# Summary of Key Proposals

# from

# The Review of Disability Policy

**Office for Disability & Mental Health**

**Department of Health & Children**

**3 December 2010**

# Introduction

A review of the efficiency and effectiveness of Disability Services funded from the Health Vote is currently underway, as part of the Government's Value for Money (VFM) and Policy Review Initiative.  The VFM Review will, *inter alia*, consider the effectiveness and efficiency of the disability services currently being provided from the Health Vote and propose any changes necessary to achieve optimal effectiveness and efficiency.   In order to inform the work of the VFM Review, an Expert Reference Group was established to review current policy in relation to disability services. The work of that Group has now been completed and its report will be submitted to the VFM Steering Group.  The Steering Group will determine, having regard to its findings in relation to the effectiveness and efficiency of the current system, whether the recommendations of the policy review will form part of its final recommendations to the Minister and the Government.

In view of the considerable interest expressed by people with disabilities, their families and other disability stakeholders in the policy proposals, the Minister has decided to put the key themes emerging from the review in the public domain, for consideration and discussion.  It is expected that a formal public consultation on the full report of the Expert Reference Group will take place in 2011.

## 1.     The current environment – where we are now...

### 1.1.   What people with disabilities and their families want

> *"I am not looking for anyone's pity or charity. I want to be treated as an equal. I don't see myself as disabled. I don't even think about the fact that I have a disability. I just need someone to assist me in doing some 'physical things' that I can't do. But once I have this support, I see myself just like anyone else – living life to the full".* Submission to the Commission on the Status of People with Disabilities from a woman with muscular dystrophy[1].

This quote captures very well what people with disabilities want.  While much has been achieved since the Commission on the Status of People with Disabilities carried out its work in 1990, there is still a way to go for many people with disabilities so that they can 'live a full life'. Findings from more recent consultations show that people want "flexible supports to suit individual needs"; "... to use local services – do ordinary things in ordinary places" and they want more opportunities for families to "play their part in supporting their family member"[2].

Many of those consulted as part of the VFM Review  were dissatisfied with the amount of choice they have over the service received from service providers and the majority wanted to choose to get different elements from different providers. Most of the respondents were also dissatisfied with the

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[1] Tubridy, J. (1995) *Views from the Inside. A qualitative analysis of submissions to the CSPwD*. Working Paper for the Commission on the Status of People with Disabilities
[2] Health Service Executive (2009) *National Review of HSE Funded Adult Day Services.*

amount of control people with disabilities had over their own lives and the amount of independence they had[3].

## 1.2    The gap between what people want and current provision

The Government's central policy objective for people with disabilities is contained in *Towards 2016;* that people should be supported "to lead full and independent lives, to participate in work and society and to maximise their potential"[4].   This closely reflects  the findings from consultations with people with disabilities. However, there is a gap between the policy objectives and what is provided by many disability services. While current policy objectives emphasise 'full and independent lives' the available information shows that many disability services are not organised or provided in a way that supports this goal.

The current provision of disability services is not just located in and funded by health, but is strongly influenced by a 'professionalised' model of provision. This model has professionalised need, such that needs are assessed from the point of view of what health and social care professionals can offer and what disability services can offer. This has significant consequences for how disability services are organised and delivered, and also on the overall cost of services. The activity of the services is largely focused on providing services in group settings, most of which are segregated from the general community. The current structure and procurement of disability services is focused on continued provision of services in this way.

There is an entangling of health and personal social services which has historical roots but also far-reaching consequences for the delivery and funding of disability services. The health vote currently funds a wide range of services under the heading of disability services, such as housing (residential places), training (day places) and employment (day places). It can be argued that the bulk of the spend on residential and day places is not providing health services at all, but rather personal social services and other supports which are available to the non-disabled population in universal services.

In addition, the almost exclusive location of many of the specialised therapy services (e.g. physiotherapy, occupation therapy, psychology etc.) within disability services means that these therapies are not routinely available outside of disability service settings. This drives demand for segregated services which are counter to policy objectives.

## 1.3    Sustainability of current provision

This model of provision must also be considered in light of the current environment with regard to the economic climate, changing demographics and changing expectations. Information on demographics show that there will be increasing demand for disability services into the future[5]. People with disabilities and their families are looking for more choice in disability services and control over how they access them.

