, building valued and active roles for the person with disability, community inclusion, building informal networks of support, developing paid supports that compliment informal support, recruiting, training and supporting staff and implementing systems to meet administrative, legal and financial requirements.

The Project will also establish a mentoring system to support networking and sharing of information.

The Project is only at the set up phase at the moment but if you would like to know more, contact Kim@family-advocacy.com

PEOPLE WITH DISABILITIES (PWD):

Individualised Funding: International Trends and Challenges

Professor Tim Stainton, University of British Columbia

Over the past 30 years or so individualised funding (IF) has gradually become part of the disability policy landscape in many jurisdictions throughout the world. Not surprisingly a variety of approaches have emerged with variations in target populations, age groups, levels of funding, comprehensiveness and support systems.

We have some reasonable evidence that suggests that users are more satisfied with IF than with traditional models of funding supports. There is also an increasingly strong body of research evidence to support the claim that IF/DP enhances both the control individuals and families feel over their own lives and the effectiveness of the support. This brief review will explore some of the commonalities of experience between jurisdictions and highlight some of the common issues and challenges.

Definitions and Models of IF

A definition can be stated as: funding allocated directly to an individual or in the case of a child their parents or legal guardian, to provide the support necessary to meet disability related needs and to assist individuals to become contributing citizens. IF has two fundamental characteristics:

1. The amount of funding is determined by direct reference to the individual and/or family's specific needs, and aspirations;
2. The individual and/or their family determine how funds are used to meet those needs eligible for funding. The two aspects are important as the first speaks to determination of level and the second to control over how those funds are spent.
3. In general most jurisdictions have more commonly done the former, but the latter usually consist of at best a menu of preset service providers. Some jurisdictions make a distinction between *individualised* and *direct* funding, the former being when the individual or family administers the funds themselves including all payee, insurance and employment related task and latter when some sort of intermediary is used.

Context

IF, of course, rarely exist in isolation from other programme or policy initiatives,

three elements seem common to most:

- support for people to articulate their claims
- support for people to identify, obtain and manage supports necessary to actualize their claims

- providing control over the resources.

A fourth element which has more recently emerged is concerned with *governance*:

that is, issues of who controls decision making within the system. I will not address this here beyond noting it as a key emergent issue.

In the first element, the concern is with issues of decision making, recognition of capacity and advocacy, but also with giving people information and support to make informed decisions.

The second element is concerned with supporting people to identify, obtain and manage necessary supports. 'Brokerage' type supports such as Local Area Coordination (used by the Disability Services Commission in Western Australia) and person centred planning are two common expressions of this element. This generally requires a restructuring of current case management systems either through internal reform or by relocating these types of supports to the community.

The third element, IF, is of course concerned with how the person's control over resources can be increased. Without the other elements however this control can be meaningless or in fact become a burden on individuals and families if they are required to hire, managed and account support.

Cost and Resources

The majority of evidence across jurisdictions supports better outcomes (cost/benefit) with IF over conventional systems without significant cost differentials:

- US and UK evidence suggests that over a relatively short time cost of IF systems produce increasing cost savings and efficiencies, though in some cases IF is initially
- cost neutral or slightly higher;
- Cost savings are dependent on implementation structures and realizing savings elsewhere in the system (i.e. reducing case management over time rather than operating a double system)
- Research indicates indirect savings in areas such as health care utilization, crisis etc.

Challenges and Issues

Enough jurisdictions have introduced IF that we can begin to identify some of the challenges in trying to implement an IF system. Many of the challenges not surprisingly are associated with the transition from the current system to an IF model.

IF in isolation of broader support and system change

The introduction of IF without any support mechanisms around planning, implementation and administration of ones own supports can in some cases add to the challenges that families face or exclude those who are not in a position to undertake these roles. To meet these challenge governments must ensure the planning, implementation and management supports are in place.

Transitioning funding

One problem that many jurisdictions have faced is the issue of unbundling funds from the current system to an IF model. This problem is more acute when services do not identify specific individuals associated with a funding stream but simply contract to provide X service for a specific numbers of eligible individuals. This problem is less acute when transitioning from institutional services where the intent is to close the former service. For this reason a direct transition to IF from institutions is the preferred method.

System Inertia

Transitioning to a new model will always create certain anxieties and resistance from those invested in the current system. Careful planning and good communication can mitigate this to some degree but it is important to be aware that a period of transition will be required before the new system will be effective.

Unionised Environments

A number of challenges can arise when unionized services are replaced by individualised supports managed directly by the person. Again, careful and respectful planning along with a strong set of controls on employment regulations, health and safety, and wages can mitigate the challenges.

Staffing

Clear guidance is needed with regards to the requirements to comply with employment standards and obtain requisite insurance. This is usually included in the IF package or in some cases a global plan is provided.

Training of independent support staff can be an issue. Some support organizations offer generic training or assist in obtaining relevant training for the support staff.

Finally, staff cover for emergencies such as staff sickness can be problematic. Many people develop their own roster of ‘on call’ staff but where this is not the case a back-up is required. One option is for the government or a support agency to contract with a care agency to provide short notice care for IF users.

Decision making-recognition of representatives

The answer to this challenge is not simple nor is it always within the purview of the State agent responsible for disability services. Progressive decision making legislation like the *BC Representation Agreement Act* is an important part of meeting this challenge. The more complex problem is building personal networks so that individuals have trusted advisors around them who are willing to help manage their supports with IF. Until this is in place, some form of direct funding with support to manage IF will likely be required.

This brief review has tried to highlight some of the key components and challenges of IF systems. While the increasing opportunity to learn from other jurisdiction is certainly a welcome aide, it is important to remember there is no cookie cutter solution to implementing IF. Each jurisdiction must develop a model which works for them. So beg borrow and steal, but in the end, make your own IF cake.

.

Individual Funding in Australia

Dr Carmel Laragy, School of Social Work, RMIT University, Melbourne

Australia, along with many countries across the globe, is promoting individual funding as a means of providing support to people with a disability. I have been studying the expansion of individual funding for the past decade in Australia and I had the opportunity to view developments in the United Kingdom and Sweden. By individual funding I mean that the person with a disability, or their representative, can decide how their allocated funding is spent. This can be for formal disability support services, for social participation activities or for a wide range of other supports to enhance their life. A common characteristic of most programs is that the person is involved in selecting their support workers or personal attendants.

Because individual funding offers flexibility and greater control to service users, it often gives the person a lifestyle more to their liking than traditional services can provide. Its expansion seems likely to continue, especially as some Australian State governments are now legislating for individual funding and promoting its implementation. While I see advantages in this model of support, there are also potential dangers if it is not well implemented. I will briefly outline some examples of individual funding programs

I have seen, the benefits they offer, and what is needed for their successful implementation.

