

REPORT OF DISABILITY POLICY REVIEW

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Expert Reference Group on Disability Policy

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Executive Summary

This report is an output of the Expert Reference Group which was convened to facilitate and support the policy review aspect of the overall Value for Money (VFM) review of disability services. 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 Review is overseen by a Steering Committee. In order to inform the Steering Group in its deliberations, particularly with respect to any changes that may be necessary, an Expert Reference Group was established to review current policy in relation to disability services. This report is an output of the Expert Reference Group.

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

1.1. Current policy objectives relating to people with disabilities

The 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”¹. Other objectives concerning people with disabilities in T2016 deal with access to services, wider environmental accessibility and support for carers.

1.2 Current disability service provision

This policy review covers “all people with disabilities who have a need for a health/personal social service and all services currently funded and provided through the health Vote”². The definition of disability used in the review is that used in Section 2 of the Disability Act 2005³: “A substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment”. This definition is based on a social understanding of disability which recognises that people with disabilities have a right to participate in, and contribute to society as equals, and that it is societal attitudes and barriers which prevent people with disabilities from reaching their full potential. This understanding runs throughout current national and international policy.

The majority of intellectual disability service provision occurs in settings that cater for groups of people and which are separate from the rest of the community. Most day service occurs in segregated, group settings (approximately 90%) and most residential services are provided in segregated group settings (approximately 90%). The proportions of people with physical and sensory disability in receipt of segregated residential and day services are smaller. Many of the individuals in disability services receive what are sometimes described as ‘wraparound’ services from a single provider. This means the person receives a residential service (i.e. a place to live and daily supports),

¹ Department of the Taoiseach (2006) *Towards 2016: Ten Year Framework Social Partnership Agreement 2006-2015*. Dublin: Stationery Office

² Terms of Reference for Policy Expert Reference Group

³ Government of Ireland (2005) *Disability Act*. Dublin: Stationery Office

a day service (i.e. occupation of varying types up to five days a week) and also a variety of health services and other personal social services depending on their needs. These are all currently funded by the Disability Services Programme Budget through the health vote. In addition, for historical reasons, disability services funded through the health vote have also provided other services that would normally be outside the remit of health, such as sheltered employment and employment-related supports of various types, training and education-related supports, transport and advocacy services.

There is little evidence of individualised service provision, with a lack of standardised needs assessment and provision largely based in groups. Even though many services purport to use person-centred planning, the quality of the person-centred plan can be negated if options are framed largely in terms of the current model of provision. For example, some day services may be described as supporting 'community participation', although this often involves service users attending a community setting as a group, on a special bus, often in a segregated manner (for example, a special hour for swimming or bowling). Those attending in the group usually have not selected that activity themselves. This is very different to an individual choosing to attend a swimming lesson, travelling to the swimming pool on public transport and taking the lesson with just a support person (not necessarily a health or social care professional).

1.3 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 dystrophy⁴.

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"⁵.

Many of those consulted more recently 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 amount

⁴ 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

⁵ Health Service Executive (2009) *National Review of HSE Funded Adult Day Services*.

of control people with disabilities had over their own lives and the amount of independence they had⁶.

1.4 The gap between policy objectives and current disability service provision

The policy goals in T2016 closely reflect what 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 objectives are, nonetheless, still relevant and reflect the thinking in national and international policy documents. However, the realisation of these objectives has not been evident for many people with disabilities.

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. The additional funding that was available in recent years was focused on providing ‘more of the same’ in terms of structures and places, rather than addressing individual needs in individualised, flexible ways.

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.

1.5 Sustainability of current policies and investment

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 future⁷. In the short to medium term, the changed economic climate dictates that there will be little or no

⁶ 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.

⁷ Doyle, A., O’Donovan, M.A. and Craig, S. (2009) *National Physical and Sensory Disability Database Committee Annual Report 2008*. Dublin: Health Research Board

additional investment for disability services. People with disabilities and their families are looking for more choice in disability services and control over how they access them.

What is required in these challenging times is a new policy that has clear objectives and outcomes not just on how services are accessed or the lives of people with disabilities, but 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.

It is the changed expectations of service users and families which reinforce the need for a 'new way'. People with disabilities and their families are not necessarily looking for 'more of the same'⁸. 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 participation⁹.

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

Based on this analysis of current disability service provision and the wider context, a policy framework is being developed to express specific policy objectives for people with disabilities and for disability services, and to support the achievement of these objectives.

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**

⁸ 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

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

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**
- **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 the full inclusion and self-determination of people with disabilities.

2.1 The life cycle framework

This policy proposes to adopt a life cycle approach and encompass all age groups; children, adults and older people. The vision and underlying principles and values of the policy apply to all. The life cycle approach “adopts the perspective of the person as the centrepiece of social policy development”¹⁰ and has therefore been adopted in the framing of this policy for people with disabilities. In accordance with the policy of mainstreaming, people with disabilities should benefit from measures at all stages of the life cycle. Disability describes a characteristic of the person that may present specific needs, but it is the life cycle category that is the primary definition of the person and ensures their ability to benefit from all the measures and services in place for that group. This means that children with disabilities are children first and should benefit from all measures directed at children. Similarly, older people with disabilities should benefit from all measures available to older people.

2.2 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*

¹⁰ Department of the Taoiseach (2006) *Towards 2016: Ten Year Framework Social Partnership Agreement 2006-2015*. Dublin: Stationery Office

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.”¹¹

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*. The Sectoral Plans also have a commitment to the policy of mainstreaming.

