

## 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.

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](http://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*