Individual funding programs vary greatly in design and there is wide variation in the degree of control and responsibility given to the person concerned. At the more flexible end of the spectrum programs tend to have the following characteristics: money is placed in the person's bank account; the person, or their representative, employs staff and purchases goods; and receipts are regularly provided to account for the money. Less flexible programs require that the money to be held by an agency or an accountant, and support can only be purchased from disability services. Each organisation, state or country implementing individual funding looks to others to gain ideas and then designs a program to suit their local conditions and culture. This development process has advantages in that it is open to new ideas and is responsive to local needs. However, it also means that individual funding cannot be labelled as good or bad, it always depends on how well the programs are implemented — "the devil is in the detail".

Across Australia, most states and territories are implementing or examining how to implement, individual funding models. Western Australia made a large commitment to individual funding when it implemented the *Local Area Coordination Program* in 1988 and the coordinator manages the funds (1). Queensland spawned a number of small programs in the 1980s to support people with a disability to live independently in the community using an individual budget, and some continue today, for example *Homes West* and *Lifestyle Options*. The *Community Resource Unit* initiated some of the 1980 programs and still operates. New South Wales trialled *Direct Funding* for people with a physical disability in recent years and the evaluation found that people were highly satisfied with the outcomes achieved (2).

Being based in Melbourne, most of my experience is with Victorian programs. I have observed the State Government support pilot projects in the early 1990s and enact the new *Disability Act* in 2006 — which promotes an individual approach. Currently they are allocating an individual budget to everybody receiving disability support. Between 2000 and 2007 I was involved with three Victorian State Government programs: *Futures for Young Adult, Support & Choice* and

Direct Payments in the Southern Region. I also evaluated UnitingCare Community Options *Individualised Funding Project* (2007) and conducted the Victorian interviews for the University of New South Wales *Disability Studies & Research Centre* study of individual funding approaches (2009).

My findings from these studies are consistent with those from other evaluations (2, 3). One of the main findings is that individual funding can result in more positive outcomes compared to using traditional agency managed support services. This is because have control to use the money in ways they choose and develop innovative strategies to meet their needs. In particular, many people find that negotiating directly with a support worker about working hours and duties results in new lifestyle opportunities. Examples of new opportunities the flexibility of individual funding presents include:

- Living independently in the community instead of in residential care.
- Negotiating evening support at times that suit instead of bedtime being determined by an agency roster.
- Negotiating support to attend work, training and education.
- Attending sporting and other social/cultural activities.
- Having less hours of support one week and paying higher wages for a support worker to work late on Saturday night so that they could have an evening out.

One mother I spoke to in Victoria told of her son with autism being expelled from the disability special school and from respite services because of his violent and uncontrollable behaviour. The only option for his future seemed to be living in a supported group home under heavy medication. After a few difficult years at home when he was frequently disruptive, individual funding has facilitated services being carefully tailored to his communication style and individual needs. He is now a young adult and does not use medication. He lives in a flat, undertakes domestic duties and has a part-time job delivering papers.

The implementation of individual funding is complex, partly because it is so flexible and different to traditional disability support. Evaluations show that a number of factors need to be in place before the potential benefits of individual funding can be realised (2, 4, 5). These are:

- Service users are involved in service design.
- Information is available about funding allocations, supports, services and costs.
- Advice and support is available in a form suitable to the person, especially if they have an intellectual disability, to assist them choose between complex options.
- Services and other opportunities are available and accessible as required.
- Support workers are available as needed.
- Sufficient funding is available to meet needs.
- There is oversight to protect vulnerable people – both the person with a disability and the worker

Existing disability support services in Victoria are currently redesigning their systems to adjust to individual funding. Radical organisational change is difficult and the move to individual funding is challenging for everyone involved. This includes the Board members, executives, finance managers, team leaders and the support workers.

It is interesting that new agencies are also emerging that are specifically designed to provide services to people with individual funding. One such organisation is *Karden Disability Support Foundation* in Ballarat (www.karden.org.au), which commenced in 2006. No full evaluation of the agency has been conducted, but some preliminary studies indicate that clients like the flexibility and support they are receiving. Based on a person centred plan and using the available budget, a contract is drawn up with the person or their representative detailing their plans and the support they will receive. Features of the model are that the agency is charging less than 10 per cent of the budget for overheads and administration, and that support workers are selected by the client and employed by the agency.

Individual funding brings with it lots of issues about support workers availability; working conditions, wages and insurance; occupational health and safety, plus the safety of person they are supporting. Although research is showing relatively little abuse has occurred to date (3), it seems prudent to provide oversight to ensure this does not develop.

The positive relationships that develop between the person and the worker is proving to be one of the strengths of individual funding. Reports from both the person and the worker show that negotiating directly is often preferred to working through an agency (2, 6). In particular, people like to receive support from staff they have selected and got to know instead of agency staff who can be strangers.

In conclusion, individual funding is offering new opportunities that many people with a disability welcome. It is an option that should be available to everyone using disability services, even though some will want to continue their current service arrangements and not bother with change. When individual funding programs are available, it is important that sufficient money is allocated and that support and information services are available. Individual funding is an idea whose time has come because people across our society are demanding more control over their lives. Individual funding can offer new opportunities as long as it is well implemented.

References

1. Disability Services Commission. Review of the Local Area Coordination Program Western Australia. Perth, Western Australian: Disability Services Commission; 2003.

2. Fisher K, Campbell-McLean C. Attendant Care Direct Funding Pilot Project Evaluation - Final Report. Sydney: Social Policy Research Centre, University of New South Wales & Disability Studies and Research Institute For the NSW Department of Ageing, Disability and Home Care; 2008 Submitted March 2008, Published: August 2008.

3. Social Care Institute for Excellence. Choice, control and individual budgets: emerging themes. London, England: Social Care Institute for Excellence. http://www.scie.org.uk/publications/briefings/files/scare20.pdf

4. Individual Budgets Evaluation Network. Evaluation of the Individual Budgets Pilot Programme: Final Report. York: Social Policy Research Unit, University of York; 2008.

5. LDC Group, Dimitriadis L, Laurie D, Lane J, Lyall M. Evaluation of the Direct Payments Project, Final Report: Community & Individual Support, Disability Services, Department of Human Services, Victoria.; 2007 August 2007.

6. Laragy C. ‘Outcomes’ evaluation 2007 Individualised Funding Project: A project conducted by UnitingCare Community Options.: La Trobe University; 2008.