There are concerns about mainstreaming, however, particularly fears that services will be diluted¹² 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 departments⁷ 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 universalism¹⁵”. 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.

2.3 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.

2.3.1 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 the individual to exercise choice and control over the lives. In this model the person is a passive recipient of a pre-determined service rather than an active determinant of an individually tailored service that meets their needs and supports the achievement of their potential.

The move to supports focuses 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

¹¹ Quote from a presenter at the *In Control* Conference February 2009

¹² Disability Federation of Ireland (2007) *Mainstreaming for Me 2005-2006*. DFI, Dublin.

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).

2.3.2 Individualised supports

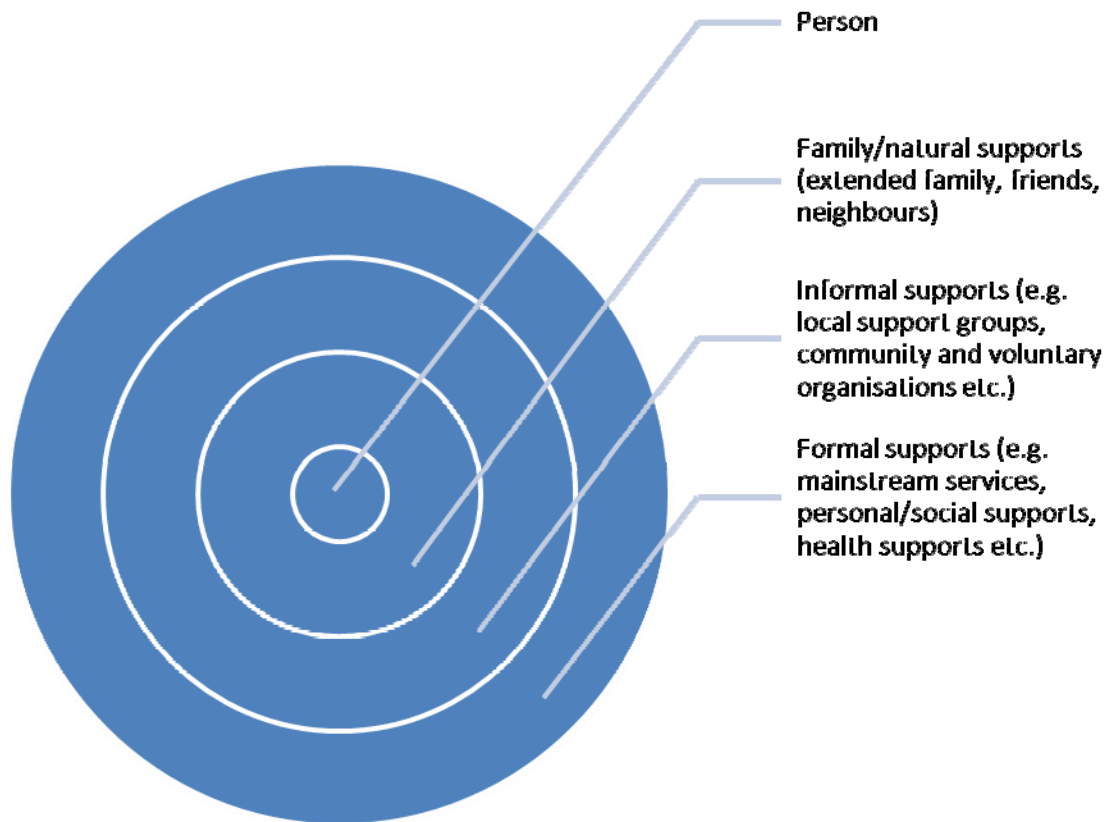
Individualised supports are a personal social service which includes a range of assistance and interventions required to enable the individual to live a fully included life in the community. Individualised supports require the provision of a flexible range of supports and services that are tailored to the needs of the individual, and are primarily determined by the person. This provision enables people with disabilities to live as full citizens instead of having to fit into standardised models and structures.

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.

2.3.3 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 system¹³

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 institutions¹⁴. 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*

¹³ Adapted from Office of the Minister for Children (2007) *The Agenda for Children’s Services: A Policy Handbook*.

¹⁴ National Disability Authority (2010) *Advice paper to the Value for Money and Policy Review of Disability Services Programme*

personal satisfaction and social inclusion".¹⁵ 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 outcomes¹⁶.

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. The fundamental importance of such a system in promoting citizenship has been acknowledged by the European Parliament:

“Access to well-functioning, accessible, affordable and high quality public services is seen as an important part of citizenship and as a fundamental right” (European Parliament 2006)¹⁷

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.*”¹⁸

The elements of such a governance framework include;

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

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.

¹⁵ 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.

¹⁶ 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.

¹⁷ European Parliament (2006) *Resolution on a European Model for the Future*, Brussels: European Parliament

¹⁸ 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

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 within existing funding limitations. 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 disability service provision to individualised supports and mainstream services

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

Source: adapted from *The Developmental Welfare State* (NESC, 2005)¹⁹

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 OECD²⁰) 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.

It could be considered that stigma and attitudes are topics that are outside the consideration of a policy for people with disabilities. However, negative attitudes and discrimination are underlying

¹⁹ National Economic and Social Council (2005) *The Developmental Welfare State*. NESCC: Dublin.

