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# **THE WINSTON CHURCHILL MEMORIAL TRUST OF AUSTRALIA**

## **Report by Theresa Williams**

### **2011 Churchill Fellow**

#### **To investigate the policy and practice of self-directed support for people with a mental illness**

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Signed  
Theresa Williams

Date  
4<sup>th</sup> October 2012

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A highlight was meeting service users and their families who shared their stories of recovery with me in the hope that this would help others.

I particularly want to thank Kevin Lewis for arranging the London meetings with key people in the Department of Health and with service providers delivering personal health budgets; Jenny Robb, Karla Muchmore and Antony Dowell for the comprehensive programme of visits in Liverpool and for connecting me to service users and carers; and finally, Professor Gerard Quinn for kindly hosting my visit to NUI Galway.

Thank you to my family for your support and sharing my excitement at the opportunity this Fellowship gave. Special thanks to my husband, Christopher, who managed accommodation bookings, juggled train timetables and carried heavy suitcases but most importantly was a wonderful companion on this extraordinary journey.

My hope is what I have learned, through the privilege of having received a Churchill Fellowship, can contribute in some way to improving the lives of people with mental illness.

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# 1. Executive Summary

**Project Description:** To investigate the policy and practice of self-directed support for people with a mental illness. In 2012 I visited England, Scotland, Ireland, Belgium and the Netherlands to learn from countries taking different policy approaches and at varying stages of implementing self-directed support to learn what might work in Australia.

## Highlights

- Discussions with policy makers in the health or disability sectors in London, Edinburgh, Dublin and The Hague;
- Meeting innovative NGO user-led services such as Per Saldo, the Independent Living Association and All Together Positive which support people with personal budgets;
- Finding out first hand from those who have implemented personal health budgets in Mersey Care NHS, Northampton NHS and Croydon DAAT or personal budgets in social care in Stockport and Glasgow;
- Visiting NGOs such as Look Ahead, Penumbra and SAMH which are transforming the way they work with people who use their services;
- Learning about innovative and creative ways of transforming systems from the Providers and Personalisation Programme and the Social Care Ideas Factory in Scotland, the Expertise Centre Independent Living in Belgium and Genio in Ireland;
- Gaining a deeper understand about the UN Convention on the Rights of Persons with Disabilities and rights based disability law reform at NUI Galway and from Amnesty International, Ireland; and
- Being inspired by the stories of recovery from personal budget holders who so generously shared their experiences.

## Conclusions

Key findings were:

1. Personal budgets can result in powerful changes in people's lives.
2. To exercise real choice and control budget holders require access to services such as information, advice and brokerage.
3. Capacity building for providers is needed to deliver personalised, recovery-oriented services.

My overall conclusion was that personal budgets can bring about significant change in a person's life; however, many people with a mental illness will continue to receive services from support and clinical providers. To achieve real choice and control, mental health budget holders need providers who can deliver personalised, recovery-oriented services. This means putting in place 'enablers' to support change as part of a systematic, sustained approach to transforming service delivery.

**Dissemination** of my findings will be through presentations to key mental health organisations and at conferences as well as publishing journal articles. A highlight since my return from the Fellowship has been the opportunity to contribute as a member of the Mental Health Commission expert panel reviewing individualised supports and funding for this new programme in Western Australia.

**Theresa Williams**, Director, WA Centre for Mental Health Policy Research, Graylands Hospital, Brockway Rd, Mt Claremont, WA, 6010, AUSTRALIA, Phone: (08) 9347 6527

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## 2. Introduction

The aim of this Churchill Fellowship was to investigate the policy and practice of self-directed support for people with a mental illness. The Fellowship provided me with the opportunity to travel to five countries, England, Scotland, Ireland, Belgium and the Netherlands, to examine a range of self-directed support programmes in different policy and service delivery settings.

Self-directed support sits within a much broader policy agenda for people with disabilities and those long term health conditions to have the right to greater control and choice in their lives. To understand this context, I've outlined a brief description of the key policy and legislative drivers.

### 2.1 Recovery, Personalisation, Human Rights and Self-directed Support

Internationally, there has been increasing policy momentum for people with disabilities to take greater control of their lives. There are two significant policy approaches at the heart of this: Recovery and Personalisation.

**Recovery** has a particular meaning within the mental health context and is conceptualized as *"...a way of living a satisfying, hopeful and contributing life even with limitations caused by the illness"* (Anthony, 1993). It goes beyond a focus on illness and symptoms and emphasizes hope and empowering the individual to seek their individual life goals. It was well captured by Alan Fels, Chair of Australia's newly established National Mental Health Commission when he addressed the National Press Club in August 2012 and said: *"by recovery I mean people leading the lives they aspire and wish to."*

**Personalisation** has its roots in the disability sector, specifically the independent living movement, and comes from a citizen rights based tradition with individual self determination at its core. Personalisation has developed into a concept which is now shaping policy in health and social care in the UK. It has two aspects: firstly, that services are shaped to fit the needs of each individual; and secondly, this individualised approach is underpinned by a fundamental change in the relationship between the citizen and the state from being recipients of services to actively exercising the right to control their lives (Alakeson, 2010). These two aspects were well articulated by the Prime Minister's Strategy Unit in 2007 where personalisation was defined as *"the process by which services are tailored to the needs and preferences of citizens. The overall vision is that the state should empower citizens to shape their own lives and the services they receive."*

Within the disability sector this **citizenship/rights based approach** has been strengthened and formalised by the Convention on the Rights of Persons with Disabilities (CRPD), adopted

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by the United Nations in 2006. Australia became a signatory to the CRPD in 2007 and ratified it the following year. The convention recognizes *“the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices.”* Article 1 of the convention explicitly includes those with a disability due to long term mental illness.

*“Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”*

[www.un.org/disabilities/convention/conventionfull.shtml](http://www.un.org/disabilities/convention/conventionfull.shtml)

Although the concepts of recovery and personalisation derive from two different sectors, they overlap in that both are fundamentally seeking the same end, that is greater choice and control in how to live ones’ life. Increasingly, the language of personalisation is finding its way into mental health policy as it is seen to support the core concept of recovery.

**Self-directed support** picks up on the values of choice and empowerment and encompasses a range of mechanisms designed to increase people’s choice over their care and support. In that sense it is one of many tools which can be used to implement and operationalise the philosophies which underpin both recovery and personalisation.

One particular approach to providing self-directed support is the use of personal budgets. This involves assessing individual needs and allocating funding to a person, as an individual personal budget, so that they can meet their support needs in a way which best suits them. The principle of choice and control is central and a personal budget is designed to achieve this by placing the person in the driver’s seat rather than the care provider.

There are varying ways a personal budget can be offered, but broadly either a person:

- receives a direct cash payment to purchase their own support services; or
- a third party holds either a cash or ‘notional’ budget with services purchased and/or provided in line with the individual’s wishes.

In summary, self-directed support is best viewed as one mechanism within a broader suite of personalisation or recovery strategies which will enable people to have greater control over the support they receive.

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### 3. Programme

I visited England, Scotland, Ireland, Belgium and the Netherlands to investigate policies and practice in self-directed support.

I chose these countries as they are at different stages of implementing self-directed support and are being driven by different policy imperatives. Consequently, this provided great diversity and much to learn about both the policies and approaches to implementing and sustaining self-directed support programmes.

Across these countries, self-directed support is embedded within different policy frameworks and health and disability service structures. In some countries a broad policy approach to personalisation and self-directed support is being developed, whereas, in others the so-called 'cash for care' personal budgets have been the preferred approach.

Some countries, such as the Netherlands and Belgium have had personal (cash) budgets in place for some years; others such as Scotland are in the process of introducing self-directed support legislation and rolling out a national programme to introduce personal budgets in social care. England has already introduced personal budgets in social care and is now extending this to include healthcare for people with long term conditions through their personal health budgets programme. In Ireland, the disability sector is developing individualised supports and individualised budgeting into their national disability policy and funding from an NGO has enabled the trial of personal budget holding for people with a physical disability.

Although the Fellowship was aimed at self-directed support for people with a mental illness, I included the disability sector as those with a psychiatric disability may receive services under this broad umbrella. Furthermore, the disability sector has often led the way in the area of individualised personal budgets and I considered that their experience and learning may well translate into mental health.

During my visits I met with a wide range of people and services. It included those who work in central government policy agencies, university researchers, service providers in both the public and not-for-profit sectors, advocacy groups and consumers and carers. I met with people in the mental health and the disability sectors. I also attended two conferences at the NUI Galway.

My observations are necessarily restricted by having spent a brief period of time in each country and so they are, by their nature, a personal reflection. In particular, I saw these systems through the eyes of someone well acquainted with the Australian healthcare

system and with the purpose of filtering the learning which could be readily translated into our own context.

The programme of visits and the people I met are detailed below.

<b>ENGLAND</b>	
<b>London</b>	<ul style="list-style-type: none"> <li>▪ Dr Alison Austin, Head of Personal Health Budgets (PHB) Team, Department of Health, responsible for the oversight of personal health budget policy development and the pilot programme across England</li> <li>▪ Vidhya Alakeson, Director of Research and Strategy at Resolution Foundation and an expert on personalisation who also works as a consultant on a range of policy and implementation projects on the development of personal health budgets</li> <li>▪ Kevin Lewis, Director, Kevin Lewis Consulting and most recently the Personalisation Programme Lead, National Mental Health Development Unit, provided expert input across the broad range of topics discussed in the meetings with Dr Alison Austin, Sue Nowak, Dr Sally Porter and Alan Colhoun</li> <li>▪ Sue Nowak, Mental Health Payment by Results Lead, Department of Health</li> <li>▪ Ceri Sheppard, Transformation Manager, Look Ahead Housing and Care</li> <li>▪ Manager and staff members, Manor House, Look Ahead Housing and Care</li> <li>▪ Dr Sally Porter, Consultant in Addictions Psychiatry, Croydon DAAT, South London and Maudsley (SLaM) NHS Trust</li> <li>▪ Alan Colhoun, Developmental lead PHB pilot and chair of the pilot operational group</li> </ul>
<b>Northampton</b>	<ul style="list-style-type: none"> <li>▪ Gill Ruecroft, Northamptonshire Personal Health Budget Pilot Lead, Nene Clinical Commissioning Group</li> <li>▪ Kim Dodd, Programme Lead for Mental Health Commissioning at NHS Northamptonshire</li> <li>▪ PHB client</li> <li>▪ Social Worker, Community Mental Health Team, NHS</li> <li>▪ Psychiatric Nurse, Community Mental Health Team, NHS</li> </ul>
<b>Liverpool</b>	<ul style="list-style-type: none"> <li>▪ Jenny Robb, Director of Social Care and Safeguarding, Mersey Care NHS Trust</li> <li>▪ Karla Muchmore, Project Support to Director of Social Care and Safeguarding, Mersey Care NHS Trust</li> <li>▪ Lynn King, Allied Health Professions Lead, Mersey Care NHS Trust</li> <li>▪ Community Mental Health Team Lead, Mersey Care NHS</li> <li>▪ Antony Dowell, Programme Manager, Imagine</li> <li>▪ Paul Butler, Liverpool Primary Care Trust</li> <li>▪ Consumers, Carers</li> </ul>