Personal Experience of Individual Funding

Robert Manga, President, People with Disability Australia

My name is Robert, a 43 year old male with permanent tetraplegia C-8 spinal cord injury. I am married and have a little boy who is 7 years old. Whilst travelling overseas in 2005, I was the victim of a ‘hit-and-run’ motor vehicle accident that almost took my life. Prior to my accident, my wife and I were both working professionals who enjoyed a quiet and stable life living in a double-storey house that we had built a year earlier.

Following the traumatic injury, I spent the next 12 months in medical institutions overseas and in Australia. During that time I came to a realisation that the independent, professional life that I had enjoyed for many decades was now over. From that point on it was obvious to me that I would have to rely on assistance from others in order to perform the necessary activities of everyday living and medical care.

As the date for my discharge from acute rehabilitation approached, I looked forward to enjoying the relative independence of community living that other citizens have the benefit of.

I was initially allocated 14 hours per week of personal care provided by government-operated home care provider. My hours were later extended to 32 attendant care hours. Twice per day, personal assistants were to attend me at my home, helping me to get ready for work in the morning and assisting with showering and toileting at night. Although the hours of care where acceptable, there where countless problems with the service delivery that made the experience stressful and traumatic for myself and for my family.

Firstly, the workers providing my personal care were accountable only to their employer, the government-operated home care provider. They were totally inflexible in their approach and unable to mould the service to suit my individual and family needs. On many occasions, I was obliged on a Saturday or Sunday morning to get up at 7 a.m as it was the only time that they could find a carer available for me.

The situation during the evenings and weekends was also very unsettling for my family. The home care provider could not always tell us in advance which carer was on duty or what time they would arrive. My wife, who was struggling to cope with the lack of routine as well as work full time and care for our son, was often upset by having to wait for carers to arrive. On one occasion when my wife had to attend to family affairs and left me in bed trusting that the carers would arrive and assist me as they were timetabled to, I was forced to spend the whole day in bed when they neither arrived nor answered my calls. As the incident occurred on the weekend, there was no answer at the home care provider and no after hours number to call for assistance. This incident was very detrimental to the quality of life of the entire family. Since that time, my wife could never leave home until I was safely helped to my wheelchair, for fear of repeating the incident.

Not knowing who was coming into our home was also a major concern for our family. Many carers interacted with our son and although there was no malice intended, sometimes the amount of attention he received from them was unsettling and at times inappropriate and disruptive to our family routine.

When an opportunity arose to participate in the DADHC *Individual Funding Pilot Project*, I took it without hesitation. While society has often disregarded the potential of people living with disability, I saw my involvement in the pilot project as an opportunity to prove that I could once again be in charge of my own life and inspire other people with disability to do the same. I never considered myself as a passive recipient of care and now enjoy the responsibility that comes with participating in this initiative. I personally believe that the society need to build the capacity of people with disability, their families and their contribution should be both encouraged and supported.

The *Convention of The Rights of People with Disabilities* recognises the “importance of people with disabilities in their individual autonomy and independence including the right to make their choices”. The preamble also states that they must be given the “opportunity to be involved in the decision-making process about policies and programs including those involving them” (UN, 2006). With my participation in the pilot project, I am able to hold, administer and manage the budget allocated to my care. Since December 2006, I’ve been able to recruit and train my own staff, and negotiate initial contract. I am also able to organise the timetable that suits my individual needs and those needs of my family.

Some of the workers that I recruited were employed by the government-operated home care provider. I had to basically retrain them so that the service they provided suited my specific needs. As the employer and recipient of services, the quality of these exponentially improved. Nearly 3 years after being recruited in the pilot project, I have had the same personal care assistants providing my care. I believe that I have treated them fairly, given them a fair salary and provided them with some levels of flexibility. In return, they are able to attend to my immediate needs even on short notice. Instead of being considered just as carers, they are almost part of our family. Over the years, we’ve developed a high level of mutual respect and trust to a degree that they are entrusted with the keys to our home.

We don’t have to worry anymore about whether or not the carer will be coming. Having carers coming to deliver care at home can be an invasion of privacy but at least my family and myself know exactly who is coming. My son knows our 3 carers well and is very familiar with their timetable too. He no longer hides under the table in fear when the doorbell rings!

Overall, my personal involvement in the IF has improved my family and my own quality of life and greatly enhanced our community participation.

NSW Liberal and Nationals Parties discussion paper: *Personalising Service Delivery*

Michael Bleasdale, PWD

In Australia the Liberal and National Parties are the first political parties to deliver policy statements about individualised funding and self directed supports. The NSW Branches of the Liberal and National Parties have released a discussion paper, entitled *Personalising Service Delivery*. This paper articulates the commitment of the parties to develop a service system that "increases choice, voice and control for people with disability and their carers". The paper also highlights the need for an effective service system to place some trust in people with disability and their carers, and their ability to manage their own car requirements. These principles are linked to the requirement of governments and their departments to respond to the articles in the United Nations Convention on the Rights of Persons with Disabilities. It would appear that the Liberal and National Parties are across the evidence internationally about the effectiveness of individualised funding in achieving the outcomes that people with disability expect from their supports, and are also aware of the significant change that will need to take place within the current disability service system to make the option of individualised funding a reality for people with disability who require support.

The paper is less detailed when it comes to how the new system is to be implemented, and this needs to be one of the main discussion points with the representatives of the Parties. International evidence tends to reinforce the need for strong and continuous involvement by resourced community organisations which remain independent of both government and service providers. No comparative evidence is provided in the paper of the funds allocated to the disability services sectors in comparative jurisdictions, which casts doubt over the assertion that a shift to individualised funding will be "cost neutral to government", whilst achieving the improvements expected for people with disability. Professor Tim Stainton has indicated that the funds dedicated to the sector in Australia are low in comparison to other jurisdictions in the UK and Canada.

The publication of this paper is very welcome start to what is hoped to be a much broader expression of support for individualised funding at the political level, on both sides of politics. This is a position statement with which community groups can engage, and allows for further and more detailed discussion on how it can be achieved, as well as flagging further efforts to get through to elected members the need for a much greater commitment of resources if Australia is to begin to meet its obligations under the United Nations *Convention on the Rights of Persons with Disabilities*.

In Control Australia: Debunking the myths around self-directed funding

Samantha Jenkinson, In Control Australia and the Australian Federation of Disability Organisations (AFDO)

The movement of people with disabilities, families, service providers and supporters of self-directed funding that is In Control Australia is gaining ground. Most recently there have been successful forums in both Adelaide and Brisbane, hosted by local organisations on self-directed funding. These forums brought together people with disabilities, families and service providers to learn about the concept of self-directed funding and discuss the strategies needed to change government policy. They were also a great opportunity for many service providers to talk about how they could provide services in a self-directed funding environment, and other roles some service providers could take on like that of financial intermediary and broker. There are people with disabilities, families and service providers who all do forms of self-management in many states, and the In Control forums have provided the opportunity for these stories to be shared, however there are still many myths, misconceptions and fears about self-directed funding which are raised.