²⁰ Organisation for Economic Cooperation and Development (2008) *Ireland: towards an integrated public service*. Paris: OECD

causes of social exclusion and a significant barrier to social inclusion and participation, an area that is a specific focus of government policy and action²¹. Policy can sometimes serve to reinforce negative attitudes towards people with disabilities;

“We often see the impact of negative attitudes in how one person treats another. But negative attitudes are also the foundation stone on which disabling policies and services are built. Harmful attitudes that limit and restrict are institutionalised in policies and services and so maintain the historic disadvantage that disabled people have faced”²².

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. It would 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.

²¹ National Action Plan for Social Inclusion 2007-2016

²² Massie, B. (2006) Participation – have we got an Attitude Problem? Paper presented to the NDA 5th Annual Conference.

[http://www.nda.ie/CntMgmtNew.nsf/0/5A19C972AF5A7B93802571E60052A06B/\\$File/conf20064.html](http://www.nda.ie/CntMgmtNew.nsf/0/5A19C972AF5A7B93802571E60052A06B/$File/conf20064.html)

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 Review is overseen by a Steering Committee, which includes representatives from the Department of Health & Children, the Department of Finance, the HSE, the Disability Sector and three independent members, one of whom is the chairperson.

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 Steering Group in its deliberations, particularly with respect to any changes that may be necessary, an Expert Reference Group was established to review current policy in relation to disability services. The membership of the Expert Reference Group is below. Members were present in their personal capacity, not as representatives of their respective organisations.

Mr. James O'Grady (Chair)

Mr. Brendan Broderick

Ms. Deirdre Carroll

Mr. Colm Desmond

Mr. Seamus Greene

Ms. Gabrielle Jacob (Replaced Ms. Marie Kennedy)

Ms. Ann Kennelly (Replaced Ms. Marion Meaney)

Mr. Christy Lynch

Mr. Martin Naughton

Ms. Mary Van Lieshout

The Terms of Reference of the Expert Reference Group were:

1. Includes all people with disabilities and all services currently funded and provided through the Health Vote;
2. Define and describe the objectives of the services;
3. Consider the extent to which existing policies are consistent with delivery of these objectives;
4. Whether current policies and the investment arising from these policies are sustainable in the context of:
 - a. Current legislative and strategic frameworks
 - b. Changing economic climate

- c. Changing demographics
 - d. Changing expectations
5. Propose policy changes, if any, to ensure that the overall objectives are met.

The group met 18 times from August 2009 to November 2010 and carried out a public consultation on the central proposals. The work of the group was informed by research conducted by the National Disability Authority and by Dr. Fiona Keogh, Independent Research Consultant. This report is an output of the Expert Reference Group. It is in three parts; Part A is a review and analysis of policy and legislation that is relevant to disability (numbers 2-4 in the Terms of Reference); Part B outlines the proposed policy framework and details the proposals under the first Policy Goal; and Part C details Policy Goal 2 and the governance framework to realise the policy goals.

PART A: REVIEW AND ANALYSIS OF POLICY

1. Scope of Policy Review

This policy review covers *“all people with disabilities who have a need for a health/personal social service and all services currently funded and provided through the health Vote”*²³. The definition of disability used in the review is that used in Section 2 of the Disability Act 2005²⁴: *“A substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment”*. This definition is based on a social understanding of disability which recognises that people with disabilities have a right to participate in, and contribute to society as equals, and that it is societal attitudes and barriers which prevent people with disabilities from reaching their full potential. This understanding runs throughout current national and international policy.

The World Health Organisation’s International Classification of Functioning, Disability and Health²⁵ defines the term ‘disability’ as follows: *“an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors (environmental and personal factors).”*²⁶ (WHO 2001 :213)

It is the interaction of the person’s health characteristics and their contextual factors (environment, personal) that produces disability. If a person with a given health condition lives in an environment characterised by barriers at every level their performance will be restricted; but if a person lives in a facilitating environment this will serve to increase their performance²⁷.

²³ Terms of Reference for Policy Expert Reference Group

²⁴ Government of Ireland (2005) *Disability Act*. Dublin: Stationery Office

²⁵ World Health Organisation (2001) *International Classification of Functioning, Disability and Health*. Geneva: WHO <http://www.who.int/classifications/icf/en/>

²⁶ Ibid. WHO 2001 p. 213

²⁷ <http://www.nda.ie/cntmgmtnew.nsf/0/6877A99815DA544980257066005369D1?OpenDocument>

The policy review covers people with physical and sensory disabilities and people with intellectual disabilities, and the services that are currently funded through the health vote for these groups. Throughout the review document, the term *people with disabilities* is used to refer collectively to people with intellectual and physical and sensory disabilities. While people with mental health difficulties come within the broad definition of disability, a comprehensive mental health policy has been endorsed by Government in the recent past (*A Vision for Change, 2006*) and is now being implemented. Mental health is therefore not covered in this policy review.

1.1 Numbers of people with intellectual disability

The National Intellectual Disability Database (NIDD) captures data on persons with an intellectual disability who are in contact with services and those who, having had their needs assessed by a service provider, are considered to require disability services in the next five years²⁸. The database is used as a planning tool by the health services. Inclusion on the database is voluntary. The nature of intellectual disability service provision ensures “an almost complete capture”²⁹ of people with moderate, severe and profound intellectual disability, as almost all those in receipt of services agree to have their details recorded on the database. Persons with a mild intellectual disability are included in the database if they are in special classes or special schools for children with intellectual disability, or are attending disability service as adults, or if they are considered likely to require such a service in the next five years. Thus, there is a significant number of people with mild intellectual disability who are not on the database.