<b>Stockport</b>	<ul style="list-style-type: none"> <li>▪ Nick Dixon, Commissioning Manager, Mental Health and Substance Misuse Services Adult Social Care, Stockport Council</li> <li>▪ Carmel Bailey, Social Inclusion Team Manager, Pennine Care NHS Foundation Trust</li> <li>▪ Barry Tildsley, Personalisation Coordinator, Pennine Care NHS Foundation Trust</li> <li>▪ Shirley Dean, All Together Positive</li> <li>▪ Co-ordinator, Wellbeing Centre</li> </ul>
<b>SCOTLAND</b>	
<b>Edinburgh</b>	<ul style="list-style-type: none"> <li>▪ Bette Francis, Head of Self-directed Support Team, Adult Care and Support Division, The Scottish Government</li> <li>▪ Geoff Huggins, Deputy Director of Health and Social Care Integration, Head of Reshaping Care and Mental Health Division, The Scottish Government</li> <li>▪ Nigel Henderson, Chief Executive, Penumbra</li> <li>▪ Dee Fraser, Providers &amp; Personalisation Programme Manager, Coalition of Carer and Support Providers in Scotland (CCPS)</li> <li>▪ Catherine Garrod, Providers &amp; Personalisation Programme Officer, CCPS</li> <li>▪ Manager, Edinburgh Crisis Centre</li> </ul>
<b>Glasgow</b>	<ul style="list-style-type: none"> <li>▪ Mark Hall, Project Manager, Business and Service Development, Scottish Association for Mental Health</li> <li>▪ Sheila Hanney, Project Manager, Scottish Association for Mental Health</li> <li>▪ Charlie Barker, Director, Social Care Ideas Factory</li> <li>▪ Charlotte Otter, Media and Communications Officer, Social Care Ideas Factory</li> <li>▪ Stephen Fitzpatrick, Head of Adult Services, Glasgow City Council</li> <li>▪ Raymond Bell, Head of Mental Health &amp; Adult Support, Glasgow City Council</li> </ul>
<b>IRELAND</b>	
<b>Galway</b>	<ul style="list-style-type: none"> <li>▪ NUI Galway &amp; Harvard University 4th International Disability Summer School: <i>The UN Convention on the Rights of Persons with Disabilities – How to use it</i></li> <li>▪ Amnesty International and NUI Galway Conference: <i>Mental Health Law Reform: New Perspectives &amp; Challenges</i></li> <li>▪ Sarah Simkin, Research &amp; Community Development Officer, Jigsaw</li> <li>▪ Dr. Mary Keys, School of Law, College of Business, Public Policy and Law, NUI Galway</li> </ul>
<b>Mullingar</b>	<ul style="list-style-type: none"> <li>▪ Dr Fiona Keogh, Research and Evidence Director, Genio</li> <li>▪ Tara Doheny, Programme Manager, Disability, Genio</li> <li>▪ Patrick McGowan, Dublin City University, Genio Board Member</li> <li>▪ Representative from Mayo Mental Health Service</li> </ul>

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<b>Dublin</b>	<ul style="list-style-type: none"><li>▪ Luke Mulligan, Principal Officer, Mental Health Unit, Department of Health</li><li>▪ Karol Balfe, Mental Health Campaign Co-ordinator, Amnesty International Irish Section</li><li>▪ Dharragh Hunt, Policy and Public Affairs Advisor, National Disability Authority</li></ul>
<b>BELGIUM</b>	
<b>Ghent</b>	<ul style="list-style-type: none"><li>▪ Linde Moonen, Researcher, Expertise Centre Independent Living</li><li>▪ Peter Lambreghts, Staff worker Expertise Centre Independent Living, Board member of the European Network on Independent Living (ENIL) and ENIL Western Regional Team Coordinator</li><li>▪ Staff member of Onafhankelijk Leven vzw (Independent Living Association)</li></ul>
<b>THE NETHERLANDS</b>	
<b>The Hague</b>	<ul style="list-style-type: none"><li>▪ Dr. Patrick Jeurissen, Economic Affairs and Labour Market Policy Department, Ministry of Health, Welfare and Sport</li></ul>
<b>Utrecht</b>	<ul style="list-style-type: none"><li>▪ Dr Barbara Da Roit, Assistant Professor, Faculty of Social Sciences, Utrecht University</li><li>▪ Frans van der Pas, Information and Policy Advisor, Per Saldo</li><li>▪ Dorien Kloosterman, Platform VG</li></ul>

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## 4. England

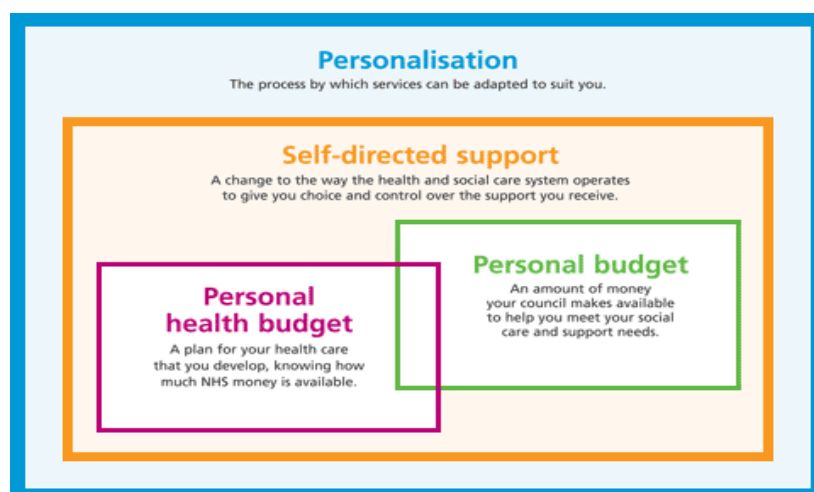
### 4.1 Background

Over a number of years the UK has been reforming public services with one of the key aims being to empower citizens. Back in 2007 the Prime Minister Tony Blair summarized the changes by saying *“these twin concerns – personalisation and equity – have been the driving force behind government reforms”* (PMSU, 2007). Shortly after their election in 2010 the Coalition Government confirmed their commitment to the choice and personalisation agenda: *“We will extend the greater roll-out of personal budgets to give people and their carers more control and purchasing power.”* (HMG, 2010)

In the UK, health and social care is provided through two separate funding and service systems, with the NHS providing health services and local councils responsible for social care. Personal budgets were first introduced in social care, with direct payments having been available since 1996. Subsequently, the NHS introduced personal health budgets in 64 pilot sites for people who had long-term conditions, including those with a mental illness. In 2009 the Department of Health announced that 20 of the 64 pilot sites would participate in an in-depth evaluation of personal health budgets. The final evaluation results will be delivered in October 2012 (NHS Confederation, 2009).

In October 2011 the Health Secretary Andrew Lansley announced that *“...we will offer personal health budgets to 50,000 people eligible for NHS Continuing Care Budgets that will give them more control over how their needs are met, allowing them to choose support and services that suit them and their families.”* This roll out of personal health budgets is subject to the results of the national pilot evaluation.

Personalisation in health care is being introduced against a backdrop of two significant policy agendas. First, the Health and Social Care Act 2012, to be enacted in 2013, which will see Primary Care Trusts and Strategic Health Authorities abolished and their funds transferred to Clinical Commissioning Groups which are largely led by General Practitioners. This legislation will result in a significant restructure of the NHS, particularly in relation to commissioning. Secondly, there is a policy drive to break down the barriers between health and social care funding and consider pooled or aligned funding streams (Department of Health, 2010). Overlaying these policy changes is the challenging financial environment in the UK at present.



Source: [www.personalhealthbudgets.dh.gov.uk/About/UnderstandingPersonalisation](http://www.personalhealthbudgets.dh.gov.uk/About/UnderstandingPersonalisation)

The above diagram provides a useful way of conceptualizing personalisation as the broad policy framework within which self-directed support sits. Health and social care personal budgets, which can have varying degrees of overlap, are mechanisms for delivering self-directed support.

## 4.2 Policy Overview

The following links to presentations by Dr Alison Austin and by Vidhya Alakeson provide an excellent summary of personal health budgets as they were in March and April, 2012.

[www.nuffieldtrust.org.uk/talks/slideshows/alison-austin-delivering-personal-health-budget](http://www.nuffieldtrust.org.uk/talks/slideshows/alison-austin-delivering-personal-health-budget)

[www.in-control.org.uk/what-we-do/staying-in-control-health/webinars/personal-health-budgets-webinar-14-march-2012](http://www.in-control.org.uk/what-we-do/staying-in-control-health/webinars/personal-health-budgets-webinar-14-march-2012).

Some key points regarding Personal Health Budgets (PHB) are:

- PHBs are part of a larger policy drive to personalise public services;
- PHBs can be taken as a notional individual budget, a real budget held on the individuals' behalf or as a direct payments (the latter is currently only available in approved pilot sites, but this will be rolled out depending on the evaluation results due October 2012);
- The care plan, which takes a holistic approach to a person's life, is at the heart of the PHB;
- It is not about new money, but using existing money to enable people to meet their needs in different ways;
- The introduction of PHBs will take time and there are still many challenges to overcome.

Within a broader discussion on PHBs, the following are interesting innovations.

- *PeopleHub*

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In April 2011 the Department of Health established a personal health budgets peer network of around 20 people, all of whom had direct experience of, or cared for someone with a PHB. They work closely with the Department's policy makers. Some members of this group then went on to establish the *PeopleHub* as a user led network to empower more people with information on PHBs. As their website states they "*build on a people's movement for change*" by giving a voice, connecting and empowering and influencing developments in PHBs.

- *ImROC (Implementing Recovery – Organisational Change)*

This two year funded project started in January 2011 as a partnership between the NHS Confederation, the Centre for Mental Health and the National Mental Health Development Unit. It uses a methodology for promoting recovery through whole of system organisational change developed by the Centre for Mental Health. It supports six demonstration sites, six pilot sites and 17 network members to embed a recovery orientation at an organisational level. One of the key organisational challenges addressed by ImROC is to increase personalisation and choice. A key aspect of the programme is intensive expert input to each site and the opportunity to learn from peers by attending 'learning sets'.

#### *Mental Health Payment by Results*

A policy development which will impact on the PHBs is the Payment by Results programme. It represents a different way of funding providers by developing processes to ensure that the allocation of money is more closely linked to the needs and service requirements of individual service users. Broadly, service users with similar types of characteristics are clustered and a price is determined for each cluster. Funding based on this model should enable providers to deliver the care which corresponds with the service needs of people in each cluster. The payment by results approach in mental health recognizes that service input can change during an episode of care.

Payment by Results is an attempt to develop a more transparent approach to funding which recognizes the varying needs of individuals. It provides a mechanism for moving from block funding to a system based more closely to the needs of individuals. The challenge is to ensure that 'cluster based funding' will not hinder the level of flexibility and responsiveness to individuals which PHBs require. Work is continuing to further refine Payment by Results and to determine its relationship with resource allocation in personal health budgets.

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## 4.3 Policy into Practice

### Look Ahead Housing and Care

This organisation provides support, care and accommodation to people with a range of needs across London and the South East. Personalisation is at the core of their approach. Their CEO, Victoria Stark, recently wrote:

*“Every day our staff support customers to have genuine choice and control over their support – and their lives – through a range of personalised support models that go far beyond individual budgets.”*

Personalisation was described as a concept where the person’s life and goals are at the centre and each individual client can expect to:

1. Choose their Support Worker;
2. Choose when and where they are supported;
3. Help control how resources are allocated and spent;
4. Help design the services they want.

1 & 2 = support and planning for the individual

3 & 4 = co-production shared by the individual and the provider

In practice this has meant training for staff and support for customers to create their own person-centred plans including how they want to be supported, who they want to be supported by and the preferred time and place of support. To achieve this has involved considerable work in developing and redesigning support planning tools and processes. Another key innovation has been the involvement of customers in all stages of the recruitment process, from identifying the skills and qualities they want in people supporting them, to incorporating this into job descriptions and participating as a member of selection panels to choose staff.

The Transformation Manager and I then visited Manor House and spoke with the manager and staff. The service provides accommodation and support for single, homeless women. There is active customer involvement in staff recruitment, decisions about refurbishing and decorating, workshops and activities. The majority of women write their own support plan. Customers choose their own support worker by opting for a preferred worker and nominating a second choice so as to make it workable. Every 6 months it is possible to re-choose your support worker. Although Manor House receives block funding, personalisation underpins the service. While *Look Ahead* also provides services to personal budget holders, there is a wider commitment by the organisation to personalising all services, regardless of the funding mechanism.

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## **Northamptonshire**

The Northamptonshire PHB (in conjunction with Nene Commissioning) is one of 20 sites participating in the in-depth national evaluation. The focus is on people with continuing health care needs, mental health problems and those who have had a stroke. At the time of my visit in April 2012, a total of 14 mental health service users had a PHB in place. Budgets ranged from approximately £1,800 to £29,000. The main aims of the individual plans were, in the following order: to reduce demand on health services, improve socialization and gain employment or return to work. The only exclusion criteria for participating in the pilot was if people were detained or in prison. Budgets were determined by the cost of services used in the previous 12 months. The budgets have provided access to a range of supports and therapies not readily available in the NHS and the guiding principle has been to focus on ensuring outcomes are achieved rather than overly concentrating on what people are buying. Factors which are vital to the success of the programme have been a close working partnership with the NHS staff, the quality of the care plan and the level of commitment of the care co-coordinators.

The overall message is that the pilot is achieving positive results for service users. The story of a person who received a PHB in the Northamptonshire pilot can be found in the recent publication *Recovery, Personalisation and Personal Budgets* (Alakeson & Perkins, 2012).

