



Towards Personalisation in Disability Support: Lessons for Ireland in reforming the sector

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Introduction



1. Personalisation - what is it?
2. Individualised Funding Demystified
3. Implications for Providers
4. Options and Alternatives for Service Reform



1. Personalisation – what is it?

- A simple definition is that: *“It enables the individual alone, or in groups, to find the right solutions for them and to participate in the delivery of a service. From being a recipient of services, citizens can become actively involved in selecting and shaping the services they receive.”*
- Personalisation means that people become more involved in how services are designed and they receive support that is most suited to them.
- Personalisation means enabling people and professionals to work together to manage risk and resources.
- Personalisation should lead to services which are person centred (both around individuals and communities), which can change when required, are planned, commissioned and sometimes delivered in a joined up way between organisations.



Personalisation – what is it?



- The underpinning philosophy of personalisation is aligned with the types of values which a number of third sector organisations have been advocating for some time now.
- Moving from providing a service to being of support.
- Personalisation has the potential to offer very different services to those that have been delivered in the past.
- Some of the mechanisms that have been introduced to facilitate personalisation (e.g. direct payments, individual budgets, personal budgets) have provoked serious debate as these ultimately represent a different way of delivering welfare services.



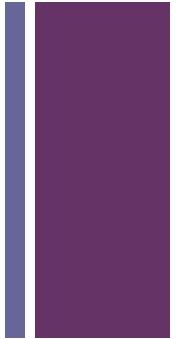
2 - Individualised Funding Demystified



Types of Individualised Funding

1. Direct Payment

- **1. Direct payments** are cash payments given to individuals in lieu of community care services they have been assessed as needing, and are intended to give persons greater choice in their support. The payment must be sufficient to enable the person to purchase services to meet their needs, and must be spent on services that they need.
- Like commissioned care, direct payments are means-tested so assume that, in many cases, people will contribute to the cost of their support.

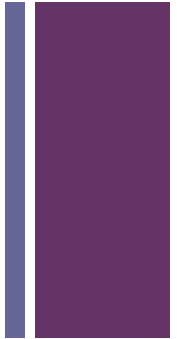




Types of Individualised Funding

1. Direct Payment

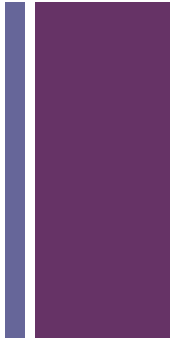
- Direct payments confer responsibilities on recipients to employ people or commission services for themselves.
- Some of these services can be contracted out and some councils have commissioned support organisations to help individuals handle these responsibilities (e.g. CIL's).





Types of Individualised Funding

2. Personal Budget



- **2. Personal budgets** are an allocation of funding given to persons after an assessment which should be sufficient to meet their assessed needs.
- Individuals can either take their personal budget as a direct payment, or - while still choosing how their support needs are met and by whom - leave councils with the responsibility to commission the services. Or they can have some combination of the two.
- As a result, PB's offer a potentially good option for people who do not want to take on the responsibilities of a direct payment.
- Developed by In Control in 122 Local Authorities. 6.5% in 2008-09 and 13% in 2009-10. Of this, 22.8% adults aged 18-64 with a learning disability. ¹



Types of Individualised Funding

2. Personal Budget

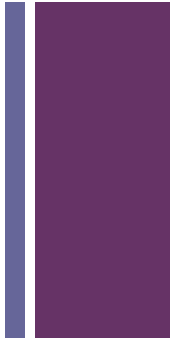


- Another type of Personal Budget is an **Individual Service Fund (ISF)**
- The ‘Individual Service Fund’ (ISF) option is when a provider holds onto the fund, but it remains restricted to the individual. In other words, it is held as a ringfenced fund in the organisation’s accounts.