In 2008, 26,023 persons with an intellectual disability were registered on the NIDD. This is significantly lower than the number reported in the National Disability Survey³⁰. This is largely due to differences in the definitions used of intellectual disability and in the method of identification of the disability. Twenty eight per cent of those registered on the NIDD also had a physical/sensory disability.

Of the 26,023 persons registered on the database, 25,433 were in receipt of services;

- Over 9,000 people with intellectual disabilities in residential settings, 90% in segregated, group settings
- Over 16,000 people with disabilities attend a day setting, with over 90% attending segregated, group settings
- 20,971 availed of at least one multidisciplinary support service³¹ (including those provided by early intervention teams). The services most commonly availed of by adults were social work, medical services and psychiatry. The services most commonly availed of by children were speech and language therapy, social work and occupational therapy.

²⁸ Kelly, F., Kelly, C., Maguire, G. and Craig, S. (2009) *Annual Report of the National Intellectual Disability Database (NIDD) Committee 2008*. Dublin: Health Research Board.

²⁹ Ibid. NIDD p.19

³⁰ In the National Disability Survey, conducted by the Central Statistics Office in 2006, 71,600 people identified themselves as having an intellectual or learning disability.

³¹ Multidisciplinary service inputs are only recorded if the individual has received, or will receive, at least four inputs of that service in a 12 month period.

1.2 Numbers of people with physical and sensory disability

The National Physical and Sensory Disability Database (NPSDD) provides an overview of the specialised health and personal social service needs of people with a physical and/or sensory disability³². Inclusion on the database is voluntary and based on people who are availing of specialised health and social services. For these reasons, the number on the database is only indicative of numbers in the total population, or of those in receipt of services. In addition there are some concerns over the quality of the data as not all records have been updated regularly³³.

In 2008, 29,946 were registered on the NPSDD. However, 2,643 records for people aged over 66 years were not included in detailed analysis as responsibility for provision of services to this group lies within older people's services rather than disability services³⁴. Thus, the report is based on 27,303 individuals;

- 697 people (2.6%) lived in full-time residential services
- 61% of registered people had a physical disability
- 11% had a sensory disability
- 18.4% had multiple disabilities
- 83% were in receipt of therapeutic intervention and rehabilitation services
- 53% were in receipt of day services
- 65% were using at least one technical aid or appliance.

1.3 Future needs

The two disability databases also report on future need for services. The NIDD reported, for example, a requirement for over 2,000 new residential places to meet need for the period 2009-2013³⁵. The future service requirements for 2010-2013 from the NPSDD included 730 residential places and 3,244 day places³⁶. The 2005 report of the Comptroller and Auditor General cited concerns regarding the assessment of need in the NIDD and the NPSDD, namely that the assessment process to identify needs is not standardised and that the assessment process is not independent (service providers make a judgement on the future needs of their current service users). It was noted that the assessment process *"has been criticised for the tendency to identify needs from a narrow perspective and in terms of capacity to deliver"*³⁷. The estimate of future residential needs has been reported as being only 50% accurate, with future need for multidisciplinary services being reported as 78% accurate³⁸.

³² Doyle, A., O'Donovan, M.A. and Craig, S. (2009) *National Physical and Sensory Disability Database Committee Annual Report 2008*. Dublin: Health Research Board

³³ Ibid. NPSDD p. 5

³⁴ Ibid. NPSDD p. 5

³⁵ Kelly, F., Kelly, C., Maguire, G. and Craig, S. (2009) *Annual Report of the National Intellectual Disability Database (NIDD) Committee 2008*. Dublin: Health Research Board.

³⁶ Doyle, A., O'Donovan, M.A. and Craig, S. (2009) *National Physical and Sensory Disability Database Committee (NPSDD) Annual Report 2008*. Dublin: Health Research Board

³⁷ Comptroller and Auditor General (2005) *Provision of Disability Services by Nonprofit organisations*. Value for Money Report No. 52. www.audgen.gov.ie/documents/vfmreports/52_disabilityservices.pdf p.20

³⁸ Craig, S. from NIDD Health Research Board. *Audit of NIDD*. Presentation to Inclusion Ireland meeting, November 2008.

In terms of linking needs to service requirements the 2009 report of the Comptroller and Auditor General noted that *“although the databases record information for individual service users, they do not capture the level of service required by each individual, in terms of the number, type and grade of staff required. As such, they do little to assist the HSE in helping to set funding levels for service providers.”*³⁹

In terms of wider information needs, there is a lack of both the data and of the information systems required to support the type of strategic management and performance reporting recommended by the Comptroller and Auditor General⁴⁰.

2. Current disability service provision

Disability services cover a wide range of provision which includes;

- Residential and respite services
- Day services
- Work and employment services
- Assisted Living /Personal Assistant Service for people with physical and sensory disabilities includes a range of personal supports for people with physical and/or sensory disability, such as Personal Assistants, Home support, Assisted living support and Home help.
- The provision of aids and appliances
- Information advocacy and support services are often provided by agencies or services with expertise in particular conditions.
- Medical and clinical therapies. Specialist services for persons with disability which may be provided to individuals in services or in community settings. Specific services may be provided to particular age groups i.e. early intervention, school going children etc.

The combined total of those registered on the NIDD and the NPSDD is almost 56,000 persons. As there is incomplete capture of persons in receipt of services on these databases, the HSE estimates that approximately 65,000 persons with a disability are in receipt of services. Table 1 provides a breakdown of service provision among those registered on the NIDD and the NPSDD.