[www.centreformentalhealth.org.uk/pdfs/Recovery\\_personalisation\\_and\\_personal\\_budgets.pdf](http://www.centreformentalhealth.org.uk/pdfs/Recovery_personalisation_and_personal_budgets.pdf)

Implementing a PHB programme has been complex and administering the programme has been time intensive for care co-ordinators. While the administrative load for care co-ordinators has been manageable during the pilot phase, this issue will need to be addressed when the roll out extends to the NHS Continuing Care Programme. The question of how care co-ordinators can be supported was raised. An option being discussed is the need for a broker or advocacy service provided by people with knowledge of the NHS but separate from it. Other challenges include developing PHBs within the new commissioning environment, refining Payment by Results clusters to ensure compatibility with PHB resource allocation mechanisms and managing the proposed expansion of PHBs through the Continuing Care programme in 2014.

Even though the PHB pilot is drawing to a close, the intention is to continue to improve the integration of health and social care personal budgets through the Integrated Care Partnerships.

## **Croydon Drug and Alcohol Action Team (DAAT)**

Work on personalisation and personal budgets began in this adult substance misuse programme in 2008 with a small pilot (20 people, £1,000 maximum each, no direct payments). Individuals used these relatively small 'recovery budgets' to purchase such

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services as educational courses. The next stage was to introduce PHBs and the lessons learned from the recovery budgets have been important in informing the implementation of PHBs. In order that an evaluation can be carried out 30 people have been recruited to a PHB group and 30 are in a comparison control group.

Two key features of the pilot are:

- developing the new role of 'Care Navigator', a member of the treatment team taking a holistic approach to treatment and recovery; and
- using independent brokers.

A detailed operational policy has been developed and considerable thought and work has gone into policy and protocols. All staff are trained in recovery care planning and once the treatment and recovery plan has been drafted it must be approved by the care navigator and their manager as well as requiring clinical sign off from the Consultant Psychiatrist to ensure that treatment needs are met. The programme is part of the national evaluation of PHBs due to be released in October 2012.

Despite challenges for a couple of clients, this programme shows promise in demonstrating that PHBs for both social and medical care are possible for people in substance misuse programmes. While a progress report on the pilot presented to the Croydon Council in January 2012 outlines a number of challenges, the overall assessment of the programme is positive.

*".....our impression has been that patients are retained in treatment for significant periods and have made some valuable and innovative choices with regard to their treatment plans."*

*"The use of personal health budgets has been associated with a change in the dynamics of the relationship between client and worker, has challenged staff and services to personalise treatments, has led to an explicit recognition that cost effectiveness needs to be explored and has led to the formulation of high quality, personalised care packages that are based on individual recovery outcomes."*

(Croydon Council, 2012)

### **Mersey Care NHS Trust/Imagine/Primary Care Trust**

- Mersey Care NHS Trust provides specialist mental health and learning disability and substance misuse services for the people of Liverpool, Sefton and Kirkby.
- Imagine is a voluntary sector mental health organisation supporting more than 1,000 people.
- Liverpool Primary Care Trust is responsible for commissioning healthcare services across the city, including assessing population needs, prioritising health outcomes, procuring products and services, and managing service providers.



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### *One-off Individual Recovery Budgets*

In 2008 the Mersey Care NHS Trust started a 12 month pilot to provide individual Recovery Budgets to service users in the Early Interventions in Psychosis service. This was subsequently expanded to include service users from a Community Mental Health Team (CMHT). A voluntary sector organisation, Imagine, was engaged to provide the support planning and brokerage to people offered a recovery budget by the clinical teams. Budgets averaged approximately £400, were one-off and were mainly used for education and training, for helping people get a job and for leisure activities. Purchased items included garden tools, gym membership, bikes, computers or short holiday breaks.

The CMHT clinicians identified potential clients. The Imagine broker then spent time with the person and, if appropriate, with their family to work through what the individual wanted to achieve. Their clinician may also be involved in this planning process. Once the plan was developed it had to be agreed with the person's clinician and it then received sign off. The budget was held by Imagine, who arranged for payment of agreed services or goods on behalf of the individual. An important principle was that while brokers had the responsibility to procure, the process was co-produced with the CMHT. The programme was expanded to include Sefton, Liverpool and Mosley. It was evaluated in 2008/09 by the University of Chester and showed promising results (Coyle, 2009).

A most powerful aspect of the recovery budgets has been the stories of service users and the impact of the recovery budgets on their lives. I was privileged to meet two consumers whose journey of recovery was assisted by their Recovery Budget. *Stories of Hope* documents the impact of the Recovery Budgets and can be found on the following site:

[www.personalhealthbudgets.dh.gov.uk/Topics/latest/Resource/?cid=8482&excludepageid=2289](http://www.personalhealthbudgets.dh.gov.uk/Topics/latest/Resource/?cid=8482&excludepageid=2289)

### *Personal Health Budgets*

Building on their work with Recovery Budgets, Mersey Care NHS Trust is now implementing PHBs and is also a pilot site participating in the national evaluation. The Mersey Care PHBs enable people to receive larger packages of support than Recovery Budgets and allow the development of joint funding packages with social care. In particular it allows people to have:

- their provider of choice;
- flexibility about the way they use funds to support agreed outcomes; and
- joint health and social care funds paid as a direct payment.

Imagine has been selected to provide the brokerage service.

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The NHS has recently published a case study on the Mersey Care PHBs (Department of Health, 2012). It notes that expanding from the pilot phase to a wider roll out will pose challenges and there is a need to build on the following lessons learned to date:

- Information is necessary for service users and clinicians;
- PHBs need to be built into the Care Programme Approach to include people with significant mental health problems;
- Clarity is required regarding sign off procedures;
- Peer support and co-production is important;
- Funding for support planning and brokerage is necessary;
- Support is needed for providers to shift from block funding to individual funding packages;
- Support is needed for people with direct payments; and
- Monitoring and review systems, including outcome measures, are important.

#### *ImROC (Implementing Recovery – Organisational Change)*

##### *Recovery Colleges*

The PHB programme has been well supported by Mersey Care's participation in the ImROC programme, where personalisation is one of the key focus areas. This national programme aims to support a recovery based approach in secondary mental health services. The publishing of a collection of personal stories of people with Recovery Budgets, *Stories of Hope*, was supported by ImROC. This has become an important national resource and demonstrates the significant impact of recovery budgets on people's lives.

Another innovation arising from the ImROC programme is the development of Recovery Colleges (Perkins et al, 2012). These colleges deliver comprehensive, peer-led education and training programmes within mental health services. The courses are developed and delivered jointly by mental health professionals and people with a lived experience of mental illness. A pilot recovery college, *Launch Pad*, has been developed by Mersey Care. In June 2012, there were four recovery colleges in England with more due to open. The South West London College was referred to as an interesting example and a video which describes the college which can be seen at:

[www.youtube.com/watch?v=VSOeQbkMVgc](http://www.youtube.com/watch?v=VSOeQbkMVgc)

#### **Stockport**

The Stockport Council and Pennine Health Care NHS Trust jointly developed a Mental Health Self-Directed Support Pilot in 2009 to explore self-directed support and adult social care personal budgets within the Stockport mental health services. The initial pilot was for one year but was extended to 18 months. It commenced with the Early Intervention Team but as the numbers were lower than expected was later expanded to include all of the mental

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health teams. At the completion of the pilot 179 service users had taken up personal budgets, which exceeded expectations. Only social care funds were used in this pilot and the median spend was £3,976 in the first year dropping to £2,989 in the second (Eost-Telling, 2010).

An evaluation by the University of Chester reported that support plans were creative and outcome focused and service users reported positive impacts on many aspects of their lives. Most care practitioners were generally positive about the underlying principles of self-directed support and felt that many participants had benefited. It was recognized that the programme required a cultural shift for both practitioners and service users. The risks were identified as the ‘professionalising’ of personalisation and the potential for personal budgets to be used to support a ‘maintenance’ approach rather than encouraging recovery and self management (Eost-Telling, 2010).

An interesting aspect of the pilot was that a number of brokerage models were explored: an external broker, internal broker, peer broker and self brokerage. An innovative model was the development of peer brokerage, where service users established a user led organisation, *All Together Positive*. This is a not-for-profit, social enterprise which describes their service as supporting “*a person through the maze of the personalisation process, which can at times seem complex.*” The organisation not only assists in the development of individual plans, but provides a brokerage service and engages with policy makers and services about personalisation and personal budgets.

Post the pilot, Stockport Council and Pennine Care NHS Trust are redesigning mental health services to discharge people from specialist services to a range of community alternatives. Facilitating easy re-entry to specialist mental health services if required is assisting this discharge process. It continues to be underpinned by the principles of co-production by bringing staff from the Trust and local user led organisations to work together in a team.

Future challenges include ensuring that the Payment by Results policy is linked to personalisation principles and supports recovery outcomes.

## **4.4 Reflections**

### *An individual budget can change a person's life*

The personal stories of people who have received an individual budget are powerful and compelling. There were positive impacts on people's lives both from the one-off Recovery Budgets (Mersey Care NHS) and Personal Health Budgets (Croydon DAAT, Northamptonshire NHS). Overall, among the people I met, including policy makers, programme administrators, service providers, clinicians and service users, there was strong support for individual budgets.

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### *Personalisation is bigger than budget holding*

Budget holding is a means rather than an end in itself and there may well be a number of people who choose not to take up a budget. The core elements of a personal plan, individualised supports and co-production can still be achieved regardless of the funding mechanisms. The core of personalisation is choice and control for the client and the importance of embedding this into service provision remains a work in progress. *Look Ahead* provides an example of a service which is explicitly committed to this process.

### *A Recovery Focus*

There has been a significant amount of work in England to connect personal health budgets for people with mental illness to a recovery framework. It is a recognition that personal health budgets in mental health need to be tailor-made to accommodate a recovery philosophy and so will differ in some respects from personal health budgets for those with other health needs. A particular issue for budget holding in mental health is it should go beyond maintenance and actively foster recovery outcomes. Some innovative approaches to supporting a recovery approach include the ImROC programme, the establishment of Recovery Colleges and the development of peer-led brokerage and support.

### *Change takes time*

England has been fortunate in that over many years there has continuing central government policy support for the personalisation agenda, including the mechanism of personal budgets. In various guises personal budgets have been in place since the ‘cash for care’ Independent Living Fund in 1988, followed in 1996 by social care direct cash payments, and most recently the development of personal health budgets for those with long term healthcare needs. The amount of time these significant system changes require to implement should not be underestimated and a policy setting which survives over time and through changes of government is invaluable for successful implementation.

### *Implementation*

PHBs have had the benefit of the experience gained through introducing personal budgets in social care. Implementation of PHBs has been staged. The first step was to start pilots in a limited number of sites, followed by an evaluation and a wider roll out of the programme. This process enables stakeholders in all parts of the system to ‘learn from doing’ and find ways to manage implementation challenges.

Innovative approaches have developed during the early implementation stage. For example, some members of the Department of Health PHB peer network have established *PeopleHub* as a network to “*build on a people’s movement for change*”.

A key feature of the services I visited was the importance of partnership across the system, between policy makers, commissioners, clinical services, NGOs, service users and carers. The engagement of mental health services and clinicians in the process has been important.

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There remain, however, some significant challenges. These include determining budgets for individuals and linking this to the Payment by Results programme; ensuring that the administrative burden both for budget holders and providers is minimized while managing overall transaction costs; providing budget holders with access to information and support; ensuring that PHBs are cost effective and good health outcomes are achieved; and developing further integration between health and social care.

#### *Outcomes*

A particular strength of the way PHBs have been introduced in England is the evaluation of the programme. Overall there are 64 pilot sites, with 20 participating in the national evaluation. Five interim reports have been published through the process and this supports continuous learning. The penultimate report from the national evaluation team in June reported positive impacts of a PHB on the health and well-being of budget holders (Davidson et al, 2012). It was an interesting period of time to visit England as the final evaluation report was imminent. The results will be important in shaping the future of the programme.

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## 5. Scotland

### 5.1 Policy Overview

#### Self-directed Support (SDS)

Social care direct (cash) payments have been legally possible in Scotland since 1996, however, in 2010 the Scottish Government launched a national self-directed support strategy setting out a 10 year vision designed to provide people with more choice and control over their support. In February 2012 the Social Care (Self-Directed Support) (Scotland) Bill was introduced in the Scottish Parliament. It is currently proceeding through the parliamentary process with the Health and Sport Committee publishing its Stage 1 report on July 6<sup>th</sup>. The Report is available at:

[www.scottish.parliament.uk/parliamentarybusiness/CurrentCommittees/48016.aspx](http://www.scottish.parliament.uk/parliamentarybusiness/CurrentCommittees/48016.aspx)

The legislation covers social care and does not include services provided by the NHS. If enacted, the Self-directed Support Bill requires local authorities to offer people four choices on how they can obtain their social care:

1. Direct payment;
2. The person directs the available support through a provider they have chosen;
3. The local authority arranges the support which has been chosen by the person; or
4. A mix of these options for different types of support.