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[3] All findings drawn from the report on the thematic analysis of questionnaires in response to the public consultation conducted by the VFM and Policy Review Group, Nov/Dec 2009 available on Department of Health and Children website www.dohc.ie

[4] Department of the Taoiseach (2006) *Towards 2016: Ten Year Framework Social Partnership Agreement 2006-2015*. Dublin: Stationery Office

[5] Doyle, A., O'Donovan, M.A. and Craig, S. (2009) *National Physical and Sensory Disability Database Committee Annual Report 2008.* Dublin: Health Research Board

In the short to medium term, the changed economic climate dictates that there will be little additional investment for disability services.

What is required in these challenging times is a new policy that has clear objectives and outcomes including how supports and services are organised and incentivised to deliver on specific, clear outcomes that people with disabilities want and which will lead to direct improvements in their lives.

The changed expectations of service users and families reinforce the need for a 'new way'. People with disabilities and their families are not necessarily looking for 'more of the same'[6]. They are looking for flexible services that meet their individual needs and systems which vest more control with the service user (and families as appropriate). As stated in a central policy objective, they are looking for support to enable them to "lead full and independent lives, to participate in work and society and to maximise their potential". The National Disability Authority has advised that better outcomes for people with disabilities can be achieved through aligning services with the policy goals of promoting community integration, independent living, choice and participation[7].

## 2.    Policy Vision – where we want to be…

The vision proposed for the policy is:

> *To realise a society where people with disabilities are supported to participate fully in economic and social life and have access to a range of quality supports and services to enhance their quality of life and well-being.*

The new policy proposals are rooted in key principles and values and have two overarching goals:

**Goal 1: Full inclusion and self-determination for people with disabilities**

Underpinning principles and values:

- **Citizenship**
- **Control**
- **Informed choice**
- **Self-determination**
- **Responsibility**
- **Inclusion**
- **Participation**

**Goal 2: The creation of a cost-effective, responsive and accountable system which will support the full inclusion and self-determination of people with disabilities**

Underpinning principles and values:

- **Equity**

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[6] As is evident from the findings of the VFM and Policy Review Consultation and from service user/family groups such as the National Parents and Siblings Alliance and their 'In Control' conferences and meetings
[7] National Disability Authority (2010) *Advice paper to the Value for Money and Policy Review of Disability Services Programme*

- **Person-centred**
- **Quality**
- **Effective**
- **Efficient**
- **Sufficient**
- **Accountable and transparent**

The first goal captures the objectives in T2016 and spells out the ultimate desired outcomes for people with disabilities. The second goal expresses characteristics of the disability service system which are required to support the achievement of those outcomes.

## 2.1    Key policy proposals under Goal 1

This policy envisages the person with a disability as a self-determining citizen and proposes a range of supports and services required to realise this vision. Central to this vision is the reframing of current disability service provision from services which act to keep the person as passive and dependent towards a system of supports which enable active citizenship and independence.

### 2.2.1    Reframing provision *from* disability services *to* individualised supports

In general, the traditional focus on people with disabilities has been on their deficits and addressing those deficits through the provision of group-based services which segregated people with disabilities from the general community. This separated people from their communities and the natural supports that are inherent in that community. The provision of services in this way tends to reinforce social exclusion and does not enable individuals to exercise choice and control over their lives.

A move to supports will focus on the wider needs of the person and the contributions they can make.  A system of individually tailored supports ensures the person with a disability gets the support they need to live a full life. Supports systems make appropriate use of family and community supports and mainstream services, resulting in a more cost-effective system.  The provision of individualised supports enables the person to exercise choice and control and to be self-determined.

This reframing of provision will require a much greater specificity in terms of response to individual need. Instead of "John needs a residential place", need will be framed very specifically to describe exactly what John needs; "John needs an accessible place to live and the supports to live a full life" (named supports for named activities).