Some myths and misconceptions include:

It takes all responsibility away from government and the community.

There is often an underlying fear that this model is putting all funding and responsibility with an individual or family, while government provides no support and is removed from taking responsibility. This is not what self-directed funding is about. The key concept behind self-directed funding is that citizens are empowered and in control of the decisions that affect them. That is why the model has multiple options for support, and management of the funding to cater for people’s different needs and capacity so they can be in control.

It is just a form of rationing.

This model is focused on empowerment – people making their own decisions – with how funding is rationed as a tool for achieving this end. It is a rights based model, with a vision of empowered citizens at its centre. The allocation of resources is based on the needs identified by the person with disability, and decisions made about how to meet those needs are made by the person with disability. It is not about new resources being allocated, this is why the lobby for a National Disability Insurance Scheme is also important.

It is only for the most able, or those that can employ their own support workers.

Self-directed funding is a model that is for everyone. The key components of this system are flexibility, choice, control and creativity. You choose whatever arrangement works best for you, which can include having someone else take care of all the technical stuff. The model In Control Australia promotes is one where there are multiple options for managing funding, such as:

- Funding going directly to the person with a disability
- Funding is managed on the person’s behalf by a trusted other such as a family member.
- Funding going to a micro-board or 'circle of support' who manage the budget and funding with constant checking of the plan and decisions with the person.
- Funding going to a financial intermediary (FI), a bit like a bank, where the person (or family member on behalf of a person) has control of the things that are purchased, but the invoices are sent to the FI who pays them and sends monthly statements to the

person.

- Funding going direct to the service provider you choose. This is a bit like many current systems, but planning and control of decisions is squarely with the person and family.
- Funding going to a case manager/broker who works with the person and/or family to develop and implement their plan, purchase services and undertake accountability.

The key point of self-directed funding is that decision-making is done by the person living with disability (and those closest to them where that is appropriate) with as little or as much support as is needed. This model also incorporates the option for people to employ their own support workers, use an agency to do payroll (insurance, tax, etc.), or negotiate a shared management model with a service provider.

It will cost more.

There is no evidence that self-directed funding models cost more for government to run. In fact research done in the UK on trials of this model show that people with disability and their families often spend their funding more efficiently than government providing the same service. This does not mean it will cost less either, as there still needs to be resources for supporting people to use the system and for provision of community development and access. In Control UK has published a document called *Economics of Self-Directed Support* by Simon Duffy which goes into these details, and is available on our website.

It is the perfect system.

Self-directed funding has been very successful in other countries such as Canada and the UK, but its not a panacea for every problem. It is merely an attempt to model the best, most practical and affordable ‘delivery system’ for social support. There is still much to learn, it is not a static model. The model is not the purpose, the model is merely a tool for good leaders. The purpose is to move to a service system driven by empowered citizens that are part of inclusive communities.

Bureaucrats and politicians do not want to give up their power it is all too hard, where do I start?

For those individuals and families with funding write to your State/Territory funder and ask for you funds to be paid directly to you as self managed funds (or a direct payment). Do not take no for an answer, send your letter and the reply to your local State/Territory member of parliament and your local advocacy group and In Control Australia.

We are still at a very early stage of thinking and practice in Australia. Some States and service providers are seeing exciting outcomes and are motivated to move further, some are still unsure. The tendency to think of self-directed funding only in terms of Direct Payments is an obstacle to developing new services and offering more varied management systems. Self-directed funding needs to be able to adapt to include (a) rehabilitation (b) crisis interventions and (c) prevention strategies.

There are also many challenges for the disability sector in making the cultural shift required to put people with disability and their families in control of the decisions that affect them. There is much more to learn about when and how case managers should be used, how to change the case management function and what range of further support is useful. Some service providers are concerned about the sustainability of their organisations in this changing environment, and may need to make major changes in the way they provide services. People will want quality services and purchase from quality providers. More attention will need to be paid to the costs of the infrastructure needed for self-directed funding, and this could include establishment of peer support centres, and/or changes to the taxation and pension systems, and the use of ombudsmen and consumer affairs for protection of rights.

We are at the stage of building momentum here, which is what In Control Australia is doing through its website and forums. This momentum is part of a wider call for change that includes the promotion and lobby for a National Disability Insurance Scheme, and the Australian Federation of Disability Organisations call for a Disability Inclusion Allowance. It is hoped that support for self-directed funding

will be part of the Federal governments *National Disability Strategy*.

For more information on In Control Australia and self-directed funding go to www.in-control.org.au or contact Samantha Jenkinson at enquiries@in-control.org.au.

Individual funding policy research in Australia

Dr Karen Fisher , Social Policy Research Centre, UNSW.

Australian disability policy research about individual funding is needed urgently because of the rapid change towards this method of organising disability support (we use the word ‘individual’ rather than ‘individualised’ for plain English). Although a lot of research about individual funding in other countries is available, very little about the experiences of people who use it in Australia is published. And yet many examples of individual funding operate around Australia. Recent Australian literature includes evaluations, discussions and policy guidelines, and important references include:

- Department of Human Services DHS 2008, Disability Services Individual Support Package Guidelines (draft), State Government of Victoria, Victoria.
- Epstein-Frisch, B., Van Dam, T. and Chenoweth, L. 2006, Presenting the Evidence: Accommodation and Support for People with a Disability, http://www.mdaa.org.au/archive/06/PresentingTheEvidence.pdf
- Fisher, K.R. & Campbell-McLean, C. 2008, Attendant Care Program Direct Funding Pilot Project Evaluation Final Report, report prepared for Department of Ageing, Disability and Home Care NSW, March, SPRC Report Series 11/08, Social Policy Research Centre, University of New South Wales.
- Fisher, K.R., Parker, S., Purcal, C., Thaler, O., Abelson, P., Pickering, E. & Griffiths, M. 2008, Effectiveness of Supported Living in Relation to Shared Accommodation, report prepared for Disability Policy and Research Working Group, SPRC Report Series 18/08.
- In Control Australia 2009, In Control Australia: About self directed funding, http://www.in-control.org.au/about_sdfunding.asp [Accessed 01/12/ 2008].
- Laragy, C. 2008, Outcomes evaluation 2007 Individualised Funding Project, paper prepared for Uniting Care Community Options, La Trobe University, Melbourne.
- LDC Group 2007, Evaluation of Direct Payments Project, report prepared for the Department of Human Services, August, Victoria,
- Productivity Commission 2007 Report on Government Services 2007, Steering Committee for the Review of Government Service Provision, Productivity Commission, Canberra.