Types of Individualised Funding

3. Individual Budget



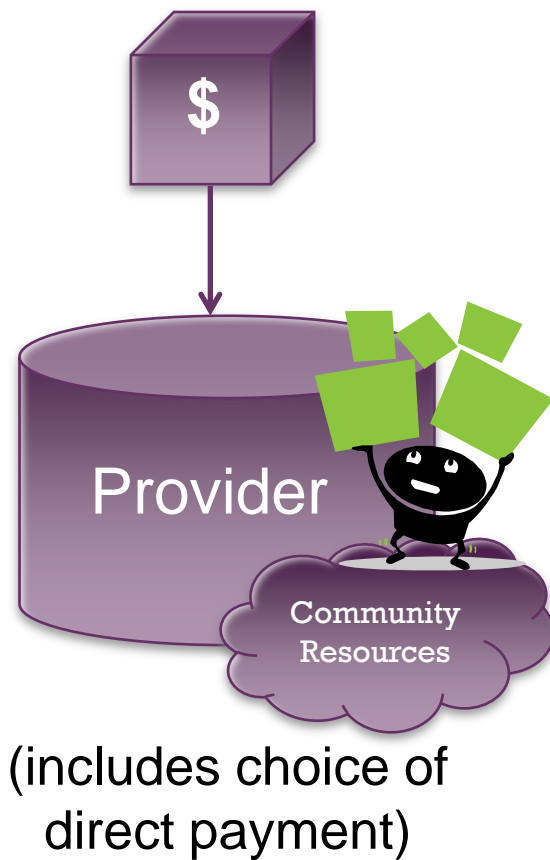
- **3. Individual budgets** differ from personal budgets in that they cover a multitude of funding streams, besides adult social care:
- E.g. Supporting People, Disabled Facilities Grants, Independent Living Fund, Access to Work and community equipment services.
- The UK government has only called for the roll-out of personal budgets - not individual budgets. The latter were piloted in 13 areas for IBSEN evaluation.



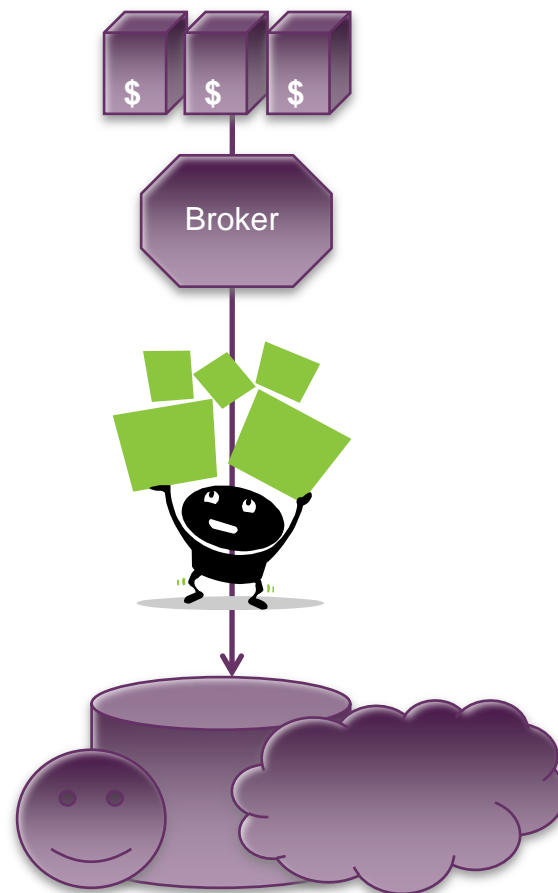
Direct Payment



Personal Budget



Individual Budget





Individual Funding Programmes



- **Canada – BC:**

- **Choices in Support for Independent Living:**

- Phase 1 – For individuals considered ‘mentally capable’ of self managing their support
- Phase 2 – For those not considered ‘mentally capable’. A support group must be formed (\geq 5 persons) as nonprofit society to manage and direct fund with individual.

- **Community Living BC Individual Funding:**

- Facilitators – to assist with the support plan
- Agents – to assist with managing the budget



Individual Funding Programmes



- **Wisconsin: Include, Respect, I Self-Direct (IRIS)**
 - Alternative to Family Care – a managed care programme
 - For individuals with physical or developmental disabilities and frail elders.
 - IRIS Independent Consultants – to assist with developing the support plan.
 - IRIS Fiscal Intermediaries – to assist with managing the budget.
 - 1,400 clients (individuals with physical or developmental disabilities and frail elders.) vs 30,773 participants on Family Care (approx 4.5%)²



Example of a
Personal
Budget
'Allowable
Spending List'
from IRIS,
Wisconsin in
the US:



IRIS Allowable Services List

Adaptive Aids	Day Services	Nursing Services *
Adult Day Care	Home Delivered Meals	Specialized Medical Equipment and Supplies *
Adult Family Home * (1-4 beds)	Housing Counseling and Housing Start - Up	Support Broker
Communication Aids	Relocation Services	Supportive Home Care *
Community Based residential Facility (CBRF)	Home Modification	Supported Employment *
Consumer Education and Training	Personal Emergency Response System	Transportation *
Counseling and Therapeutic Resources	Prevocational Services	Vocational Futures Planning
Customized Goods and Services *	Residential Care Apartment Complex (RCAC)	Note: IRIS Independent Consultant Agency and IRIS Financial Service Agency services are provided at no cost to monthly budgets
Daily Living Skills Training *	Respite *	* denotes a support or service that may be provided by a qualified legally responsible person



3 – Implications of Individual Funding for Providers

+ General Implications



- Closer relationship between users and professionals – has the potential to strengthen ties and collaboration.
- Greater accountability of organisations to individuals and citizens.
- An increase in direct payments and individual accounts that give individuals greater control.
- Increased public participation in decision making.



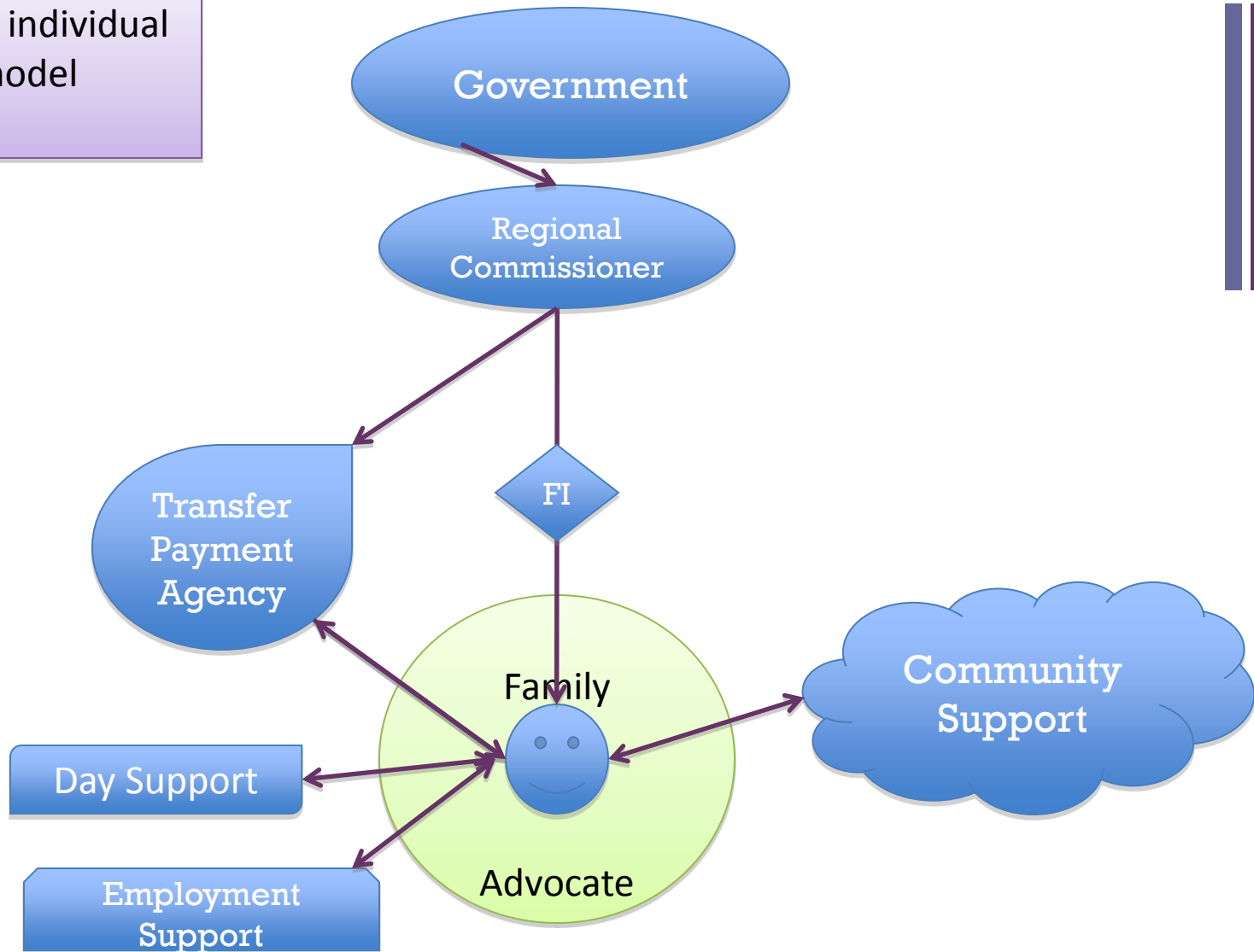
Implications for Providers



New Funding Arrangements:

- Reduction in block contracts
- Diverse sources of funding:
 - Direct Payments
 - Managing Individual Service Funds
 - Spot contracts (for individual or small groups)
- New forms of commissioning:
 - Framework agreements (Zero Volume Contracts)
 - Mini-tenders (for a specific part of a service)

A 'typical' individual
funding model





Responding to Personalisation?



- To what extent is your organisation prepared to listen to and involve individuals?
- Do you feel confident that your organisation fully understands your users and their needs?
 - Need to understand what individuals want and need in terms of services and support!
- Are you developing any tools to enable person driven support?
- Do you capture learning and knowledge from your front line staff?
- What role do your users have in feeding into your future strategy?



What do People spend their Personal Budget on?



- There is continuing demand for 'disability services' (e.g. day services, domiciliary care, speech and language therapy etc.)
- People are spending more of their money on social support that can **help keep them independent and connected to local activities**.