³⁹ Comptroller and Auditor General (2010) *Report of the Comptroller and Auditor General Accounts of the Public Services 2009. Volume 2.*

http://www.audgen.gov.ie/documents/annualreports/2009/ReportVol2_09_rev2.pdf

⁴⁰ Ibid. Comptroller and Auditor General (2005) p. 20 and p.34

Table 1: Numbers in receipt of the main areas of disability service provision⁴¹

Service Area	ID	Physical and Sensory
Early childhood / family support services	7,000	- *
Therapeutic supports	13,900	22,580*
Home-based supports	2,140	4,980
Adult day services	13,660	4,000
Rehabilitative training	1,656	430
Sheltered work	4,130	100
Employment services	1,190	170
Residential places		920
	8,450	
Respite	4,760	3,150
Aids and appliances	-	17,730

*The NPSDD 2008 doesn't contain a breakdown of those over and under 18 receiving therapeutic supports. Therefore the 22,580 figure refers to all people with physical and sensory disabilities receiving therapeutic supports and would include those receiving early intervention supports.

2.1 Bundled or 'wraparound' services

Many of the individuals in disability services (particularly those with intellectual disability) receive what are sometimes described as 'wraparound' services from a single provider. This means the person receives a residential service (i.e. a place to live and daily supports), a day service (i.e. occupation of varying types up to five days a week) and also a variety of health services and other personal social services depending on their needs. These are all currently funded by the Disability Services Programme Budget through the health vote. In addition, for historical reasons, disability services funded through the health vote have also provided other services that come within the remit of other departments and agencies, such as sheltered employment and employment-related supports of various types, training and education-related supports, transport and advocacy services.

2.2 The funding of disability services

For 2010 the total investment in specialist disability services, as outlined in the HSE National Service Plan 2010⁴², is €1.476bn reduced from €1.583 in 2009. This represents 10.5% of the €14 billion health budget. This funding provides disability services throughout the country.

The majority (90%) of disability services are delivered through the non-statutory/voluntary sector service providers. In 2009, 280 service providers in the voluntary sector received funding from the HSE amounting to €1.2bn. Twenty-three agencies received an average of €24m each and 68 agencies averaged €1-10m. Table 2 below shows the breakdown of the allocation to agencies across funding levels.

⁴¹ Figures from NIDD 2008: Kelly, F., Kelly, C., Maguire, G. and Craig, S., (2009) *Annual Report of the National Intellectual Disability Database Committee 2008*; and NPSDD 2008: Doyle, A., O'Donovan, M. and Craig, S., (2009) *National Physical and Sensory Disability Database Committee Annual Report 2008*.

⁴² Health Service Executive (2010) National Service Plan 2010.

<http://www.hse.ie/eng/services/Publications/corporate/National%20Service%20Plan%202010.pdf>

Table 2: Allocation to disability service providers. 2009.

	Number of Primary Service Providers/ Agencies	% Total Agency No.	Total €	% Total €
Agencies over €100 Million	3	1%	408,005,801	33%
Agencies €100 Million to €10 Million	20	7%	607,101,639	50%
Agencies €10 Million to €5 Million	11	4%	77,023,129	6%
Agencies €5 Million to €1 Million	38	14%	98,749,398	8%
Agencies €1 Million to €500K	19	7%	14,065,393	1%
Agencies €500K to €250K	25	9%	8,755,428	1%
Agencies under €250K	164	59%	7,306,883	1%
Grand Total	280		1,221,007,671	

Source: HSE

As shown in Table 2, there are approximately 72 significant non-statutory service providers (i.e. those receiving over €1m in funding). These are a mixture of national, regional and local organisations. The bulk of this funding was to intellectual disability services with the remainder to physical and sensory disability services. Residential disability services account for about half the total budget for disability⁴³, with adult day services accounting for a further quarter. This means approximately three-quarters of the budget for disability services (about €900m) goes on services for the 9,000 people in residential services and the 18,000 people receiving adult day services, most of whom are people with intellectual disability⁴⁴.

⁴³ Excluding the budget for allowances, which is now being transferred to the Department of Social Protection. The Revised Estimates for 2010 shows estimates for 2010 of €858m on intellectual disability and autism services; €551m on physical and sensory disability; €56m. on other services; and €10m on allowances.

⁴⁴ National Disability Authority (2010) *Advice paper to the Value for Money and Policy Review of Disability Services*. Dublin: NDA.

2.2.1 Staff numbers

About 80% of the specialist disability budget consists of staff costs⁴⁵. As at September 2009 there were over 15,000 people employed in disability services⁴⁶. The breakdown of this number is as follows:

Table 2: Staff breakdown and numbers

Staff category	Numbers*
Medical/dental	133
Nursing	4,039
Health and social care professionals	3,039
Other patient and client care	5,917
Sub-total	13,127
Management/admin	1,299
General support staff	1,355
Total	15,781

*Numbers have been rounded and are subject to final validation by the HSE.

The number of staff involved in direct care is over 13,000. Of this number, 46% are medical, nursing and health and social care professionals, the remainder are other staff involved directly in the provision of care (care assistants for example). This staff profile points to the highly professionalised nature of disability service delivery in Ireland. This mix of staff also has a very different skill set to that required to support people to live fully included lives in the community.

2.2.2 Funding framework

Health and personal social services are delivered in accordance with the Health Acts 1947 to 2007. In the Health Act 1953, non-government agencies delivering services "similar and ancillary" to those delivered by the state were formally recognised. In the Health Act 1970 a framework for funding Section 26 agencies, who delivered services on behalf of the State, and Section 65 agencies, who deliver service with assistance from the state, was established. The funding framework was updated in the Health Act 2004, but the distinction between those disability organisations which deliver on behalf of the State (now called Section 38) and with the assistance of the State (now called Section 39) was maintained.