In 2008-09, the Australian Department of Families, Housing, Community Services and Indigenous Affairs (FAHCSIA) asked the University of New South Wales to examine the effectiveness of individual funding of disability support to inform policy change. The report will be published as a FAHCSIA Occasional Paper later this year.

The reason for the research is to learn from people who use and offer individual funding about how they manage the risks and maximise the benefits of this way of organising support. Considerations in managing effective individual funding examined in the research include: consumer preferences; support according to capacity and vulnerability; administrative systems for managing support responsibilities; viability of the support type and amount of funding; workforce and quality of care; service integration; and contextual impact.

The research includes interviews, questionnaires and observation with people with disability whose support is organised through individual funding and their families, service providers who offer this method of funding and government officials. The research summarises what individual funding is offered in each state.

Although individual funding in Australia has many forms, the key elements for the purpose of the research are that they are portable individual packages that facilitate consumer control over choices about how disability support funds are spent. The funds to purchase disability support is:

- held by the person or their family, a facilitator or service provider, and
- portable between service providers or facilitators when the person chooses, and
- used to buy support from service providers or in an open market.

Acknowledgements: Social Policy Research Centre, UNSW (Ryan Gleeson, Robyn Edwards, Christiane Purcal, Tomasz Sitek, Denise Thompson); Disability Studies and Research Centre, UNSW (Rosemary Kayess, Brooke Dinning, Carmel Laragy, Lel D'aegher); and the people who participated in the interviews and questionnaires.

In Control Australia in NSW

Belinda Epstein-Frisch AM, In Control NSW and Family Advocacy NSW

In Control Australia is a group of individuals and organizations who aim to bring about systemic policy change in Australia to enable individuals with disability and their families to manage their own support. The organisation is an affiliate of In Control-UK and works to provide an avenue for information exchange, critical inquiry, dialogue, collaboration, leadership and influence.

In Control Australia held its first seminar in NSW in December 2008 in Sydney. The seminar was targeted at people committed to seeing self directed support and individualised funding widely available in NSW. Tim Stainton described the system of individualised funding in British Columbia, Robbi Williams reported his observations of individualised funding on the ground in the UK and Belinda Epstein-Frisch outlined what is happening with individualised funding and self directed support in other states of Australia.

On the day, Lauren Murray, then Director Community Access, DADHC outlined four new pilot programs of ‘packaged support’ planned by DADHC to explore the impact of moving more control to the person with disability and their family.

Those present at the seminar debated and affirmed the key elements of self directed support that would provide the basis for future negotiations within NSW, finalizing the position statement below.

Key Elements of self directed support

Self directed support describes an approach that aims to place the individual at the centre of decision making and treats family members as partners. The process focuses on discovering the person’s skills and capacities, and on identifying the priorities of the person specifically in terms of the goals, lifestyle choices and aspirations. Self directed planning is underpinned by the values of independence, choice and social inclusion and is designed to enable people to direct their own services and supports rather than attempting to fit within pre-existing service systems.

Core elements of a self directed approach include:

- self directed planning: planning that is personalized and directed by the person and their family/support network or in the case of children is family centred;
- self directed funding: resources that are allocated to the individual and their family/support network early in the process to support the design and identification of supports that are flexible and responsive to individual needs;
- self directed support: support approaches that involve a combination of formal and informal, public and privately provided services coordinated to deliver the best outcomes in response to the individual’s circumstance.

Principles

Principles for the use of self-directed support have been drawn from the United Nations

Convention on the Rights of Persons with Disabilities (2006) and include:

- respect for inherent dignity;
- individual autonomy and independence;
- self-determination and choice;
- opportunities to realise individual capacity for physical, social, emotional and intellectual development;
- opportunities to participate in the social, economic, cultural, political and spiritual life of society;
- adequate resources being available to meet needs.

In Control UK states these principles on behalf of people with disability as:

1. Independent Living: I can get the support I need to be an independent citizen.
2. Individual Budget: I know how much money I can use for my support.
3. Self-Determination: I have the authority, support or representation to make my own decisions.
4. Accessibility: I can understand the rules and systems and am able to get help easily.
5. Flexible Funding: I can use my money flexibly and creatively.
6. Accountability: I should tell people how I used my money and anything I've learnt.
7. Capacity: My capacity is assumed, and I can also get information and support to build my vision of what is possible in my life.

To facilitate self directed support, the 'system' must enable people with disability and their family/support network to:

- have control over the what, when, where and by whom of support;
- be assisted to plan, implement and change supports by a person who is accountable to the person with disability and independent of government and service providers;
- delegate financial, legal and administrative responsibilities to an intermediary;
- build their knowledge and skills to direct their own support.

Funding mechanisms consistent with self directed support:

- funding can be held by the person and/or their representative;
- funding can be held by a financial intermediary;
- funding can be held by a service provider but are spent according to the person's

requirements under a self directed approach.

In Control Australia's work toward systemic change in NSW

In Control Australia has been actively working with DADHC to shape its moves toward greater individualsation. Presentations have been made to the two DADHC committees guiding its work - an internal Working Group and the External Working Group on Individualised Support.

In April this year, In Control Australia was invited to become a member of the DADHC External Working Group on Individualised Support. In addition, members of In Control sit on the DADHC Evaluation Steering Group overseeing research that will assist in the development of a more individualised approach.

In Control Australia will hold its second seminar in Sydney in November where the transformation taking place in disability services in Victoria will be showcased.

Interrelate and Personalised Budgets

Jenny Speed, Manager Individual Advocacy, Logan City Queensland, PWD

At the International Initiative on Mental Health Leadership (IIMHL) exchange and networking meeting in Canada in 2007, consumer leaders from existing and emerging national consumer organisations from Canada, the US, England, Scotland, Ireland, New Zealand and Australia agreed to form an international coalition of national consumer organisations to share knowledge and experience, support each other in efforts to influence developments in mental health policy and service delivery within our own countries, and to lend strength to the development of consumer movements in other parts of the world. This group, Interrelate, has continued to meet regularly by teleconference, and is well on the way to becoming an established organisation.

In March 2009, we all met again in Brisbane for another IIMHL exchange and meeting, following which Interrelate members met with local Queensland, Australian and New Zealand consumers for a two day forum exploring ideas around recovery, rights and leadership, leading to an ongoing group of Queensland consumers continuing to meet with the objective of developing an independent Queensland consumer group. This group, too, continues to meet, and is called “A Way Ahead Queensland”.