### 2.2.2    Individualised supports

Individualised supports are a personal social service which includes a range of assistance and interventions required to enable the individual to live a fully included life in the community. Individualised supports require the provision of a flexible range of supports and services that are tailored to the needs of the individual, and are primarily determined by the person.
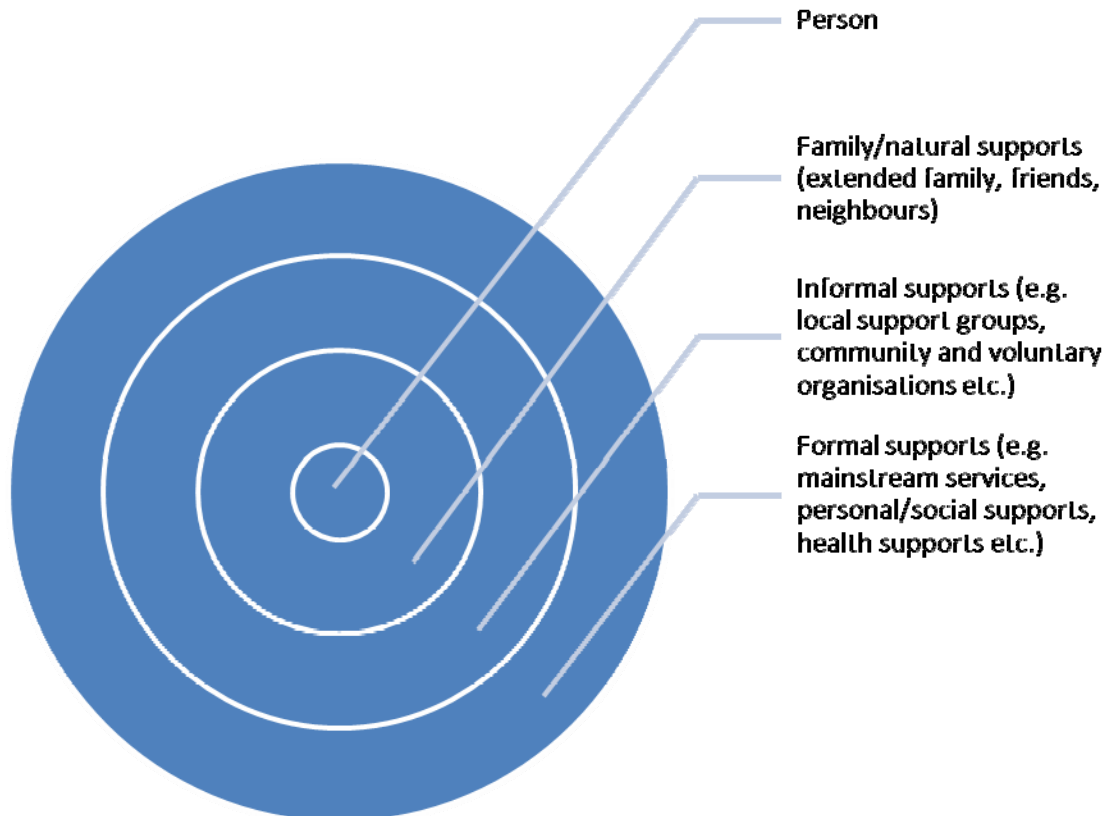
Supports include assistance provided by others, whether in the form of personal care, communication or advocacy support, learning support, therapeutic interventions, aids and equipment, adaptations to the physical environment, and so on. Individualised supports are characterised as being primarily;

- 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 responsive, 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.

### 2.2.3 Supports model

A system of individually tailored supports is designed so that the person with a disability gets the support they need to live a full life. These supports also embed the person in their natural support system and wider community, only drawing on formal supports when necessary. Figure 1 below presents a visual representation of these supports, from the family/natural supports, which are the first line of supports, through informal and community supports and finally formal individualised supports.

**Figure 1: Representation of typical support system[8]**



- Person
- Family/natural supports (extended family, friends, neighbours)
- Informal supports (e.g. local support groups, community and voluntary organisations etc.)
- Formal supports (e.g. mainstream services, personal/social supports, health supports etc.)

[8] Adapted from Office of the Minister for Children (2007) *The Agenda for Children's Services: A Policy Handbook.*

As most people with disabilities live with their families; parents, siblings and adult children are key providers of the individualised supports described above. This type of family support is provided by many families on a 24/7 basis, often with little input or support from formal disability or other health services, and has been central to keeping many children and adults with disability out of residential services. Under the new policy proposals a person living in the family home would also have access to individualised support packages, although the components may vary depending on the level of input families can make. Various models of respite support would also be available to families.