Centrally raised funds are allocated by block grant to a variety of service providers to provide a range of services to people with disabilities under a service level agreement. This block funding is generally to provide services in a designated "catchment area". However, it is not based on standardised unit costs nor is it based on a model of funding whereby allocations are based on a standardised needs assessment and resource allocation process⁴⁷. There is also a lack of focus on

⁴⁵ National Disability Authority (2010) *Advice paper to the Value for Money and Policy Review of Disability Services*. Dublin: NDA.

⁴⁶ Figures from HSE, subject to final validation

⁴⁷ Research team led by Prof. Anthony Staines DCU (2010) *Towards the development of a resource allocation model for Primary, Continuing and Community Care in the Health Services*. Vol 1. Executive summary.

outcomes for individuals and “the evaluation of outcomes is hampered by a failure to specify desired outcomes in service level agreements”⁴⁸.

Funding for disability organisations in Ireland is calculated using two processes. Firstly, what is known as the “incremental determination process”, whereby organisations and the HSE regional management negotiate a level of funding based on the organisation's previous year's funding adjusted up or down on the basis of a variety of factors and the funding required to meet the demand for services in the organisation's “catchment area”. The second process is where new capital and current “development” money including the Multi-annual Investment Programme 2006 - 2009, is disbursed. This involves Consultative and Development Committees considering how to address the intellectual disability service needs for the region in line with priorities laid down in the HSE Service Plan and any other conditions placed on the funding. Large Section 39 agencies negotiate with the HSE on the basis of historical allocations of funding and new service commitments identified in the HSE service plan.

The 2005 report of the Comptroller and Auditor General (C&AG) on disability services noted the risk of this approach to funding (i.e. incremental increases and the cost of new placements) was that, over time, the core funding would become “*weakly linked to levels of identified need and as a result funding might not always be targeted to areas of greatest need*”⁴⁹. The 2009 report of the C&AG noted that “*there had been no substantial change in the HSE's approach to funding non-profit organisations since these matters were examined in 2005. Annual allocations continue to be made by reference to historic levels of funding, adjusted for new service developments*” and that it would be “*desirable to move towards a situation where funding is informed by standard costing*”⁵⁰.

As noted by the Comptroller and Auditor General, the current funding framework shows little evidence of allocations based on need/dependency of individuals served and has also resulted in a lack of clarity in the relationship between need, the amount allocated and the places provided.

2.3 The delivery of disability services

Most disability services are provided by the voluntary or non-profit sector⁵¹. A total of 280 service providers/agencies were funded by the HSE in 2009 to provide services, or were given grants towards the cost of their services (see Table 2 above). The sector is extremely diverse, ranging from small single-focus groups to large organisations employing several hundreds of people. Across this diverse sector there is wide variation in service design, in service provision and in costs⁵². It is estimated that non-profit organisations provide approximately 90% of all intellectual disability

⁴⁸ Comptroller and Auditor General (2005) *Provision of Disability Services by Nonprofit organisations*. Value for Money Report No. 52. www.audgen.gov.ie/documents/vfmreports/52_disabilityservices.pdf

⁴⁹ Comptroller and Auditor General (2005) *Provision of Disability Services by Nonprofit organisations*. Value for Money Report No. 52. www.audgen.gov.ie/documents/vfmreports/52_disabilityservices.pdf

⁵⁰ Comptroller and Auditor General (2010) *Report of the Comptroller and Auditor General Accounts of the Public Services 2009. Volume 2*. http://www.audgen.gov.ie/documents/annualreports/2009/ReportVol2_09_rev2.pdf

⁵¹ The term non-profit as defined in the Comptroller and Auditor General Report 2005, will be used to cover the variety of organisations providing disability services which are private and non-state; self-governing; do not distribute profits and include some element of voluntary contribution (p.17 C&AG report).

⁵² Ibid. Comptroller and Auditor General (2005)

services and approximately 60% of physical and sensory disability services⁵³. Approximately 70% of the direct health spend on disability services in 2004 was in non-profit organisations (€877 million)⁵⁴.

Non-profit organisations contribute to the delivery of services for people with disabilities in a variety of ways, including the direct provision of day and residential services, rehabilitative care and respite. The current delivery system for disability services has been characterised as interdependent and relational, with organisations in receipt of State funding interacting with the State within an interdependent and complementary relationship⁵⁵. However, it should be noted that outside of the funding relationship, the State and non-profit organisations have their own separate roles. Non-profit organisations developed for a multiplicity of purposes, and do not exist solely for the purpose of welfare delivery on behalf of the State. For example, these organisations sometimes provide services for unmet needs or services that complement statutory services, or to provide services within a specific ethos.

2.4 Characteristics of disability service provision

The majority of intellectual disability service provision occurs in settings that cater for groups of people and which are separate from the rest of the community. Most day service occurs in segregated, group settings (approximately 90%) and most residential services are provided in segregated group settings (approximately 90%) (see Section 1.1 above).

There is little evidence of individualised service provision, with a lack of standardised needs assessment and provision largely based in groups. Even though many services purport to use person-centred planning, the quality of the person-centred plan can be negated if options are framed largely in terms of the current model of provision. For example, some day services may be described as supporting 'community participation', although this often involves service users attending a community setting as a group, on a special bus, often in a segregated manner (for example, a special hour for swimming or bowling). Those attending in the group usually have not selected that activity themselves. This is very different to an individual choosing to attend a swimming lesson, travelling to the swimming pool on public transport and taking the lesson with just a support person (not necessarily a health care professional, possibly a volunteer).