Knowing that Australian consumers are neither unique in our needs nor alone in our efforts is encouraging, and the awareness that we can learn from and lend strength to people experiencing or recovering from mental distress throughout the rest of the world is empowering. Having the development of initiatives in one country informed by experience in other countries is a rich and valuable resource for us all. During the early stages of Interrelate, Canada, Australia and New Zealand all had active national consumer organisations, and Scotland, the US and England were still developing. Now, the groups in Australia and New Zealand are no longer funded, Scotland and England have established bodies and the US is still developing. We have all been able to support each other through these critical stages in our individual and joint histories.

One of the most exciting current issues we are discussing about is the complex area of personalised budgets. These are cash payments given to service users in lieu of community care services they have been assessed as needing, and are intended to give users greater choice in their care. The payment must be sufficient to enable the service user to purchase services to meet their needs, and must be spent on services that users need. These payments confer responsibilities on recipients to employ people or commission services for themselves. They take on all the responsibilities of an employer, such as payroll, meeting minimum wage and other legislative requirements and establishing contracts of employment.

In the US, there are five states which have individualised budgeting, or self-directed care as it is also known as either pilots or established programs for adults with serious mental illness. These are in Florida, Iowa, Maryland, Michigan and Oregon. Early evidence indicates that outcomes for self-directing consumers improve. Participants have been shown to make less use of crisis stabilization units and crisis support and greater use of routine care and supported employment than non-participants in the traditional community mental health system.

Self-direction has been shown to improve consumer satisfaction with services compared to traditional community mental health services. In interviews, consumers attribute this to the following features of self-direction: the focus on recovery rather than symptoms; its flexibility in meeting individual needs; and the support provided by counsellors and peers in articulating goals and developing spending plans.

In Scotland and England, personal budgets or individual budgets are at the core of the government's aim of personalising adult social care services around the needs of users. Through the *Putting People First initiative*, councils will be expected to significantly increase the number of people receiving direct payments and roll out a system of personal budgets for all users of adult social care, from 2008-11. In the long-term all users should have a personal budget from which to pay for their social care services, apart from in emergencies.

Individualised Funding in British Columbia

Brian Salisbury, Director of Strategic Planning, Community Living British Columbia

Individualized funding [IF] was first proposed in British Columbia in 1976 as way for adults with developmental disabilities and their families to purchase needed community supports and services. Families, whose sons and daughters lived in Woodlands School, a large provincial institution, believed that by combining IF with independent planning support, which they called service brokerage, they could create the kinds of supports needed by their family members to live in the community with autonomy and dignity. Now, after many years of dealing with the many barriers that true social innovations must overcome, IF is now a province wide payment option for adults with developmental disabilities that is supported by clear public policy.

IF assists adults to participate in activities and live in community in a way that works best for them. People can use money allocated to them by Community Living British Columbia to create new, innovative service options and to make individual choices about how the supports and services they require are provided. CLBC is the Crown agency in B.C. responsible for funding supports and services for adults with developmental disabilities.

Any adult eligible for CLBC-funded services can apply to receive IF. The amount of funding is based on a person’s disability-related needs, the estimated cost of needed supports, and CLBC’s financial resources. If CLBC does not have available funds, a person may receive part of their request, be offered an existing service or placed on a waitlist. If a request is approved and funded, the person will be able to purchase supports that qualify for CLBC funding, like help to live in community or help finding a job. IF cannot be used to increase the personal income of an individual or family and it does not cover costs related to medical supplies or equipment, home renovations, electronic equipment or leisure, recreation and personal or family costs.

A person’s first step is to contact a CLBC facilitator, who is available to help with planning, at their local Community Living Centre. A facilitator will explain how CLBC manages and prioritizes funding requests and will clarify whether or not an Individual

Support Plan needs to be developed. With IF, a person can determine and arrange his or her own mix of supports. The individual, or the person assisting them (their agent), might hire people directly to help them, or they may work with a Host Agency that will help choose and hire support staff.

Direct Funding is an IF payment option where money is paid directly by CLBC to the person or their agent for the purchase of supports and services agreed to by the person, their agent, and CLBC. A person does not have to manage Direct Funding alone, but they must be able to demonstrate they have chosen a friend, family member or representative who can act responsibly on their behalf and manage the money.

The person or their agent manages the funds, arranges for the supports needed, pays employees, and reports to CLBC on how the money is spent. In this instance, the individual will likely have the legal responsibilities of an employer if they use the money to pay support workers. It is the person's responsibility to manage the services within the amount of money approved in their Direct Funding agreement. There is no provision for over-expenditures. If more money than CLBC has agreed to fund is spent, the person will need to cover the additional costs from their personal funds. CLBC can also ask the person to repay funds if they do not spend the money on the supports agreed to, or in a way that does not meet the conditions of the agreement, or if they did not require the full amount.

A Host Agency is an agency approved by CLBC that a person can select to administer the money allocated by CLBC. The Host Agency works with the IF recipient to arrange and manage the supports required. This option provides the benefits of IF, but with less responsibility for paperwork and record-keeping. Individuals applying for IF need to identify in their plan which service provider they would like to use. CLBC facilitators are able to provide the names of CLBC-approved Host Agencies in various communities.

A person can choose the payment option that works best for them. If Direct Funding is chosen, they and CLBC must agree that they, or their agent, are able to manage this responsibility. If it appears it would be difficult for the person or agent to manage the funds, CLBC will assist the person to work with a Host Agency.

For those receiving Direct Funding, the person or their agent are responsible for ensuring any services purchased are appropriate and effective. For those who receive Host Agency Funding, the Host Agency, as well as the person, their family or personal network must ensure the services being purchased are appropriate and effective in meeting the person's identified needs. CLBC will also receive reports from the person, family and agent or Host agency to help them confirm that supports are meeting the person's goals and CLBC standards.

For people who want to make changes in their staff, because people arrange their own supports, they and the person helping them can make that change. However, those who receive Direct Funding must follow the Employment Standards Act. Those who receive Host Agency Funding can ask their Host Agency to help them.

If a person is already receiving CLBC-funded supports, a facilitator will work with them and a quality service analyst [the CLBC staff responsible for allocating funding and monitoring contracts] to confirm the possibility of moving funding to IF. If some or all of a person's funding can be moved, a facilitator will assist them to develop or modify their plan to request a change to IF. A quality service analyst will review this request and determine the level of support they will receive.

At this juncture, IF is a welcome payment mechanism for many BC families as it will help increase the array of choices and options for them. However, for the foreseeable future, it is likely that uptake will remain at conservative levels as people become more familiar with this approach.