A wider strategy accompanies the development of the legislation including:

- Investing in support/advice organisations for budget holders;
- Supporting social care support providers; and
- Supporting local councils.

Details of much of this work are available on the Scottish Government's Self-Directed Support (SDS) website.

[www.selfdirectedsupportscotland.org.uk/](http://www.selfdirectedsupportscotland.org.uk/)

SDS has been piloted in three test sites: Glasgow, Dumfries and Galloway and Highland. While none of these sites focused exclusively on implementing SDS in mental health, there has been recognition that mental health has some sector specific issues which require consideration. The Scottish Government has recently jointly funded the Mental Health Foundation, the Scottish Mental Health Cooperative and the Scottish Service User Research Network to work with mental health NGO service providers and service users to identify and address implementation challenges.

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## Mental Health

*The Mental Health Strategy 2012 – 2015* has recently been released by the Scottish Government. It specifically commits to adopting a person-centred approach to give people greater control and to be involved in decision making. This philosophy is consistent with the SDS agenda.

## Health and Social Care

The Joint Improvement Team (JIT), based in Edinburgh in the Directorate for Health and Social Care Integration, was established in 2004 to work directly with local health and social care partnerships across Scotland. JIT is co-sponsored by the Scottish Government, the Convention of Scottish Local Authorities and NHS Scotland. A JIT project which supports the personalisation and SDS agenda is *Talking Points: A Personal Outcomes Approach*. This combines user and carer involvement in developing an approach to measuring outcomes for individuals. This approach fits well with the outcome focus of individual support plans which are a core part of the personalisation and SDS agenda.

[www.jitscotland.org.uk/action-areas/talking-points-user-and-carer-involvement/](http://www.jitscotland.org.uk/action-areas/talking-points-user-and-carer-involvement/)

## 5.2 Policy into Practice

### Coalition of Carer and Support Providers in Scotland (CCPS)

The CCPS has a membership of over 70 not-for-profit care and support providers in Scotland. The Providers and Personalisation Programme (P&P) is hosted by CCPS. It commenced in 2010 as a four year policy and practice change programme, funded by the Scottish Government, *“designed to increase the provider voice in the development of national and local SDS policy and to support providers to increase their knowledge, skills and confidence in preparing for fully self-directed support”*. Details of their programme and extensive work agenda can be found on their website:

<http://ccpscotland.org/providers-and-personalisation>

P&P is an impressive programme which recognizes the extent of the changes which providers will need to address in order to personalise their services and manage the shift to SDS. It also provides a voice for providers to shape the development of SDS. In the CCPS submission on the SDS Bill to the Health and Sport Committee in 2012 they reported that there was support among care providers for SDS, however some key concerns were:

- Direct payments should be sufficient to enable a person to purchase an equivalent level of support as other SDS funding options;
- Information and advice is insufficient and it is preferable that this advice is provided by an organisation which is independent of the local authority or provider; and
- There are a number of cost implications in shifting to SDS such as increased staffing costs associated with providing more personalised, flexible care.

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While their work supports providers across the spectrum of social care, a recent project specifically addressed issues in mental health. This was a partnership project with CCPS's Workforce Unit, Loretto Care, Creative Frontline and IRISS which was designed to engage service-users and NGOs to develop SDS for people with mental health issues. The final report states that *"The SDS framework does need to be interpreted to make it work for people with mental ill health. Priorities, flexibility and outcomes will be different to other groups accessing SDS and so local authorities need to ensure any restrictions on SDS do not impact on mental health."* (IRISS, 2012)

## **Penumbra**

Penumbra is a mental health not-for-profit organisation. Their CEO, Nigel Henderson, is a member of the steering group for the proposed legislation on SDS and co-chaired the *Changing Lives* report on personalisation (Scottish Government, 2009).

Penumbra services are personalised and recovery-oriented. Their innovative services are person-centred and direct payments and individual budgets are seen within the broader concept of personalisation.

*"Personalisation of services means that rather than presuming that "one size fits all", it is essential to enable people to have care and support built around their personal needs, choices and aspirations. Penumbra feels strongly that, as far as possible, all services should be personalised so that people have more choice and control over their lives."*

<http://www.penumbra.org.uk/innovation/personalised-services>

Penumbra's work is underpinned by the HOPE model (Home, Opportunity to pursue meaningful activity, People in your life, Empowerment to be involved in decision making). HOPE is used to carry out individualised assessments and set goals and plans. As part of the personalisation agenda, Penumbra is measuring individual outcomes through an instrument called i.ROC (Individual Recovery Outcomes Counter), a facilitated self-assessment questionnaire linked to their HOPE model of recovery. Penumbra is working with Abertay University to assess the reliability and validity of i.ROC.

There are a number of challenges provider organisations have to address in making a transition to SDS. These include managing the workforce while providing increasingly flexible services, shifting from block contracts to funding via personal budgets and developing ways to measure individual outcomes rather than outputs.

## **Edinburgh Crisis Centre**

While I was at Penumbra I was offered the opportunity to visit Scotland's first crisis centre. The service is open 24/7 every day for people over 16 years who have used or are using mental health services and are experiencing a crisis. The service provides an alternative to



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hospital. It provides face-to-face support, has facilities to enable a maximum of 4 people to stay up to a week as well as providing a 24/7 telephone help line. Access to the service is via the free phone helpline as self referral is required.

### **Glasgow City Council**

The importance of the *Changing Lives: Report of the 21<sup>st</sup> Century Social Work Review*, published in 2006, was highlighted. Much of the impetus for personalisation and subsequently the development of SDS had its origins in this report which specifically requires social services to develop new commissioning models based on delivering personalised services.

SDS was described as being fundamentally about changing the dynamics in the relationship between service providers and service users. Co-production is a part of this changing dynamic, as is transparency of the budget. Although it has been possible for people to have a direct payment, historically only a small number of people have exercised this right. The SDS Bill, if passed, will require councils to offer a greater range of options for people to take control of their social care support.

The Glasgow City Council is a pilot site for SDS. At the time of my visit in early May 2012, the Council had just commenced their SDS pilot for people with mental health issues. The first phase of the pilot included 70 clients who were in the process of undertaking their self assessments. While the SDS programme is confined to social care and doesn't include joint health/social care funds as do England's Personal Health Budgets, social workers continue to be embedded in CMHTs so that the strong links between social care and mental health are maintained.

The practical steps in the process of providing SDS are:

1. Self Evaluation Questionnaire(SEQ);
2. Social Work assessment;
3. Resource allocation process based on the above to get an estimated budget;
4. Outcome based support plan.

A significant amount of work has been done to date and continues in the following areas:

- developing a financial framework;
- managing risk;
- linking funding to outcomes;
- workforce development including supporting changes in professional practice;
- enhancing information systems;
- re-defining the role of commissioning; and
- strengthening communication and engagement with stakeholders.

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An area which will become increasingly important is to develop ways for people to tap into local services and resources to become more linked into their community. Overall SDS requires significant cultural change and this will be an on-going process.

### **Scottish Association for Mental Health (SAMH)**

The Scottish Association for Mental Health is a not-for-profit organisation which has been in existence for over 80 years. SAMH is very aware of the wider personalisation agenda within which SDS is developing. They define personalisation and self-directed support on their website as:

*“Personalisation” stresses that a person should rightly be at the centre of planning and reviewing the support they need to live their life.*

*“Self-directed Support” (SDS) – is about an individual deciding and shaping the way in which their Individual Budget will meet their personal needs and goals – in partnership with others.*

Examples of ways in which SAMH provides personalised services are:

- One to one support which takes into account how, when and where a person wants to be supported;
- Tools for Living Programme, a series of 21 individual workshops grouped into 3 streams:
  - Personal Development – looking at each persons current situation and making personal plans;
  - Personal Resilience – building confidence and skills;
  - Personal Progression – future activities such as volunteering, learning, work.

<http://www.progressforproviders.org/index.html>

With the focus on outcomes based support plans in SDS, there is considerable work happening in this area. SAMH is using *My Outcomes*, a tool which can be used both for individual outcomes and then can be rolled up to the organisational level. I was also referred to other projects on measuring personal outcomes including *Talking Points* which was developed by the JIT (described in the previous section) and a paper, *Measuring Personal Outcomes: challenges and strategies*, which was recently published by the Institute for Research and Innovation in Social Services (Miller, 2011).

SAMH is working with care managers in local authorities to raise awareness about mental health and fluctuating support needs which may require assessments at more than one point in time to take account of changes in people’s mental health.

There is recognition that there is much to be gained from the introduction of SDS. However, it is also important to ensure that that individuals purchase recovery, not maintenance, packages of support and that the SDS system is not overly bureaucratic and builds on what is already being done well so as to do it better.

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## Social Care Ideas Factory

The Social Care Ideas Factory is a membership organisation, operating in Glasgow since 2006, whose purpose is to bring “*fresh ideas to social care*”. Through a range of highly innovative activities they improve networking and drive social change and partnerships.

The Social Care Ideas Factory has been very involved in SDS and was commissioned by the Scottish Government’s Self-directed Support Team to help launch the SDS Support Bill in March 2012. Other innovative SDS events have been:

- *The Art of Living Lifestyle Show* which enabled providers to showcase their services around the themes of home and community, love and relationships, health and care supports, money and contribution and spare time. It provided opportunities for individuals to consider SDS as a real opportunity for them to increase their choices and for providers to consider how to meet the future needs of their customers. Mystery Shoppers were included to provide feedback to providers.
- *The Festival of Ideas* was a series of events, interactive workshops and presentations designed to raise awareness around Personalisation and SDS.
- *Inspirers*, involves testimonies from individuals about their experiences with Personalisation and SDS.
- *Trendspotters*, where the organisation explores the world of ideas in other places and services and brings these possibilities to the table.

An interesting issue which was raised was that of needing to build ‘aspirational’ person-centred planning and practice. An important part of this is recognizing the need for the people involved in developing support plans and providing support to build inspiration into their work and lives so that they can in turn inspire the people they are supporting to recognize the possibilities in their lives.

## 5.3 Reflections

### *Supporting Providers*

The Scottish Government has recognized the immense change that SDS will bring for care providers. To support them through this change they have funded the Personalisation and Providers Programme for four years. It is a dynamic programme which provides an active voice for providers in SDS policy development and also works on key and emerging issues to increase the knowledge and skills of providers. Examples include recent seminars on “*Personalisation and Workforce Issues*” and “*Brokerage and Self-directed Support*”. Their regular information exchange among providers encourages organisations to raise issues and work on solving them as well as sharing examples of good practice. A recent example was the information exchange on outcomes based support planning.

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### *SDS embedded within Personalisation*

The organisations I visited are all very aware that SDS is embedded within a broader personalisation agenda. There is a significant amount of work happening within Penumbra and SAMH to personalise their services. This includes developing individual planning tools, tailor-making services to respond to individuals requirements for how, where and when they receive their support and then measuring individual recovery outcomes. Introducing individual budgets is a complex process and there is always a danger that the 'mechanics' of budget holding will capture the agenda. What was impressive about all of the organisations I visited is that they had maintained their focus on personalising services for individuals. There is a strong awareness that budget holding is just one way of achieving the larger aim of increasing people's choice and control.

### *Innovation with flair*

The Social Care Ideas Factory is a unique, Glasgow based organisation. In some ways the name of the organisation says it all. Their aim is to create connections and partnerships to improve people's lives and achieve social change. A significant focus of their work at present is in the area of personalisation and SDS. With a small staff they harness the energy and enthusiasm of their social care provider membership to achieve a great deal. The Festival of Ideas and Art of Living Lifestyle Show are only two of the creative ways in which they engage with their membership on personalisation and SDS.

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## 6. Ireland

### 6.1 Policy Overview

#### Mental Health

In 2006 the Irish Government endorsed a comprehensive mental health policy, *A Vision for Change*. A recovery approach underpins this policy direction which “*envision[s] an active, flexible and community-based mental health service where the need for hospital admission will be greatly reduced.*” Phased changes were to be implemented over a 7 to 10 year period and funds released from mental hospital closures were to be re-invested in mental health services to achieve the policy objectives.