Institutional service provision for people with disabilities developed for a variety of reasons, one of which was the predominance of a paternalistic attitude towards the provision of care and protection for vulnerable individuals. These were individuals who, by virtue of their disability, were judged to be at risk if living in wider society. However, institutions did not necessarily represent places of safety for vulnerable children and adults. The *Report of the Commission to Inquire into Child Abuse* cited reports of abuse from 58 witnesses in relation to their time in special needs schools and residential services (section 13.03)⁵⁶. Admission to these facilities was cited as being "*principally related to the perceived educational and treatment needs of children with specific impairments or disabilities, for example hearing and sight impairments and learning disabilities*" (Section 13.15).

⁵³ Ibid. Comptroller and Auditor General (2005)

⁵⁴ Ibid. Comptroller and Auditor General (2005) p.14

⁵⁵ Ibid. Comptroller and Auditor General (2005) p.18

⁵⁶ Report of the Commission to Inquire into Child Abuse (2009) <http://www.childabusecommission.ie/>

3. Policy overview

This section addresses items 2 to 4 of the terms of reference for the policy review group;

2. Define and describe the objectives of the services;
3. Consider the extent to which existing policies are consistent with delivery of these objectives;
4. Whether current policies and the investment arising from these policies are sustainable in the context of:
 - a. Current legislative and strategic frameworks
 - b. Changing economic climate
 - c. Changing demographics
 - d. Changing expectations

While the terms of reference require a description of the “current policy objectives for disability services”, the objectives in relation to disability are generally framed around people with disabilities and not disability services per se. The assumption is made here that these policy objectives are to be acted upon by disability services and therefore can be considered, in the main, to be ‘objectives for disability services’.

3.1 Commission on the Status of People with Disabilities

The Commission on the Status of People with Disabilities was established in 1993 to advise the government on “*the practical measures necessary to ensure that people with disabilities could exercise their rights to participate, to the fullest extent of their potential, in economic, social and cultural life*”⁵⁷. *A Strategy for Equality*⁵⁸, the Report of the Commission on the Status of People with Disabilities, was a wide-ranging, comprehensive report, which made many recommendations on legislative change, new structures and new ways of providing services. It was recommended that services for people with disabilities would be provided in the mainstream, with appropriate supports, a policy later referred to as “mainstreaming”.

The Government made a commitment to the policy of mainstreaming in 2000, which was re-iterated in the 2001 Health Strategy – *Quality and Fairness*⁵⁹; “*specific services for people with disabilities should be the responsibility of those government departments and state agencies which provide services for the general public*” (p.141). In 2000 the National Disability Authority was established to support the achievement of mainstreaming, followed by the National Disability Strategy in 2004 and the Disability Act in 2005.

A review of the implementation of the recommendations of the Commission on the Status of People with Disabilities in 1999, reported that 20% were fully implemented, 47% were in the process of

⁵⁷ Report of the Commission on the Status of People with Disabilities (1996) *A Strategy for Equality*. Dublin: The Stationery Office p.iii

⁵⁸ Ibid.

⁵⁹ Department of Health and Children (2001) *Health Strategy: Quality and Fairness – A Health System for You* Dublin: Stationery Office

implementation or were implemented in part, 20% were under consideration 8% were not yet implemented and 5% of the recommendations were rejected or not implemented⁶⁰.

3.2 National Disability Strategy

The National Disability Strategy⁶¹ (NDS) is the focus for government policy in relation to people with disabilities. The over-arching objective of the NDS is to put in place the most effective combination of legislation, policies, institutional arrangements and services to support and reinforce equal participation for people with disabilities⁶². The Disability Act, 2005 is a central element of the NDS and its focus on mainstreaming and social inclusion is given particular emphasis through the Sectoral Plans provided for in Part 3 of the Act.

The (NDS) comprises five elements:

1. Disability Act 2005;
2. Education for Persons with Special Educational Needs (EPSEN) Act 2004⁶³;
3. Sectoral Plans published in 2006 by six Government Departments;
4. Citizens Information Act 2007⁶⁴;
5. A Multi-Annual Investment Programme (allocated across a number of Departments) to support the development of high priority disability support services over the period 2006-2009.

The Strategy built on existing policy and legislation including the Employment Equality Act 1998, the Equal Status Act 2000 and the Equality Act 2004, and the policy of mainstreaming provision for people with disabilities within the State agencies that provide 'universal services' to citizens generally. The three pieces of legislation that are part of the Disability Strategy are considered in more detail here.

3.2.1 Disability Act 2005

The Disability Act 2005 defines disability as *"a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment"* (Section 2). Part 2 of the Act provides a statute-based right for people with disabilities to an assessment of disability-related health, personal social service and education needs. The process is independent of existing services or cost constraints.