This model of support to live independently in the community is one which has been in place in many other jurisdictions for some time. Sweden closed its residential institutions for people with intellectual disability by 2000 and there are now eleven US states which have no residential institutions for people with intellectual disability. The UK, New Zealand and several Australian states are also working towards closing residential institutions. Other countries are taking this action because there is such strong evidence that the quality of life of people living in community settings is better than people living in institutions[9]. A recent European Commission Report concluded that *"available studies confirm that if high quality community services are provided, most formerly institutionalised users have a clear preference for community living and display higher level of personal satisfaction and social inclusion"*.[10]   International evidence also shows that there is genuine potential for community-based services to be more cost-effective for the vast majority of service users, that is, less cost for better outcomes[11].

## 2.3    Mainstreaming

 Mainstreaming is about people with disabilities having access to the same services as the general population, known as 'universal services'. Properly applied, mainstreaming has the potential to provide a wider range of supports and services to a greater number of people with disabilities than is currently the case. Social inclusion of people with disabilities is 'built into' this system because these are the same supports and services provided to the general population. In addition, because there is less duplication of services there is significant potential for greater cost-effectiveness.  The desirability of mainstreaming was expressed very clearly by the parent of a young woman with a disability; *"I don't want my daughter getting on a 'special' bus to a 'special' school and to be totally separated from the rest of the community... I want her to go to the same school as the other children and to have the same opportunities."*[12]

Mainstreaming is a central mechanism to realise the proposed policy vision. A "whole of government" approach can ensure people with disabilities will have access to the universal services they need. The government has a strong commitment to mainstreaming which is underpinned by legislation such as the *Disability Act 2005*, the *EPSEN Act 2004* and the *Equal Status Acts 2000 and 2004*.

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[9] National Disability Authority (2010) *Advice paper to the Value for Money and Policy Review of Disability Services Programme*

[10] Directorate-General for Employment, Social Affairs and Equal Opportunities (2009) Report of the Advocacy Hoc Expert Group on the Transition from Institutional to Community-based Care. European Commission.

[11] Mansell, J., Knapp, M., Beadle-Brown, J. and Beecham, J. (2007) *Deinstitutionalisation and community living – outcomes and costs: report of a European Study.* Canterbury: Tizard Centre, University of Kent.

[12] Quote from a presenter at the *In Control* Conference February 2009

There are concerns about mainstreaming, however, particularly fears that services will be diluted[13] and that the implementation of mainstreaming will mean that specialist supports will no longer be available for people with disabilities. However, mainstreaming does not mean that there is a 'one-size fits all' approach to the provision of services and supports.  Under existing Government policy all services (health, education, transport, employment etc.) are required to adjust their services to accommodate people with disabilities.  Within a mainstream system, disability-specific supports can be provided where the needs of the individual require such supports. Concerns have been expressed by the NDA that the *Sectoral Plans* of many departments[7] have taken a narrow view of Departmental responsibility towards people with disabilities. The successful achievement of mainstreaming, where people with disabilities are fully supported to access all the services and supports available to their peers, will require all Government departments to commit to an approach of "tailored universalism[15]. The adoption of such an approach has benefits for the whole population which are not just confined to people with disabilities. For example, the use of universal design ensures not just access for people with disabilities, but results in buildings that are suitable for all throughout the lifecycle, incorporating the changing needs of older people and young children.

## 3.      Key policy proposals under Goal 2

The second overarching goal of the policy is to create a high quality, cost-effective, responsive and accountable system which will support the inclusion and self-determination of people with disabilities.

A strong governance framework is needed to underpin the provision of the supports and services for people with disabilities that are recommended in this policy. Governance has been defined as "*the set of responsibilities and practices, policies and procedures, exercised by an agency's executive, to provide strategic direction, ensure objectives are achieved, manage risks and use resources responsibly and with accountability.* [14]

The elements of such a governance framework include;

- Processes for assessing needs
- Processes for allocating resources
- Processes for procurement and commissioning
- Quality assurance systems
    - o   Including processes for managing risk
- Processes for performance management, review and accountability
- Appropriate information systems
- Management structure

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[13] Disability Federation of Ireland (2007) *Mainstreaming for Me 2005-2006.* DFI, Dublin.