An Independent Monitoring Group was established to track progress in implementing *A Vision for Change*. The 6<sup>th</sup> Annual Report has recently been released. They noted that there has been progress in implementing the policy, albeit more slowly than had been anticipated, and importantly a recovery ethos is starting to be adopted across the country.

When considering personalisation and self-directed support it was interesting to note the committee’s observation that “*there needs to be a cultural shift in how mental health services are delivered. This involves moving from professional dominance towards a person-centred, partnership approach.*”

To complete the implementation of *A Vision for Change* the Independent Monitoring Group recommends that “*...mental health services need to be able to demonstrate the following:*

- *An ability to identify and respond to the individual needs of the person and his/her family;*
- *Develop a relationship with the service user based on partnership;*
- *Provide a timely, appropriate and quality level of service intervention which is recovery based;*
- *Offer each and every service user and their family the hope of recovery.”*

The implementation of *A Vision for Change* has also taken place against a backdrop of organisational restructuring with further change on the horizon. The monitoring group provides a detailed history of the structural and management changes the Health Service Executive has undergone to date. There are plans for its eventual abolition in 2014 with a reallocation of responsibilities as part of the shift to a proposed universal health insurance system. This will also result in changes to the roles and responsibilities of the Department of Health.

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### *Mental Health Legislation*

The Irish Department of Health is reviewing the *Mental Health Act 2001* and the Joint Committee on Justice, Defence and Equality is reviewing proposed legal capacity legislation. Self-directed support, with its aim of increasing choice and control, is becoming increasingly linked to the principles of human rights for people with disabilities. While I was at the Centre for Disability Law and Policy at NUI Galway I attended two international conferences. This enabled me to learn more about international human rights law, specifically, the human rights standards contained in the *United Nations Convention on the Rights of Persons with Disabilities* (CRPD) and also the proposed mental health and legal capacity legislation in Ireland (*Review of the Mental Health Act 2001* and the *Assisted Decision-Making (Capacity) Bill 2012*).

- *4<sup>th</sup> International Disability Summer School: The UN Convention on the Rights of Persons with Disabilities – How to Use it*

The conference was jointly sponsored by the Centre for Disability Law and Policy, NUI Galway and Harvard University, Harvard Project on Disability. A highlight was the opening address given by the President of Ireland, Michael D Higgins. The programme covered the nature of the Convention on the Rights of Persons with Disabilities (CRPD) including the treaty interpretation in general and the general obligations of States to reform. It then proceeded to consider each of the articles of the convention with particular discussion on core rights such as the right to legal capacity, to independent living and to political participation. The presentations were from international experts including Dr Michael Bach (Inclusion International and Canadian Association for Community Living, Toronto), Professor Jerome Bickenback (University of Lucerne, Switzerland), Camilla Parker (Just Equality) and Andrea Coomber (Interights, London).

Highlights included debate around Article 19 which provides for the right to live independently and be included in the community. There was considerable discussion on issues of residential care of various types, particularly for people with mental illness, and whether these accommodation arrangements are compliant with the CRPD. The other significant area covered by the conference revolved around capacity and supported decision making and the complexity of reaching the correct balance between autonomy and protection which is consistent with international human rights law and the CRPD.

- *Conference Mental Health Law Reform: New Perspectives and Challenges*

The conference was jointly sponsored by NUI Galway and Amnesty International Ireland. The programme covered both international developments in mental health law and local issues relevant to the review of the Mental Health Act 2001. Leading national and international experts on mental health law and policy spoke at the conference. Presenters included Professor Phil Fennell from the Cardiff Law School, Professor Amita

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Dhanda from the Nalsar University of Law, Hyderabad, Dr Mary Donnelly from University College Cork and Professor Bernadette McSherry from Monash University.

Just 2 days prior to the conference the Irish Minister for Disability, Equality, Mental Health and Older People, Ms Kathleen Lynch, released the *Interim Report of the Steering Group on the Review of the Mental Health Act 2001* (Department of Health, 2012a). The report noted an intention to reflect a recovery approach with the “*involvement of service users as partners in their own care and in the development of the service*”, and in the context of the CRPD to “*realize our developing obligations under international human rights law to the maximum within available resources*”.

The Minister said:

*“I fully endorse the recommendation of the Steering Group that a rights based approach to mental health law should be adopted. A move away from the paternalistic approach of the 2001 Act was a strong feature of the views expressed in the consultation process. It is important that each person should have a right to determine and participate as much as they possibly can in their own care and treatment. The imminent publication of the Assisted Decision-Making (Capacity) Bill 2012 will also be a significant improvement in this regard.”*

(Department of Health, 2012a)

An Expert Group is to be put in place to advise the Government on mental health legislation and the expectation is that their report will be delivered by early 2013.

Amnesty International Ireland sees mental health as a human rights issue and they have been a significant and effective advocacy group campaigning on mental health since 2003. They have been working in partnership with their Experts by Experience Advisory Group to provide a voice and to lobby to improve the lives of people with mental illness. A human rights framework has driven their campaign to bring about change in a number of areas including reforming the mental health and capacity legislation and implementing *A Vision for Change*. In addition to arguing that the 2001 Mental Health Act be updated in line with the CRPD, Amnesty International have also put the case that new legislation should place a statutory obligation on the health services to delivery community based services as described in *A Vision for Change*, particularly in light of the current budget constraints. Details of their extensive programme of work can be found on their website.

<http://www.amnesty.ie/mentalhealth>

## **Disability**

Disability policy in Ireland is being shaped by the *Value for Money and Policy Review of the Disability Services* which was initiated by the Department of Health in June 2009.

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Although people with a disability due to mental illness are included within the definition of disability, the emphasis in the Value for Money (VFM) Review was on people with intellectual, physical and sensory disabilities. Despite this, the Review findings are relevant to personalisation and self-directed support in mental health as the directions adopted by the disability sector internationally are relevant to policy development in Australia. This is particularly so in light of the proposed National Disability Insurance Scheme which will include people with a psychiatric disability.

Broadly, the Value for Money (VFM) Review recommends moving to a model of person-centred, individually chosen supports with individualised budgeting where *“the individual is given more choice and control over how the money allocated to meet their need is utilised.”* (Department of Health, 2012) The VFM report is quite clear about the components in a system providing individualised supports and specifies:

*“Following the needs assessments, individual support plans would be drawn up and individualised budgets allocated, from which the supports and services needed would be purchased. A number of mechanisms are proposed to achieve this, including direct payments (where the person manages the budget and purchases the supports themselves) or a broker system (where the person has the choice and control but the broker administers the budgets and commissions supports and services on their behalf).”* (Department of Health, 2012, p165)

The Review makes reference to two key policy documents which strongly shaped the findings:

- The Expert Reference Group’s *Report of Disability Policy Review* (2011); and
- The National Disability Authority’s (NDA) *Advice Paper to the Value for Money Policy Review of Disability Services Programme* (2010).

The Expert Reference Group’s report proposed changing how supports and services should be provided in the future (Department of Health, 2011). To enable people with disabilities to live as full citizens the approach would change from providing disability services to individualised supports. These individualised supports should have the following characteristics:

- *“Determined by the person (in collaboration with their family/advocate as required and in consultation with an independent assessor) not the service provider or other ‘experts’;*
- *Directed by the person (with their family/advocate as required);*
- *Provided on a one-to-one basis to the person and not in group settings (unless that is the specific choice of the person and a ‘natural’ group activity such as a team sport);*
- *Flexible and responsible, adapting to the person’s changing needs and wishes;*
- *Encompassing a wide range of sources and types of support so that very specific needs and wishes can be met;*



- 
- *Not limited by what a single service provider can provide;*
  - *Having a high degree of specificity. Provision that is expressed in terms of residential, day or respite does not capture the specific nature of an individual's support needs."*

The NDA paper providing advice to the VFM Review recommended *".....moving to more flexible models of support focused on greater independence of individuals, and by introducing a transparent system of resource allocation"* (NDA, 2010). The NDA is currently undertaking a resource allocation feasibility study to develop a model to assess individual need and resource allocation as a basis for determining individual budgets.

The Department of Health press release accompanying Minister Lynch's launch of the Value for Money Review noted:

*"In the context of delivering a more person-centred service, and in line with commitments in the Programme for Government, the Minister intends that the actions recommended in the Review will lay the groundwork for a system of individualised budgeting, once sufficient analysis of the benefits is carried out in the Irish context and adequate financial management, resource allocation and governance structures are in place to ensure its long-term viability. Individualised budgeting, the Minister explained, is an approach whereby a monetary value is placed on the supports required by the individual to live a fully included life in the community. It may be implemented in many ways, but the essence of individualised budgeting is that the individual is given more choice and control over how the money allocated to meet their needs is utilised. This approach must be underpinned by a standardised needs assessment to ensure fairness and transparency in the way in which funding is allocated"*.

(Department of Health, 20 July 2012b)

[www.dohc.ie/press/releases/2012/20120720.html](http://www.dohc.ie/press/releases/2012/20120720.html)

## **6.2 Policy into Practice**

### **Genio**

Genio was founded in 2008 as a not-for-profit organisation to support the transition from institution based care to individualised supports in the areas of disability, mental health and dementia. It receives funding from the Atlantic Philanthropies, the Department of Health and the Health Service Executive. In 2012 the Health Service Executive allocated €2 million recurrent funding to Genio to fast track innovation and service modernisation to realize *A Vision for Change*.

Genio is an 'intermediary' organisation which works collaboratively with Government, health and social service providers, policy experts, NGOs, the business community and service users and carers to bring about service transformation. It has three parts to its strategy to achieve this:

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- Financial Support – grants to support change (approximately €50,000 average);
  - Capacity Building – covering service users and their families, service providers and policy makers; and
  - Evidence – both providing and disseminating evidence on individualised supports and services.

The funding grants are used to ‘incentivize’ change. They add value to the grant making process by working with the grant holding organisations and individuals to support the process of change. Genio requires that whatever change the project is set up to achieve is sustainable into the future. They work with all stakeholders and have some family/service user led projects which showcase and present possibilities for change. As Genio works across disability/mental health/dementia there is the opportunity for learning across these sectors.

In their latest report on the implementation of *A Vision for Change* (AVFC) the Independent Monitoring Group noted the impact of new funding initiatives which have provided momentum in mental health and made specific mention of the role of Genio:

*“Blending philanthropic and statutory sector monies GENIO has introduced a welcome level of strategic co-ordination and independence to the allocation of innovation funding that has prioritized recovery-oriented measures in line with AVFC.”* (Independent Monitoring Group, 2012).

Genio currently has five funding streams for grants in disability and mental health:

- Community Living (disability and mental health) – develop non-institutional models of residential support for individuals in the community;
- Alternative Respite (disability and mental health) – non-institutional respite models;
- Supporting school leavers (disability);
- Supporting Recovery (mental health) – individualised responses to recovery particularly re-gaining roles through work and re-connecting with the community; and
- Capacity building (disability and mental health) – capacity building and training opportunities to support individualised responses for people with a disability/mental health difficulty.

Genio has commissioned the University of Ulster to undertake an evaluation of individualised supports for people in Genio funded initiatives. It is a longitudinal study to be conducted from mid 2011 to mid 2013 and will include over 200 individuals across a range of disabilities in 23 Genio projects. The research will examine outcomes for individuals, direct costs to support individuals, cost effectiveness of the initiatives and the processes which led to facilitated change and transition.

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Some examples of Genio funded projects are:

- *Áiseanna Tacaíochta*  
Áiseanna Tacaíochta translates into English as Supported Facilities. Through this project entitled “*Direct Payment: Laying down new tracks*” five individuals have been supported to establish a system for managing their own funding and directing their own supports. It is funded from the Genio disabilities programme. The twin aims of the project are to test out and learn about implementing direct payments and to influence policy so as to make direct payments a reality in Ireland. To my knowledge it is the first service in Ireland to pilot a model of individualised funding and direct payments to enable people with a Personal Assistant to manage their service independently within a mainstream labour market.
- *PROSPER (Peer support to Promote Recovery)*  
PROSPER is a Genio Trust funded project undertaken by the Mayo Recovery Consortium, which comprises service users (the Mayo Advocacy Group), a voluntary sector service provider (Mayo Mental Health Association) and the Mayo Mental Health Services.  
[www.mentalhealthmayo.ie/node/30](http://www.mentalhealthmayo.ie/node/30)

While the broad aim of the project is to provide peer support to help individuals move from institutional to more independent living, the specific objectives are to:

- build a sustainable model of peer support to be available to everyone with mental illness;
- train and support service users to become peer support workers; and
- develop the infrastructure and provide training to enable mental health service providers to work with the peer support model.