- The biggest increase in spending was in the use of **personal assistants** and **leisure services** (e.g. swimming, sports club).
- Other items include public transport, internet access, adaptations to the home, help with cleaning and ironing.



What do People spend their Personal Budget on?



Other items:

- decking in the garden, arts materials, an IT course, hygiene training, driving lessons, a car harness, a shed, skip hire, a caravan, photography classes
- ...and a snooker cue!
- In practice, these generally have to be agreed in consultation with the key stakeholders in the support planning process.

For further information, see: Bartlett, J. (2009) *At your service: navigating the future market in health and social care*, Demos, London; and the IBSEN pilot site evaluation

+ Implications for Policy

- Changes in levels and types of demand placed on providers will need reviewing as a part of market management so that we can understand what individuals want and need in terms of services and support;
- If there is an increased role for third sector organisations in terms of advocacy or brokerage then it is important that this role is appropriately funded and supported;
- How can the 'irregular' usage of services be co-ordinated in a multi-provider system?
- It is important that the full implications of this agenda are understood and thought through at some length.



Ireland's Disability Support Model



Ireland's 'relaxed control' model:

- De-centralisation
 - HSEAs & Non-profit sector
- Delivery
 - 2 year Service Level Arrangements
 - Professionalised workforce
- Accountability
 - Block funding
 - No mandatory standards

Extent of individual funding:

- Grass-roots provider-led unbundling of group support
- Potential commitment to individualised funding signalled – most likely individual service fund model and option of direct payments



Allocating an Individual Service Fund



- Example: Based on €80,000 as set out in an individual resource allocation tool

Service allocation:

- 13.5% (avg.) – Service Co-ordination and Development Costs (weighted)
- 9.5% (avg.) – Company Costs
 - Incl. 3% (avg.) – Insurance contribution
- Remainder (avg. 77%) – Direct Support Costs (individually determined) e.g. €61,600



Allocating an Individual Service Fund



Service Co-ordination and Development Costs

- Fixed: Cost of annual support co-ordinator
 - Weighted: senior management involvement, allocated average contract hours to psychologist, social worker, consultants, team leaders, etc.
- (This is weighted depending on level of input required in designing, setting up and reviewing supports.)