[14] Department of the Prime Minister and Cabinet (2006) *Implementation of Programme and Policy Initiatives. Making implementation matter. Better Practice Guide.* Australian Government.
http://www.anao.gov.au/uploads/documents/Implementation_of_Programme_and_Policy_Initiatives.pdf

## 3.1     Provision based on need

The system of individualised supports and mainstream services proposed in this policy requires an approach to needs assessment that is driven by the person and family (as appropriate), who are centrally involved in the entire process; covers the important domains in a person's life; uses a standardised, reliable process; and is independent of those providing supports and services.

**The allocation of resources based on need is essential to achieve equity in the provision of supports and services, provision that is fair and transparent and efficiency in how resources are used, i.e. that resources are related to need.**  The proposed mechanisms are as follows:  An independent comprehensive assessment of need will shape the individual support plan for each person. Individualised supports will be used to identify an individualised budget, which is a sum of money that attaches to the person and is used to provide the supports and services they need. The service user (and family as appropriate) will have an input into how this individualised budget is used and which providers will provide which supports. A number of mechanisms can be used to achieve this, including direct payments, where the person administers the budget themselves, or a broker system, where the person has the same amount of input into 'designing' their supports and services, but uses the broker to administer the budget and to commission supports and services on their behalf. This new approach to resource allocation at the individual level will have several benefits, including:

- An explicit transparent link between amount of resources and support needs (which does not exist in present system);
- Built-in resource constraints and prior agreement on unit costs;
- A focus on sourcing supports from mainstream provision and informal supports as appropriate;
- Creation of service user/family awareness of the amount of funding allocated for them;
- Provides choice in terms of level of control over funds and between different providers;
- An explicit statement of outcomes leading to regular review, accountability and performance management on the basis of individual outcomes.

## 3.2     A new system of supports and services

The creation of a governance system to deliver the comprehensive system of individualised supports and services described above will require existing processes to be reconfigured.  The table below summarises the change that is required; the characteristics of the current system and how the new system would look.

**Summary of shift from current provision to individualised supports and mainstream services**

| Current disability provision | Individualised supports and mainstream services |
|---|---|
| *From* ...service defined by agency | *To* ...service jointly defined by service user and family, commissioning authority (e.g. HSE) and Government |
| *From* ...service deliverer accountable for inputs and compliance | *To* ...service deliverer accountable for outputs and quality |
| *From* ...compliance with rules | *To* ...attainment of outcome-based standards and demonstrated commitment to continuous quality improvement |
| *From* ...provides categorical services | *To* ...provides integrated services |
| *From* ...service delivered through credentialed professionals | *To* ...services and supports delivered through professionals, non-professionals and service user representatives |
| *From* ...funds isolated projects | *To* ...levers local innovations into improvements in mainstream services |
| *From* ...one size fits all | *To* ...assumption of need for diversity |

Source: adapted from *The Developmental Welfare State* (NESC, 2005)[15]

## 3.3    Implementation planning

If the changes proposed here are adopted by Government, they will pose significant challenges and careful implementation planning will be required to ensure they can be made. This is likely to be a long-term process occurring over a 5-10 year period. Significant redeployment of financial resources will be required, as well as significant flexibility and redeployment of staff. However, both are already happening on a small scale in several providers. The appropriate skill mix for this new model of provision will also have to be identified and the unbundling of health and personal social services will be required. A 'whole of Government' approach that interlinks policy, people, money and organisations (as recommended by OECD[16]) will be essential.

## 4.    Change at the societal level

The changes required under the proposed policy are significant and will not come about by simply framing policy goals. We need to think very differently about how we perceive people with disabilities and how supports and services will be provided in the future. This policy proposal envisages the person with a disability as a self-determining citizen and sets out a range of supports and services required to realise this vision.

Policy development presents an opportunity to challenge the negative attitudes that can be held towards people with disabilities. The proposed framework serves to support people with disabilities in realising their own lives, not in providing a menu of services to passive recipients in separate, segregated settings.  If implemented, it will enable us as a society to make significant progress towards our stated objective, as expressed in *Towards 2016*, to bring about full inclusion for people with disabilities.

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[15] National Economic and Social Council (2005) *The Developmental Welfare State*. NESC: Dublin.
[16] Organisation for Economic Cooperation and Development (2008) *Ireland: towards an integrated public service.* Paris: OECD