Peer workers have now been employed by an NGO and have begun working with service users. As the project progresses, the consortium partners are working through a range of implementation issues such as identifying and managing risk and how best to deal with information sharing while maintaining confidentiality.

There are links between the PROSPER initiative and the participation of one of the consortium partners, the Mayo Mental Health Service, as a national lead site in the Implementing Recovery – Organisational Change (ImROC) programme. As one of the ImROC network sites, the Mayo Mental Health Service leaders participate in the UK based learning sets. The PROSPER project is addressing some of the challenges which have arisen in the ImROC initiative such as delivering user-led education and training programmes by establishing a ‘Recovery Education Centre’. Sharing experiences and innovation in other mental health services through the ImROC learning sets has been valuable.

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### **Dublin City University (DCU): Service Improvement Leadership Course**

This two semester course, which carries degree level credit points, has been delivered at DCU since 2007/08. The programme is based on the concept of bringing together three groups with different perspectives (service users, carers and mental health professionals) to achieve service improvements. Service users and carers are paid to participate in the programme and on average 21 people participate each year. Mental health services sponsor and recruit teams of three participants and additionally nominate a senior manager from the sponsoring service to mentor the team and assist in implementing the service improvement project. The programme has been identified by Genio (previously known as The Person Centre) as an example of good practice (The Person Centre, 2009).

### **Jigsaw**

I had the opportunity to visit Jigsaw as I was particularly interested in this service as an example of personalisation in action. Jigsaw is part of a national initiative being developed by Headstrong, the National Centre for Youth Mental Health. It provides a city centre drop in service for young people aged 15 to 25 with mental health difficulties to access a multidisciplinary team for support.

The Youth Advisory Panel is a particular feature of the service. The Panel is made up of service users who have been involved in meeting Government Ministers, choosing the colour schemes for the offices, advising on the location of the service, speaking at conferences and representing the service on a radio programme. In the voice of one of the Youth Panel:

*“Jigsaw even got members of the Youth Panel to interview staff! That was an incredible experience. The interviewees would have a formal interview with the main board and then an informal interview with the Youth Panel after. The aim of us interviewing the possible staff was to get a feel of how they related, connected and conversed with young people in order to get the most youth friendly professional and non-judgmental staff.”* (Jigsaw, 2010)

## **6.3 Reflections**

### *‘Incentivizing’ change*

Genio provides an interesting model of how to bring about system change. It has been described as a ‘funding enabler’ and that is an apt description in that it does much more than a traditional funding body would. It encourages creativity, showcases new ways of providing services and supports larger scale system change. Five features stood out for me:

- Although partly funded by Government, it is independent and can work with a range of provider groups;
- It facilitates and encourages successful outcomes by working with providers during project implementation;

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- Projects have to be sustainable, so it is expected that existing services are reconfigured to fund the project into the future after Genio funding ceases;
  - There is opportunity for cross-sector learning as Genio funds mental health, disability and dementia projects; and
  - There is a commitment to evaluating project outcomes so as to provide an evidence base to their work.

#### *Individual budget holding starts in the disability sector*

Ireland is not unusual in that the concept of individual budget holding gains traction in the broader disability sector before it is taken up in mental health. The recent Value for Money Review which covers people with a physical, sensory or intellectual disability recommends moving towards a model of person-centred, individually chosen supports with individualised budgeting (Department of Health, 2012). Interestingly, the Genio project on individual budget holding, *Áiseanna Tacaíochta*, is for people with a physical disability.

#### *Individualised Supports and Individualised Budgets – both are needed*

In the Report of Disability Policy Review the expert group provides an excellent description of the criteria which must be met for a support to be considered to be individualised. This is the clearest statement which I have seen to date. It is worth repeating:

- *“Determined by the person (in collaboration with their family/advocate as required and in consultation with an independent assessor) not the service provider or other ‘experts’;*
- *Directed by the person (with their family/advocate as required);*
- *Provided on a one-to-one basis to the person and not in group settings (unless that is the specific choice of the person and a ‘natural’ group activity such as a team sport);*
- *Flexible and responsible, adapting to the person’s changing needs and wishes;*
- *Encompassing a wide range of sources and types of support so that very specific needs and wishes can be met;*
- *Not limited by what a single service provider can provide;*
- *Having a high degree of specificity. Provision that is expressed in terms of residential, day or respite does not capture the specific nature of an individual’s support needs.”*

It raises the question as to whether it is possible to achieve the level of choice and control embedded in these criteria without also having specific funding associated with an individual. Interestingly, the VFM considers individualised budgets as a necessary corollary to individualised supports and I would agree with that position. Without a specified level of funding attached to each individual, decisions about the level of resources allocated to that individual remains largely in the hands of providers.

#### *Rights based approach to mental health and capacity legislation*

Ireland is in the midst of an intensive period of change in disability law reform, including a review of both their mental health and capacity legislation. The Centre for Disability Law and Policy at NUI Galway and Amnesty International Ireland have both been strong advocates

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and drivers of that process of change. There is a commitment from the Irish Government that both mental health and capacity legislation will be rights based and in line with The United Nations Convention on the Rights of Persons with Disabilities. The concept of supported decision making, where people are provided with varying levels of support to exercise their legal capacity to make their own decisions, is a strong policy driver in this area.

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## 7. Belgium

### 7.1 Policy Overview

Belgium is a federal state with three regions: Flanders (northern area: Dutch speaking), Brussels (central: bilingual) and Wallonia (southern area: mainly French speaking with a German speaking minority). Welfare policy is the responsibility of each region. The budget holding schemes I discuss in the following section relate only to Flanders.

#### **The Expertise Centre Independent Living**

The Expertise Centre Independent Living operates as a partnership with provider organisations which each work at the grassroots level with people with disabilities. The partners are:

- Equal Rights for Each Person with Disability (Gelijke Rechten voor Iedere Persoon met een Handicap GRIP vzw);
- Focus on Emancipation (Fokus op Emancipatie vzw); and
- Independent Living (Onafhankelijk Leven vzw).

The focus of the Centre is on gathering knowledge about independent living, particularly direct payments, then disseminating that knowledge and using it to lobby for improvements in direct payments. They provide education, policy advice and undertake research. The Centre arose from an idea developed by Dr Adolf Ratzka (Independent Living Institute, Sweden) and Jan-Jan Sabbe (budget holders association BOL-BUDIV, Belgium) where they concluded that various countries have developed interesting and innovative approaches to direct payment budgets but were not learning from each other.

At an international conference presentation on Direct Payments in 2010 the Centre used the following definition of a direct payment:

- *The budget is personalised and is destined for the disabled person (or his/her representative).*
- *The disabled person is thus the budget holder. The subsidies no longer go directly to the care providers.*
- *Disabled people can freely determine the amount of control they exercise over their own assistance; assistance which corresponds with their need, abilities, actual living conditions, preference and desires.*
- *This freedom of choice also includes the right of the disabled person to determine the content of the assistance all by him/herself. The budget holder decides who is to work as an assistant, for which assignments, at what time and where and how the assistance is to take place. (Robbroeckx, 2010)*

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In Flanders there are two types of budget, the Personal Assistance Budget (PAB) and the Personal Budget (PGB).

### *PAB*

In 1987 the independent living movement began active lobbying to provide budget holding for people with disabilities. The first pilot personal assistance budgets (PAB) started in 1997 for 15 people with a physical or sensory disability. In 2000 the Flemish Parliament passed the PAB Decree to provide a legal basis for personal budgets. Since that time over 1,600 people have a PAB, with a waiting list of approximately 5,000. It is primarily being taken up by people who are living at home but who, as a result of receiving a PAB, no longer have to rely as heavily on their informal support networks.

A detailed description of the PAB is provided in the report on de-institutionalisation in Belgium (Huys, 2008). However, in summary, the PAB is a cash budget, assessed on the basis of need for support in daily living or to enable an individual to travel to participate at school or work. It is also possible to use the PAB for short stay/respite. It is not available to purchase equipment but rather is designed to pay the wages and associated employment costs of a personal assistant. It is possible to be a direct employer or to use a care provider and most people use a combination. There are agencies which help with this process, such as Independent Living. While psychiatric disability is not excluded it is not a priority area.

The process for obtaining a PAB is as follows:

1. Application to the Flemish Agency for People with Disabilities (VAPH) asking to be recognized as having a disability;
2. Assessment by a multidisciplinary team;
3. Assessment provided to the Provincial Evaluation Commission (PEC) who determine the severity of the disability and need for services. The PEC then provides a formal determination which decides which services which a person is eligible to receive. It provides a care formula with attached Government funding.
4. Since 2011 the Regional Priority Commission provides each individual with a priority rating. This is intended to ensure providers give preference to those with the highest need.
5. If an individual is recognized as having a disability they can request a PAB. Another assessment determines whether a person falls into one of five categories. Funding is attached to each category, with category 1 providing approximately €9,000 per annum through to category 5 which attracts approximately €43,000 per annum.
6. The person then goes onto a waiting list for a PAB. There is a defined pool of funding available for PABs so funds cannot currently be provided to all eligible applicants. In 2011 only those people assessed as being in category 5 received a PAB due to funding constraints.



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The Flemish Government recognizes that associations of budget holders have a role in supporting and advising individual budget holders and they receive subsidies in addition to individual contributions from budget holding members for the services they receive (Huys, 2008).

Overall feedback from PAB holders is positive, however, not everyone wants to be a direct employer as it can be administratively complex and time consuming. In 2010 Linde Moonen presented a conference paper reporting on the research she had undertaken on PABs and quality of life. There were 84 participants in the study. When asking people about the advantages of the PAB, most noted the importance of receiving support from someone they trust and from a person who respects them. They also felt less dependent on support offered by friends and family. Respondents noted that the advantage for the family is that there is more time for family life and some commented that family roles had normalized. Disadvantages of the PAB were the burden of administration and that the budget is not necessarily high enough to provide good working conditions for the assistants.

#### *PGB*

In 2009 the PGB pilot extended the existing options available through the PAB to include care in a facility. It also permitted the purchase of certain types of equipment. People with a physical, intellectual or multiple handicaps took part in the pilot. Approximately 200 people were assessed as eligible to apply. Although this was a pilot it was agreed that if people chose to participate they would be able to continue with a PGB for as long as they chose. There were a number of implementation challenges including determining the correct budgets required to meet the individual's needs. By 2011 the pilot had concluded with 132 participants remaining. While there were a variety of reasons for leaving the programme, one important issue was that the budget amount was lower than the price being charged for the 'care in kind' they had been assessed as requiring.

An interesting aspect of the pilot was the recognition of the need for budget holders to be able to access advice, information and support. As part of the PGB, each budget holder received €50 to enable them to join a budget holders association and budget holder associations received €150 per member direct from the Government to provide a range of support services.

A detailed description of the PGB programme is provided in the Expertise Centre Independent Living report *The PGB experiment in Flanders* (Decruynaere, 2009).

Belgium is currently reviewing its disability policy. Key areas of discussion are how best to fund disability services, including the possibility of introducing a Disability Insurance Scheme. The option of notional rather than cash budgets has also been considered. By the end of 2012 the policy direction should become clearer.

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The idea of consumer run personal assistance service cooperatives has also been under consideration by budget holders. In Norway and Sweden there are long standing self sufficient consumer cooperatives. STIL, the Stockholm Cooperative for Independent Living, was founded in 1984 and is an example of such a cooperative. The basic arrangement is that budget holders invest the funds from their individual budgets in the cooperative and this entity is then the employer. A comprehensive review of this approach, including detailed case studies, is outlined in a report undertaken for the US Department of Labor (Jans, 2007).

In May 2012 Dr Adolf Ratzka, a founding member of STIL, visited Belgium and was interviewed by Peter Lambreghts at the Expertise Centre Independent Living. Their conversation provides some interesting insights into a diverse range of issues from cooperatives, to peer support, the CRPD and an update on the current situation regarding disability policy in Sweden. The interview can be viewed at:

[www.youtube.com/watch?v=-XEsR5PWR5Y](http://www.youtube.com/watch?v=-XEsR5PWR5Y)

## **7.2 Policy into Practice**

### **Independent Living (Onafhankelijk Leven)**

The organisation started in 2001 as the Budget Holders Association Independent Living (BOL). It provided support to those who held a PAB or who had requested one and was primarily focused on people with a physical or sensory disability. In 2007 it joined with BUDIV which supported people with intellectual disabilities. In 2011 BOL BUDIV changed its name to Onafhankelijk Leven (Independent Living) as it reinforces that the core values of the organisation are based on the independent living movement.