Lessons from England on the support broker role

Steve Dowson, Associate Consultant, National Development Team for Inclusion (NDTi), UK

Editorial Note: in the UK local councils are the funding and administrative bodies for a range of services, including disability service, education, health, Police etc., hence the reference throughout this article to "councils".

Councils in England are now racing to transfer thousands of social care users from care managed services to Personal Budgets, the version of individualised funding that has won official favour over the last six years. Central government has set councils the target of moving 30% of adult users to Personal Budgets by March 2011, and there is every expectation that this pace will continue until total system change has been achieved.

If numbers are all that matter, then this may be more achievable that it seems at first sight. Personal Budgets, as defined by the government, only require that councils provide social care users with an 'up-front allocation' (1) of funding that offers the recipient choice over the way the money is spent. The individual is still free to leave the money with the council, and to rely on the care manager – just as before - to plan and organise their services. So moving to Personal Budgets could mean little more than letting people know the cost of their service. Comparing Personal Budgets may become a new topic of conversation at the day centre.

But the government's stated goal is to give disabled and older people more choice and control over their lives, and over the purchase of their supports and services, with the option to look beyond the familiar limited menu of specialist support agencies. If that is to happen then Personal Budget recipients must be willing and able to grasp the control when it is offered. For some people that may be straightforward enough. For example, an older person might be given a Personal Budget of £5000 a year to hire the domestic help they need in order to remain in their own home. Making the choice and organising the help may mean little more than a call to a commercial support agency, or placing an ad. in the corner-shop window. But when the budget rises (as it often will, for disabled people) beyond £30,000 a year, and sometimes much higher, and calls for a series of well-coordinated and complex support arrangements, the challenge is much greater. It's plain enough that many people won't be able to complete this complex planning and organisational task – in a way that has successful outcomes for them and would also satisfy the taxpayer – without some assistance.

Although this might seem obvious, interest in the development of brokerage assistance has lagged well behind the spread of individualised funding programmes in England. For many disabled people and families, the term 'professional' in social care has come to mean impersonal, disempowering, and untrustworthy. One of the attractions of individualised funding, as presented in England, was that it would banish these professionals from people's lives. Thus, almost inevitably, brokers were regarded suspiciously as a way to let the professionals back in.

As Personal Budgets have become incorporated in policy, the need to ensure people have help with brokerage has become undeniable. About three years ago the government took the position that this assistance could come from a variety of sources, including family members, neighbours, community groups, and organisations of disabled people. Help from support brokers - people delivering it as a specific, paid service – was acknowledged as another option, but not favoured.

This remains the government's official position, and guidance to councils only requires them to establish 'enabling frameworks' around Personal Budget recipients (2). But work by the National Development Team for Inclusion (NDTi (3)) over the last three years has helped to establish the case for independent brokers (4), and provided a definition of the broker role that has the support of key national organisations. Work by the NDTi for Skills for Care – which sets standards for qualifications in social care - has laid the foundations for national accredited broker training (5). Although councils are being pressurised by government targets to put quantity ahead of quality, there is growing recognition by councils that their local 'enabling frameworks' should include independent brokers.

The NDTi fully supports the government position that help with the tasks of brokerage can come from many sources, and acknowledges that it would be wrong, as well as impractical, to try to impose standards on the quality of help that is given informally. On the other hand, the NDTi argues, when people deliver brokerage assistance as a specific, paid service they occupy the role of broker. To make a comparison beyond social care, many of us may have some plumbing skills that we can offer to a neighbour with a leaking tap. But providing help with plumbing does not, in itself, turn us into plumbers. On the other hand, if hire someone who calls themselves a plumber, we will have expectations of the service we get – in terms of competence, the nature of the relationship, and the context of standards and safeguards surrounding the delivery of the service.

In exactly the same way, people who receive the paid services of a broker (whether the payment is as a direct fee for service, or via a publicly-funded salary) are entitled to have expectations about the service they will receive. These translate into a set of implications for the development of support brokers:

Brokers should provide their services as contractors delivering a service to customers.

It is right to conceive the relationship in this way, because it is a paid service. It is also helpful, as it underlines the accountability of the broker to the customer. The empowered position of the individual as customer should be emphasised by developing broker resources so that people can choose, in their own time and on whatever basis they prefer, the broker that suits them.

There should be standards of competence for the work of brokers.

People who receive the services of a broker should have reasonable confidence that the broker brings a minimum set of skills and knowledge. This in turn implies the need to define training requirements and to provide training opportunities. Through a series of consultation exercises, and also drawing on experience in training brokers, the NDTi identified the minimum competences required by brokers in terms of 17 skills and knowledge areas. These have yet to be converted into an equivalent training course, but they suggest training that could be completed over a few weeks. This is likely to be reassuring to many disabled people and carers who fear that lengthy training would imbue brokers with the less desirable 'professional' characteristics.

People who receive broker services should have confidence that the broker is able to focus solely on their interests, free of conflict of interest.

It has been suggested that everyone brings their own personal values, and that conflict of interest is therefore inevitable. Others have argued that it is for the recipient to decide whether it is important that their broker is independent. However, for many people who have been on the receiving end of care-managed services, where the care manager role embodies a basic conflict of interest, the certainty that the broker is free of conflict is a distinguishing feature of the broker role, and one that is very important. At the very least, support brokers should be independent from the council and from service providers.

Brokers should not be involved in the delivery of secondary support services.

These secondary support services underpin the supports that are offered directly to the individual, and begin once the individual's plan has been implemented. They typically take the form of payroll services, accountancy, recruitment, and support coordination. They are part of the support plan, which means that the broker should be ready and able to help people identify what secondary supports they need. However, if brokers also offer these services then there is obvious conflict of interest. In addition, secondary supports call for a very different set of skills from those required to plan and organise supports.

People requiring broker services should be able to access brokers who have been accredited for their competence and integrity.

Without some form of regulatory mechanism, standards for training, independence, reliability, and honesty become meaningless. Legally, however, anyone who wishes can describe themselves as a support broker and offer their services. The best available solution at the moment is to establish a voluntary accreditation scheme. This could be achieved through a national register, but this seems likely to encourage the over-professionalisation of brokers. In its work for Skills for Care, the NDTi recommended a system of accreditation based on local accrediting committees under the control of disabled people and carers. This should fit well with a separate government initiative which aims to establish use-led organisations in every council area (6).