Company costs

- Service management, training, admin, payroll, human resources, recruitment, etc

Insurance contribution

- unexpected costs not covered by HSE, e.g. sickness

Direct Support Costs

- Individually allocated and determined by individual/Circle of Support



Allocating an ICF



Direct Support Costs:

- Informing everyone (individual, family and staff) how much money is available and working together to get the best from it. The individual is involved in deciding how to spend the money
- Treating the money as 'restricted' for the benefit of a named individual

E.g. of Direct Support Costs:

- Hourly rate of Personal Assistance
- Night-time support
- Speech and language therapy
- Psychology
- Community Nursing
- Physiotherapy

The process can ensure that the hours available are used as creatively as possible and that everyone's opinions are listened to.



Allocating an ICF



- A person gets an individual allocation and their budgets are converted into hours, based on the company's hourly rate paid to staff.
- Families in particular found this much easier to understand - The families involved feel that they have an opportunity to work in partnership with their chosen provider where the focus was on working things out together.
- Annual review – e.g., '4 plus 2' review
 - 4 Qs: what's been tried, what's been learned, pleased about, concerned about?
 - 2 Qs: what can we do next? How do we share what we've learned?



4 - Options and Alternatives for Service Reform



New Roles for Providers



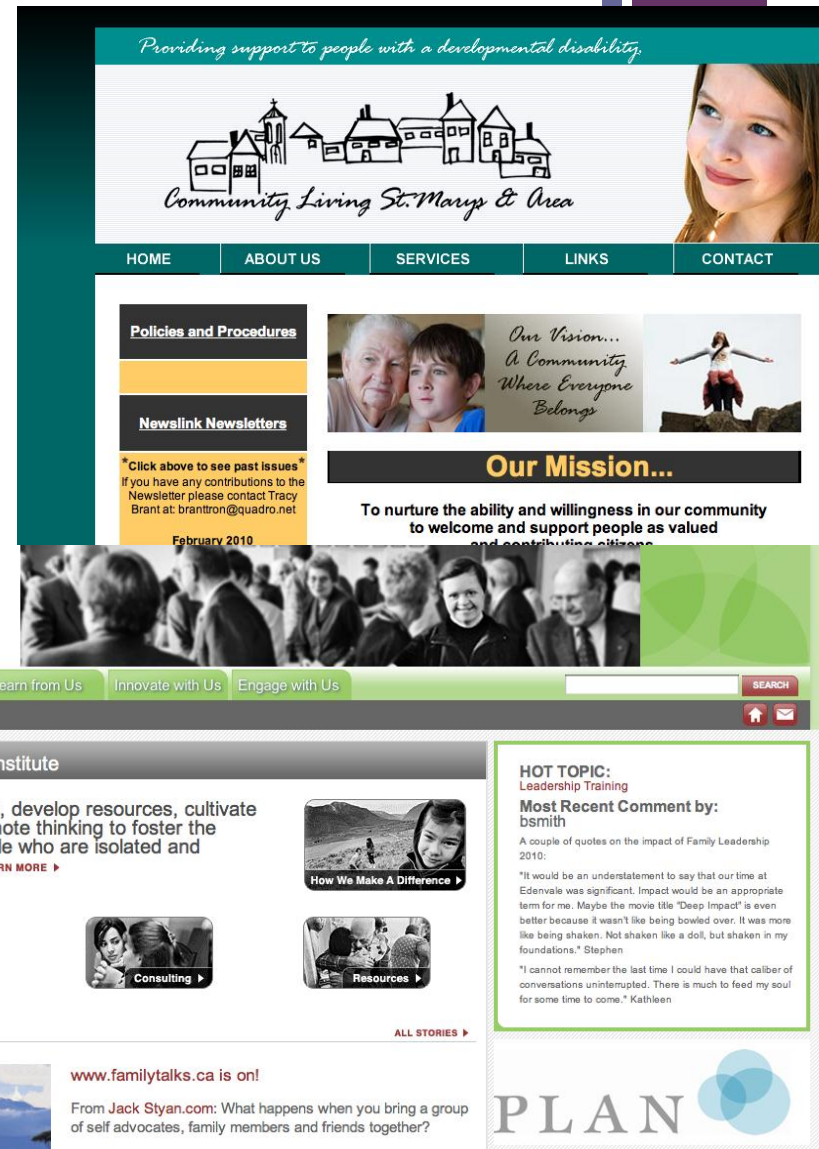
New Roles:

- Brokerage role
- Mentoring role
- Independent Planning
- Fiscal Intermediary
- Direct Support Role - Supporting people in their own lives
- Community Participation – Linking in with mainstream activities and services

+ New Support Models

Examples of New Support Models in Canada:

- Community Living St. Mary's, Ontario
- Options, Ontario
- PLAN Institute, BC



+ New Support Models

Examples of New Support Models in the UK:

- CILs,
- Choice Support,
- MacIntyre,
- Together with Mental Wellbeing,
- Keyring,
- Inclusion Glasgow

Par-funded through:

- Commissioned blocks (Social Care Budget)
- Framework Contracts (Zero Level Contracts)
- Direct Payments



You are here: Home

Together is a national charity working alongside people with mental health issues on their journey to leading fulfilling and independent lives

By working intensively with each and every person who use our services, focusing on their hopes and needs, we can support them in building a positive and meaningful future for themselves – however long it takes.

We **aspire** to a world where each individual can play their part in breaking down the barriers that exist around mental health through ignorance and lack of understanding.

We **believe** that people with mental health issues benefit from leading their own lives and shaping the services they receive.

We **promote** our conviction that the best mental health services are delivered in partnership with the people we work alongside.



The Big Cycle for Together

04 May 2010

A trio of mental health professionals from **Lancashire Care NHS Foundation Trust** have recently embarked on a challenge of a lifetime, having started their attempt to cycle from Land's End to John O'Groats - the length of mainland Britain - in aid of **Together**.

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Focus on
depression



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No Limits is a bespoke person centred service making a difference every day to young people accessing their community. Find out more here!



MacIntyre My Way is the bespoke service supporting people in transition to take greater control of their lives. Click here to find out more about this innovative service.



Sunday 4 July will see over 60 teams take to the water in the annual Dragon Boat Festival on Willen Lake in Milton Keynes. Find out how MacIntyre are preparing for the event by clicking

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Characteristics of organisations who have implemented personalisation



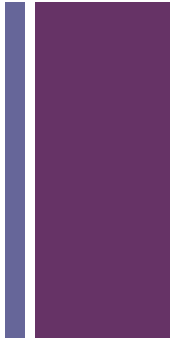
1. The impetus to individualise principally came from values-based leadership within the agency;
2. All agencies believed that they had achieved what they had with individualisation by simply moving ahead with individualisation one person at a time, no matter what;
3. The agencies had individual options in place for the entirety of the people that they served, including those deemed 'difficult to serve';
4. The agencies paid due respect for and effective engagement of families and other natural supporters;
5. The net costs of individualisation in the aggregate were within the range of normative per capita costs in that system;



Characteristics of Organisations who have implemented Personalisation (contd.)

6. All of the agencies had been able to maintain a balanced budget throughout the entirety of their period of individualisation;
7. All of the example agencies were fully compliant with system and funder requirements;
8. All of the agencies had in place some form of functional individual budgets;
9. All agencies were able to coexist and thrive throughout multiple changes in political parties, administrations and policies;
10. All agencies saw their principal task as developmental and ongoing in regards to a person's life at a given moment.

■ Source: Kendrick (2009) Some lessons concerning agency transformation towards personalised services, *The International Journal of Leadership in Public Services*, 5(1) 47-54.





Things to Consider in Managing the Transition



- Listen to the Individual
- Develop a Strategic Vision
- (Re)connect with Families & Communities
- Enable Peer Support
- Get all Personnel working together
- 'One Person at a Time'
- Develop a Human Rights Panel
- Addressing Health & Safety Concerns
- Become a Learning Organisation
- Sustaining Change – Drawing Lines in the Sand



Resources



1 Community Care Statistics 2007-08: Referrals, Assessments and Packages of Care for Adults, England, Information Centre for Health and Social Care, Published May 2009.

2 IRIS <http://www.lafollette.wisc.edu/publications/workshops/2010/iris.pdf>

■ For further reading, see:

■ <http://www.supportplanning.org/Support Planning Downloads/SP 40 What are we learning about Individual Service Funds Sept 08.pdf>

■ <http://www.in-control.org.uk/site/INCO/Templates/General.aspx?pageid=807&cc=GB>

■ <http://www.change.org.uk/Supported Living/Individual Service Fund.html>