A requirement of the PAB is that 95% of the budget is to be spent on employing personal assistants, including all indirect labor costs such as workers accident and liability insurance and payroll administration costs. All expenditure must be based upon written contracts with personal assistants or service delivery agencies. The remaining 5% of the budget can be spent on incidentals such as transport and light refreshments for the personal assistant when they are accompanying the budget holder.

*Independent Living* supports people through the start up process of a PAB. It is committed to ensuring that the budget holder decides where, when, how and by whom the assistance is provided. They provide an extensive range of services to assist people manage their personal budget including an advice line, training and face-to-face support in people's own home.

When a person first receives a PAB, a worker from *Independent Living* will visit the person at home and assist them in making a detailed plan for the first year. They look at which service providers they wish to engage and whether they would like to hire their own personal

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assistant or some combination of both. The plan has to be very specific about what service is being provided, by whom, how often and for how long, and then the costs are detailed. It usually takes about 2 hours to develop a plan. Once the plan is in place *Independent Living* can help with a job description and hiring of the assistant if that is required by the budget holder. It provides a secretarial and administrative service and does the audit of accounts and payments to ensure accountability regarding acquittal of the funds. It also provides a coaching service to assist in negotiating and managing any issues which might arise between the personal assistant and the budget holder. In the event that there is no adequate proof of expenditure on approved services or some funds are unspent, the outstanding funds are returned to the funding agency.

### 7.3 Reflections

#### *Learning across countries: research, policy, education*

The Expertise Centre Independent Living is unique in that it stays well connected to grassroots organisations which support people with disabilities and at the same time gathers knowledge about direct payment budget holding across Europe. It has a broad range of functions including research, policy development, lobbying and education and in addition provides a valuable source of information about developments in a range of countries. Unfortunately, the funding from European Regional Fund will shortly cease and this will impact on the Centre's staffing.

#### *Supporting budget holders*

There is widespread acknowledgement in all the jurisdictions I visited that budget holders receiving direct payment require access to a range of support services. *Independent Living* (Onafhankelijk Leven) is an example of an organisation with a long history of supporting budget holders with a physical, sensory or intellectual disability. It is run by budget holders for budget holders and as a consequence remains very committed to the principles of the Independent Living Movement where choice and control for the individual is a core value guiding their services.

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## 8. The Netherlands

### 8.1 Policy Overview

In 1991 the first pilot personal budgets were developed in the Netherlands. Personal health budgets (persoonsgebonden budget) known as PGB were introduced in 1996 through the Exceptional Medical Expenses Act 1968. Although initially limited to those who needed home help and nursing the eligibility criteria were expanded in 2003 to encompass a broader range of people with long term care needs.

There were two key drivers in the 1990's: firstly, the emergence of the independent living movement where people with disabilities were seeking greater empowerment and control over their lives and the secondly, the reshaping of the welfare state. In addition to providing greater choice and control to people over their support services, it was also expected the PGB would control costs by substituting traditional 'care in kind' from a healthcare provider with informal or other support care. A further aim of the PGB was to encourage competition between providers and encourage greater flexibility and responsiveness.

In the Netherlands people pay a national insurance levy (AWBZ) of 12.5% of taxable earnings up to a maximum of approximately €4,000 per annum, deducted through their income tax to provide long term care. Eligibility and an assessment of the care required are determined by an independent organisation, the Centre for Needs Assessment (CIZ). If assessed as eligible, the person can then choose between a personal budget or 'care in kind' through a healthcare provider.

The PGB covers personal care, nursing care, support and respite. Medical services are not included. Local governments provide equipment such as wheelchairs, home adaptations, and transport. Some services currently provided through the nationally administered PGB are being shifted to become the responsibility of local municipalities.

The PGB allows family members to be paid to provide support this has raised concerns about mixing the carer/employee role. It has been debated for some years in the Netherlands and has been described as the "*commodification of family care*" (Kremer, 2006)

The value of the PGB is 25% lower than 'care in kind' on the basis that overheads are lower. Those who hold a personal budget can choose to purchase care from family and informal networks such as neighbours or from care providers. The average budget is €43,000 for those assessed as requiring residential care and €12,000 for others (Van Ginneken et al, 2012).

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The growth of the number of PGB holders has been significant, rising from 13,000 in 2002 to 130,000 by 2011. This has been accompanied by cost increases where the expenditure on personal budgets has increased from €414 million in 2002 to €2.2 billion by 2010, a growth of 23% annually compared to a 4% annual growth for 'care in kind' over the same period. By 2010 about 20% of those eligible for long term care benefits through the AWBZ held a personal budget. Part of the growth in numbers can be attributed to children and adolescents with autism and learning difficulties who had previously received informal, unpaid care (Van Ginneken et al, 2012).

The Dutch Government has been increasingly concerned about a number of aspects of the PGB. In June 2011, in a report to Parliament, the State Secretary for Health, Welfare and Sport reached the following conclusions regarding personal budgets:

- 1. the regulation is no longer tenable in its current form, partly because of the way it soaks up money and due to the monetisation of informal care;*
- 2. own control is not always the driving force behind choosing for a Personal Budget, which means that responsible care is not always guaranteed;*
- 3. the regulation is sensitive to fraud and leads to dubious Personal Budget expenditure on the basis of the supervision function.*

(State Secretary Veldhuijzen van Zanten-Hyllner, 1 June 2011)

[www.government.nl/ministries/vws/documents-and-publications/parliamentary-documents/2011/06/01/programme-letter-concerning-long-term-care.html](http://www.government.nl/ministries/vws/documents-and-publications/parliamentary-documents/2011/06/01/programme-letter-concerning-long-term-care.html)

By January 2014 the Dutch Government will change the PGB to address the issues raised above by both significantly changing eligibility to restrict access to the scheme and changing the way the PGB operates. In summary:

- Access will be limited to people who would otherwise have to move to residential care;
- Budget holders will be required to have a separate bank account for PGB funds;
- Specialised agencies will not be able to purchase on their behalf;
- A care plan will be required to detail how funds will be used; and
- A new reimbursement mechanism will require approval prior to purchase for care which cannot be provided through a regular care provider. This is designed to enable current budget holders to keep tailor-made care options.

(Van Ginneken et al, 2012).

While personal budgets are popular, the issue of cost has to be managed. Theoretically the PGBs should be cheaper than institutional care as only 75% of the estimated cost of care in-

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kind is provided. However, the cost drivers have been explained in various ways including that personal budgets:

- have been used to fill gaps in current services, particularly for children;
- personal budgets are an add on rather than a substitution of services as some recipients of the PGB wouldn't use existing 'care in kind' social services because they rely on family/informal carers, and
- perhaps the programme was too open in both eligibility and the range of services which could be purchased.

Taking a broader European view, there is an excellent overview of 'cash for care' and long term care policies in six European countries, including the Netherlands, in a publication the Milbank Quarterly (Da Roit & Le Bihan 2010). In addition to outlining the different policy settings in each country, some of the more complex issues regarding informal care, payment of family members and the wider social care workforce are discussed.

In summary, going back to the original aims of the PGB which were to empower people with disabilities to control their own lives, contain costs and encourage competition, flexibility and innovation among providers, only the first aim appears to have been largely achieved (The Health Foundation, 2011a).

It is unclear what impact the national elections in the Netherlands in September 2012 may have on the future of the PGB.

## 8.2 Policy into Practice

**Per Saldo** is the Netherlands association of people who organise their care with a personal budget. It was started in 1995 by people with a personal budget and today, is still run by budget holders. It aims to support people with a budget and campaigns to improve the PGB. It has 25,000 members who are PGB holders out of the approximately 130,000 budget holders in the Netherlands. Per Saldo provides information and advice, support and representation including a telephone help line from Monday to Thursday from 9.00 a.m. to 5.00 p.m. Its membership includes people with a disability, a chronic illness and psychiatric problems.

**Platform VG** is an umbrella organisation of 18 national associations of parents of people with an intellectual disability. Platform VG is associated with Naar-Keuze (For-Choice), an advocacy group for parents and families of people with intellectual disabilities who have a PGB.

The origins of the PGB were firmly rooted in the independent living movement with its core concept of a person with a disability having the right to choice and taking control of their

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life. The underlying drive for personal budgets was succinctly described as “*Just give me the money and I’ll do it myself.*”

The current national insurance budget is approximately €23 billion and the PGB comprises about 10% of that budget. Approximately 20% of people eligible for funding through the national insurance scheme are PGB budget holders and 80% use in-kind services. The PGB is for people with disabilities of all ages, that is, there is no separation of aged care. Employment work agreements and records of payment are required so that care is not purchased outside the requirements of employment and taxation law. The PGB has expanded the social care workforce as it taps into a broader group of people such as neighbours and students, many of whom would not normally consider working in this sector.

Personal budgets are popular with those who have them and their major advantage is that it improves their quality of life. There are however, some disadvantages, primarily the administrative burden of record keeping which accompanies the financial accountability and reporting requirements.

The announcements by Government that the programme is changing have been a cause for concern for budget holders. It has been estimated that in 2014 the PGB budget will be reduced by approximately €700 million and the number of people who hold a PGB will fall from the current 130,000 to 13,000 (The Health Foundation, 2011b). The proposed changes raised several issues among stakeholders and the following captures some of these views:

- The change to the reimbursement mechanism means that people will lose control up front and an agency will have to approve purchases in advance. This financial control will have an associated cost as an agency will have to be paid to administer this process.
- There is some concern about the assessment process. Assessments at the moment are paper based and there is some support for these assessments to be conducted face to face.
- The issue of payment for family carers is being debated and is contentious.
- A personal budget is not for everyone. It is appropriate for those who want the control and the emancipation that a personal budget brings. Other options should be in place to provide a range of flexible community supports for those who don’t want a personal budget. The PGB is not necessarily the solution to dealing with service gaps or a lack of innovation and flexibility among providers.

### **8.3 Reflections**

*Programme design is important or there can be unintended consequences*

There is much to be learned from the PGB in the Netherlands. While the aims are commendable and it has had a positive impact on the quality of life of recipients, the way it

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is designed has lead to a rate of growth and cost increases which the Dutch Government regards as unsustainable. Consequently, the programme is being significantly cut back, mainly by introducing tighter eligibility criteria. Clear programme design, especially regarding who is eligible and what personal budgets should fund, is a useful lesson for other jurisdictions. The issue of payment for informal/family carers is one which remains a feature of the PGB and which continues to be debated.

*User led support for direct payment budget holders*

Per Saldo is made of 25,000 people who hold a PGB. It is a long standing organisation, run by budget holders and includes people with a disability, a chronic illness and psychiatric problems. It is clear that many people who receive a direct payment budget require varying types and levels of support to enable them to successfully manage a budget. As it is run by budget holders it stays responsive to their needs. The other key role of a user led organisation is that it provides an effective lobbying voice for budget holders to influence policy development.



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## 9. Conclusions and Recommendations

The purpose of the Fellowship was to investigate the policy and practice of self-directed support for people with a mental illness.

I learned something unique from each of the five countries I visited and have outlined the key messages in the previous section of the report.

In summary, each country is taking a different approach to implementing self-directed support and personal budgets:

- England is building on its experience with personal budgets in social care and is introducing personal health budgets for people with long term health conditions using NHS funds. Trials are being conducted in 64 pilot sites, with 20 of these sites participating in an in-depth evaluation. The final evaluation results will be delivered in October 2012 and subject to the results, personal health budgets will be offered in 2014 to the 50,000 people eligible for NHS Continuing Care.
- The Scottish Parliament is currently considering the Self-directed Support Bill. It aims to replace the current single option of direct cash budgets with a broader range of choices designed to empower people to decide how much control and responsibility they want over their social care support arrangements. Importantly, Scotland has embedded SDS and budget holding into a broader personalisation framework and has recognised the importance of supporting providers by funding a four year programme to assist them to manage the impact of SDS and to personalise their services.
- Ireland is reshaping its disability policy and reforming its mental health and legal capacity laws. While there are currently no personal budgets provided by Government, the national disability policy is moving towards individualised supports and individualised funding. At this stage the option of personal budgets, described as individualised budgeting, is still being considered subject to adequate financial and governance structures to ensure long-term viability.
- Belgium has direct cash budgets, but is currently debating the future of its disability policy and considering how best to manage waiting lists and future demand.
- The Netherlands has had direct cash budgets in place for a number of years as the alternative to 'care in kind'. However, the PGB personal budget programme is currently being scaled back because of escalating costs.