We have yet to see fully-fledged broker services in any part of England that demonstrate all these principles in action, though some initiatives are getting close. Sadly, there has been a reluctance in England to use the learning from individualised funding initiatives in other countries, with the result that progress has been delayed while wheels were reinvented. The fresh but hard lesson we are now learning is that high quality, independent, customer-accountable support broker services can only be sustained if councils shed their command-and-control mentalities. But, in truth, the entire enterprise of 'personalisation' of social care will only succeed if councils learn to connect with citizens and communities in a new and very different way. So the successful development of independent broker services is not only an important part of the implementation of individualised funding system. It is also a litmus test for the government's ability to deliver on its promise of choice, control, and citizenship for people who require social care.

1. Department of Health (2008) LAC(DH)(2008)1: Transforming Social Care, London, Department of Health

2. Department of Health (2009) LAC(DH)(2009)1: Transforming Social Care, London, Department of Health

3. http://www.ndti.org.uk

4. Dowson S. (2008) Custom and Control: the training and accreditation of independent support brokers, Bath, National Development Team

5. Skills for Care (2009) The independent broker role and training requirements: Summary report, London, Skills for Care London, http://www.dhcarenetworks.org.uk/_library/Resources/Personalisation/Personalisation_advice/SfC_ISB.pdf

6. http://www.dh.gov.uk/en/SocialCare/Socialcarereform/Userledorganisations/DH_079159

For a more in-depth look at the issues around support brokers in the UK, see the following article: Dowson, S. and Greig, R. (2009), The Emergence of the Independent Support Broker Role, Journal of Integrated Care, Vol 17, Issue 4, pp. 22-30).

Disability Reform Agenda in Tasmania: A Person Living With Disability (PLWD) Perspective

Jane Wardlaw, University of Tasmania

'Our starting point is the principle that everybody in society has a positive contribution to make and that they should have the right to control their own lives' (Stainton 2009 quoting Department of Health, English Green Paper 2005).

The Tasmanian state government is implementing a disability services reform agenda; a systems change, to respond to the current and future challenges of providing support to people living with disability (PLWD). It is an ideal time for systemic transformation in the way that PLWD can have more ownership over decisions that impact on their daily living and an opportunity for ideal inclusion because the system largely in Australia is 'broken' and 'broke' (NPWDACC 2009).

An ideal system embraces and acknowledges diversity and difference surrounding disability by highly valuing self-determination, choice, flexibility and responsibility of the PLWD (and/or their family/carers) and community living (Stainton, 2009). As Stainton (2000) points out, the interest is with capacity; how decisions are made, and providing the means to enact those decisions to enable

PLWD to reach their full potential.

It is expected that in contemporary society, processes in developing system changes and good policy formulation effectively engages and consults with all key stakeholders to determine all factors and devise instruments to consider impacts for example 'the legitimacy of much public policy now rests on an exchange between citizens and their government' and, '[the government] must find ways to discuss with relevant communities of interest and draw them into the policy process while avoiding

unreasonable delays...' (Bridgman and Davis 2004 p.78). Further, 'experience shows that good process is integral to consistently good policy' (Bridgman and Davis 2004 p.32). Importantly, it brings fresh new workable ideas to the table for contemporary systems reform and innovative social care

change that meets the needs of the people and reduces stress on a system.

PLWD, in particular customers of Disability Services are fundamentally citizens and a

'relevant community of interest' or key stakeholder.

The issue with the state government's reform agenda is that PLWD have been excluded as key stakeholders in the reform design process and implementation. The reform agenda has largely been championed by other key stakeholders: service providers and government (facilitated by professional consultants (KPMG)). PLWD are excluded from the negotiating and systems reform design table.

Unfortunately, it signals to the broader community that PLWD are not worthy and not capable to contribute to ideal system change.

Not engaging PLWD as key stakeholders in all facets of system reform misses the opportunity for PLWD to assist in shaping workable partnerships within balanced, inclusive power relationships, ‘seeking a viewpoint from those affected by a policy decision is sometimes a legal requirement and often, just smart policy making’ (Bridgman and Davis 2004 p.78). It also minimises the opportunity for PLWD to become self-determining and responsible for their own lives because they are not at the discussion table engaging with the other key stakeholders sharing information and experiences. There is a lost opportunity to have ownership of shaping an ideal social care system for future generations.

Without acknowledging PLWD as ‘a relevant community of interest’ at the system reform table, strengthens the ‘paradigm of professional control’ instead of ‘emphasising self-determination and community involvement’ (Fisher et al. 2008); and blocks the ‘humanisation’ movement of PLWD (Ward and Meyer 1999).

The very fact that PLWD have been excluded from shaping a new system that affects their lives, places the reform agenda at high risk of failing to meet the needs of PLWD in contemporary society. PLWD (and their families/carers) are demanding systems change where they are at the centrepiece of decision-making about their own lives.

This very action of ‘missed consultation’ perpetrates charity, benevolence, and professional control of PLWD. Such imagery does not highlight diversity, difference and worthiness of PLWD as citizens.

The opportunity for true transformation is now remote. Unless PLWD are enrolled in a partnership strategy to draw them into decision making, in the shaping of a new system reform, the possibility of true systemic transformation is missed.

At worst the Disability Reform Agenda will unwittingly perpetrate exclusion of PLWD and the chance to become self-determining and responsible for their futures in Tasmania is lost. At the very heart of the reform design, the power and control remains within the relationship between the government and the service providers. PLWD are excluded.

The reform is at high risk of regurgitating an already broken system into another form which is not the intention of government, rather, a careless possibility.

So questions remain. How can the voices of PLWD be heard? Why have PLWD been excluded from the fundamental shaping of system reform? How can PLWD have self-determination and choices that includes an independent life, when the very system that controls them does not include them in the process of shaping appropriate reform?

Bibliography

Bridgman, P and G Davis. 2004. The Australian Policy Handbook. 4 Edition. Crows Nest, NSW: Allen & Unwin.

Fisher, K.R., S Parker, C Purcal, O Thaler, P Abelson, E Pickering, S Robinson and M Griffiths. 2008. "Effectiveness of Supported Living in Relation to Shared Accommodation." Sydney: University of New South Wales Consortium.

NPWDACC. 2009. "Shut Out: The Experience of People with Disabilities and their Families in Australia." ed. FaHCSIA. Canberra: Commonwealth of Australia.

Stainton, T. 2000. "What is Self-Determination?" In The First International Conference on

Self-Determination and Individualised Funding. Seattle.

Stainton, T. 2009. "Case management in a rights-based environment: structure, context and roles." In Planning and Support for People with Intellectual Disabilities.

Ward, M.J. and R.N Meyer. 1999. "Self-Determination for People with Developmental Disabilities and Autism: two self-advocates' perspectives." Focus on Autism and Other Developmental Disabilities 14(3):133-139.

Yours sincerely

Joyce Bellchambers

NSW