### 9.1 Overall Findings

When I began my visits I had expected that I would be learning mostly about personal budgets as a way of increasing people's control over their support services. However, it became clear that building the capacity of service providers to deliver personalised services

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is equally important. These visits reinforced my view that personal budgets are only one mechanism, albeit a powerful one, which is part of the broader policy direction to empower people to take charge of their own lives.

My key findings were:

*1. Personal budgets can result in powerful changes in people's lives*

While they come in many forms, from one-off recovery budgets to direct cash budgets for on-going services, there was significant support from the people I met for individual budget holding.

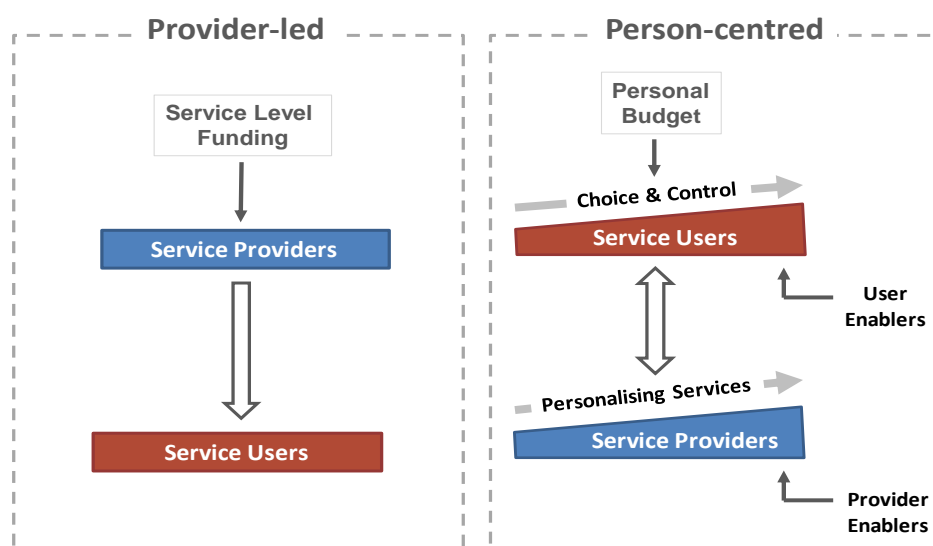
*2. Supporting budget holders to exercise real choice and control*

In order to have real choice and control, people taking up a personal budget require varying levels of access to information, advice, brokerage and support. Introducing this support infrastructure is a necessary part of developing a service system which supports personal budgets.

*3. Supporting providers to deliver personalised, recovery-oriented services*

The majority of people with a personal budget continue to receive support services from providers. To increase choice and control for budget holding 'customers' means that services need to be more personalised and able to respond flexibly to the needs and preferences of each of their clients. This represents a fundamental shift to working in partnership with clients and sharing power. While budget holding is sometimes viewed as a means of driving provider change, my view is that it requires a more systematic, supported approach to transforming service delivery. Introducing mechanisms which build the capacity of providers to deliver personalised, recovery-oriented services is a vital part of this system change process.

I have captured these observations about personal budgets, self-directed support and personalised services in the following graphic.



## Shifting from provider led to person-centred services

Traditionally, providers are direct funded through 'block' contracts, with service users often receiving care determined by the provider and with services largely restricted to what each provider can deliver. This has been a provider-led service system. There are two key components which help shift to a person-centred service system: personal budgets and personalising services.

### Personal budgets

Personal budgets are designed to improve the lives of individual service users by increasing the choice and control they have over the services they receive. While personal budgets can come in many forms they have two features in common:

- they are based on each individual's assessed needs and preferences; and
- the individual funding attached to each person shifts the power relationship between a service provider and service user.

To effectively exercise choice and control service users require varying degrees of support. Introducing personal budgets into any system entails the development of support infrastructure to ensure that people have real choice. This support can include accessing information, advocacy, assisting in the development of individual support plans, managing the financial accountability for cash budgets, employing support workers and providing grassroots budget holders with a voice to shape services and policies. Examples include:

- Independent Living (Onafhankelijk Leven) (Belgium): a user run organisation which provides a variety of support for cash budget holders who have a physical, sensory or intellectual disability.

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- Per Saldo (Netherlands): a user run budget holders association providing information, advice, support and representation for people with a disability, a chronic illness or psychiatric problems.

### *Mental Health Specific Strategies*

Tapping into the expertise of those with a lived experience may be particularly helpful in providing supports for people with a mental illness who wish to take up personal budgets and/or personal health budgets. *All Together Positive* is an interesting example of a user led organisation set up to provide peer brokerage for social care personal budgets in Stockport as part of the Mental Health Self-Directed Support Pilot. This organisation was established as a social enterprise specifically to assist those who are mental health service users with developing and managing their personal budgets. The organisation not only provides practical support assisting people develop their individual plans and broker services but also provides a voice for budget holders to engage with policy makers and service on personalisation and personal budgets. Although this particular example is in social care personal budgets, it would be just as relevant for personal health budgets.

It is also important to recognise the requirement to build capacity within provider organisations to support service users with personal health budgets. Examples include the key role of care co-ordinators in the Community Mental Health Teams in England in providing significant support to personal health budget holders and the development of new roles such as the Care Navigators in the Croydon Drug and Alcohol Team.

### **Providers: Personalising Services**

While in some jurisdictions the focus has been on cash budgets, others have developed personal budgets within a broader policy of personalisation – the process whereby services are adapted to suit the individual.

Many people with personal budgets will still choose to receive services from care providers and will expect these providers to deliver individually tailored services. Consequently, an important part of shifting a system to one which is person-centred is to support providers' capacity to increase choice and control for their 'customers'. To personalise services required that providers build the capacity to deliver services which meet each individual's needs and preferences as well as developing a variety of ways of working in partnership with service users. The shift to individual budget holding provides an incentive for providers to personalise their services. It also brings with it a number of issues with two of the key challenges being how to manage the shift from block funding to the complexities of funding via personal budgets and the implications for their workforce in providing more flexible, individualised services.

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Some services I visited have embedded personalisation in their organisations and there is much to learn from the way they have approached this. They include Look Ahead Housing and Care (London), Penumbra (Edinburgh) and the Scottish Association for Mental Health (Glasgow).

In Scotland and Ireland there are organisations/programmes which specifically support providers to develop more personalised services:

- Scotland has strongly linked their SDS and personal budget initiatives to the broader policy objective of personalisation and as part of this have provided specific support to assist providers:
  - Providers and Personalisation Programme: funded for four years to support practice change and support providers work on emerging issues as well as sharing examples of good practice.
  - Social Care Ideas Factory: a Glasgow based not-for-profit organisation building connections and partnerships to achieve social change with a focus at the moment on personalisation and SDS.
- In Ireland, Genio, a not-for-profit organisation is supporting system change through funding and directly assisting providers transform their services to deliver individualised supports.

#### *Mental Health Specific Strategies*

Many support providers and clinical service providers in mental health are undertaking significant work within their organisations to personalise their services and ensure they are recovery-oriented. There does seem to be significant benefit from developing programmes and strategies which support the embedding of these changes throughout an organisation.

The issue of culture and organisational change is a vital part of both personalising services and reinforcing the take up of personal health budgets. The importance of continuing to support mental health services to become more personalised and recovery-oriented was summed up in the analysis of service user and carer views on personal health budgets:

*“Many participants did not see how having a personal health budget would make a difference to their care if the culture of mental health services continued to be non-participatory and coercive. If clinicians and managers did transform the way they practiced in this way, it was questioned whether personal health budgets would still be needed.”*

(Mental Health Network & National Mental Health Development Unit, 2011b)

England has developed the ImROC programme to support secondary mental health services become more recovery-oriented. Although not specifically linked to the personal health budget pilots, the ImROC programme demonstrates how secondary mental health services can be supported to provide recovery-oriented services and increase personalisation and

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choice. The scope of this support is comprehensive and includes clinicians' practices, the range of services which are provided and the organisational culture. Increasing personalisation and choice is one of the key target areas within the programme.

The Scottish Government has recognized that there may be unique issues in introducing personal budgets and SDS into mental health and as a result they have recently funded a consortium to work with service users and providers to identify and address challenges. Ensuring that support services are recovery-oriented will avoid the risk of delivering support which fosters dependency and maintenance but rather empowers people to achieve their recovery goals.

## 9.2 Translating into an Australian Context

The key challenge when observing policy or service innovations in another country is to translate that knowledge into a local context. The policy directions and solutions which are appropriate in one country do not always readily transfer into another policy environment where the politics, issues, culture and service structures are different. Some of the policy and service language used in other jurisdictions often needs to be modified to fit.

However, the following recent developments in Australia provide a policy environment with opportunities for introducing some aspects of self-directed support and personalisation:

- In 2011 the Productivity Commission recommended a National Disability Insurance Scheme (NDIS) which proposed individually tailored support packages where people could *"....choose their own provider(s), ask an intermediary to assemble the best package on their behalf, cash out their funding allocation and direct the funding to areas of need (with appropriate probity controls and support), or choose a combination of these options."* People with significant and enduring psychiatric disability were included in the proposed scheme (Productivity Commission, 2011).
- In January 2012 the Prime Minister established the National Mental Health Commission as an Executive Agency within her portfolio as part of a commitment to mental health reform. In August 2012 Alan Fels, Chair of the National Mental Health Commission addressed the National Press Club and observed:

*"The National Disability Insurance Scheme (NDIS) is very welcome. I have three comments: First, it is critical that it not only applies to persons with physical disability but also to persons with significant and enduring psychiatric disability. After some debate, the Productivity Commission recommended this and I believe the government broadly supports this. It is a key need for the mental illness agenda. We are conscious there will be pressure to reduce costs by restricting the scope of the programme. The NMHC will closely watch to ensure that current policy is maintained."*

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- In 2010 Western Australia established the first Mental Health Commission in Australia. The Commission is committed to encouraging individualised support and individualised funding and has invested in 100 packages designed to give people greater control over their lives through tailor-made support services provided by NGOs.

There are many innovations in the area of personalisation and self-directed support which could be adapted to the Australian policy environment and service system to benefit Australian mental health consumers and their families. There are examples of innovative service models and practice which I have described in this report which could inspire change. The following recommendations provide some options for introducing aspects of personal budgets, self directed support and personalisation in Australia.

#### **Recommendation 1:**

##### **Introducing personal budgets for people with psychiatric disability through an NDIS pilot**

The history of personal budgets is that they usually commence for people with physical, sensory or intellectual disability. Although mental health is included in the proposed NDIS, it has traditionally been viewed as being somewhat separate to the broader disability sector. This pilot roll out of the NDIS in Australia provides an opportunity to ensure that mental health is included in the early development of what could be a significant national scheme. The National Mental Health Commission has a key role to play in ensuring mental health remains on the NDIS agenda and a pilot is developed which specifically trials individualised supports and personal budgets for people with a psychiatric disability.

#### **Recommendation 2:**

##### **Individual Recovery Budgets**

One-off Recovery Budgets provide a powerful tool to increase choice and control and have a positive impact on people's lives. Relatively small amounts of funding and limited transaction costs can result in significant benefit. This innovation could translate well into an Australian context as the model developed by the Mersey Care NHS Trust operates through a partnership between the Community Mental Health Teams and an NGO. Such partnership arrangements are common practice in most mental health services across Australia. An expanded model could include a wider range of support which is on-going if required.

The Western Australian Mental Health Commission is leading the way in putting in place a programme of individualised supports and funding for 100 people as part of their Individualised Community Living Strategy. The next step in this strategy would be to develop ways of expanding this programme so that all support services which are funded by the Commission are individualised and based on a recovery plan developed by an independent agency with specific funding attached to each service user.

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**Recommendation 3:****Building capacity in the NGO sector to personalise support services**

A capacity building programme for support providers would facilitate the personalisation of services. This strategy should be provider-led, adequately funded and have a system-wide approach. It also needs to be recognized that this level of system change requires a sustained effort over a period of time.

**Recommendation 4:****Building a mental health service system which is recovery-oriented**

A systematic approach to transforming clinical services through organisational change would go a long way to providing recovery-oriented, personalised services. There is much to learn from the ImROC programme which is embedding recovery-oriented change into an entire service system. Although the lead agency at each participating site is the mental health service, it includes as partners, the service users and carers as well as the NGO sector. This approach could be implemented in pilot service sites across Australia. The 'learning set' strategy is a particularly useful way of services sharing best practice and innovation.



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