The Act also provides for a statutory basis for accessible public services. Sections 26, 27 and 28 of the Act place obligations on public bodies to make their services and information accessible to

⁶⁰ Department of Justice, Equality and Law Reform (1999) *Towards Equal Citizenship: Progress Report on the Implementation of the Recommendations of the Commission on the Status of People with Disabilities*. Dublin: The Stationery Office

⁶¹ National Disability Strategy <http://www.justice.ie/en/JELR/NDS.pdf/files/NDS.pdf>

⁶² Department of Health and Children (2009) *Towards 2016 Strategic document. National Disability Strategy Vision, Mission and Strategic Objectives*.

http://www.dohc.ie/publications/pdf/nds_towards_2016.pdf?direct=1

⁶³ Government of Ireland (2004) *Education for Persons with Special Educational Needs (EPSEN) Act*. Dublin: Stationery Office

⁶⁴ Government of Ireland (2007) *Citizen's Information Act*. Dublin: Stationery Office

people with disabilities. Mainstreaming is underpinned in Section 26 of the Disability Act 2005, which provides that where a service is provided by a public body, the provision of access to the service by people with and without disabilities be integrated where practicable and appropriate.

3.2.2 Education of Persons with Special Needs Act 2004 (EPSEN)

This Act is part of the National Disability Strategy and sets out how education is to be provided for persons with special educational needs in the future. In addition to the provisions that exist in current legislation (Education Act 1998, Education Welfare Act 2000 etc.), the Act makes further provision for the education of people with special educational needs aged 0-18 years. The purpose of the Education of Persons with Special Educational Needs Act 2004 (EPSEN Act) is to:

- provide that the education of people with special educational needs shall, wherever possible, take place in an inclusive environment with those who do not have such needs;
- provide that people with special needs shall have the same right to avail of and benefit from appropriate education as do their peers who do not have such needs;
- assist children with special needs to leave school with the skills necessary to participate to the level of their capacity in an inclusive way in the social and economic activities of society and to live independent and fulfilled lives;
- and provide for the greater involvement of parents of children with special educational needs in the education of their children.

The Act applies to children (persons aged not more than 18 years) and in Section 1 defines special educational needs as *“a restriction in the capacity of the person to participate in and benefit from education on account of an enduring physical, sensory, mental health or learning disability, or any other condition which results in a person learning differently from a person without that condition.”*

The Act established the National Council for Special Education (NCSE) which has responsibility for implementing the legislation. The NCSE published a plan for the phased implementation of the EPSEN Act in 2006. While certain sections of the Act have been commenced, *“the implementation of key sections which confers statutory rights to assessment, education plans and appeals processes on children with special educational needs has been deferred due to the current economic circumstances”*⁶⁵.

3.2.3 Citizens Information Act 2007

The Citizens Information Act 2007 (which amended the Comhairle Act 2000) established the Citizens Information Board (CIB) as a statutory body. The mandate of the CIB, as defined by the Acts, is:

- To ensure that individuals have access to accurate, comprehensive and clear information relating to social services;
- To assist and support individuals, in particular those with disabilities, in identifying and understanding their needs and options;
- To promote greater accessibility, coordination and public awareness of social services;

⁶⁵ http://www.ncse.ie/about_us/About_the_NCSE.asp

- To support, promote and develop the provision of information on the effectiveness of current social policy and services and to highlight issues which are of concern to users of those services;
- To support the provision of, or directly provide, advocacy services for people with a disability.

Under the Act, the CIB decides the terms and conditions under which information, advice and advocacy services are provided by Citizens Information Services and other voluntary bodies and sets out the development of the Personal Advocacy Service for people with a disability.

3.2.4 Monitoring Arrangements

The *National Disability Strategy Stakeholder Monitoring Group* was established to monitor progress on the overall implementation of the NDS. This group meets twice yearly and reports are submitted to the Cabinet Committee on Social Inclusion and to the Implementation Steering Group under the Social Partnership Agreement.

The *National Disability Strategy* was endorsed by the Government and social partners in *Towards 2016* and it forms the focus of policy in the area of disability.

3.3 Partnership Agreement Towards 2016 (T2016)

This partnership agreement represents the government's strategic framework for meeting economic and social challenges in the coming years. *Towards 2016*⁶⁶ developed a new framework based on a lifecycle approach, which tackles social challenges faced by different groups by assessing the risks and hazards facing key groups and the supports available to them. It is acknowledged that this approach poses a major challenge, namely, "*that public services will need to be designed around individuals and their requirements, rather than based on different administrative boundaries*".

The high-level, long-term objectives for people with disabilities have been described within the framework of *Towards 2016* (T2016) as follows:

- Every person with a disability would have access to an income which is sufficient to sustain an acceptable standard of living⁶⁷
- Every person with a disability would, consistent with their needs and abilities have access to appropriate health, education, employment and training and personal social services.
- Every person with a disability would have access to public spaces, buildings, transport, information, advocacy and other public services and appropriate housing;
- Every person with a disability would be supported to enable them, as far as possible, to lead full and independent lives, to participate in work and society and to maximise their potential;
- Carers would be acknowledged and supported in their caring role.

The pursuit of these objectives is through:

⁶⁶ Department of the Taoiseach (2006) *Towards 2016: Ten Year Framework Social Partnership Agreement 2006-2015*. Dublin: Stationery Office

⁶⁷ This objective is not considered any further in this analysis as it is outside of the remit of the policy review – to consider disability service objectives related to the health vote.

- the implementation of the National Disability Strategy, including the development of guidelines to ensure that investment in the Strategy delivers value for money and real and tangible benefits for people with disabilities;
- the implementation of Part 2 of the Disability Act 2005 and of the EPSEN Act 2004;
- the provision of appropriate supports and services to meet identified need;
- an increase in the capacity of the system to meet identified need and to respond to emerging and emergency need;
- the collection and analysis of information to underpin the planning, monitoring and delivery of services;
- the development and implementation of quality standards;
- partnership and cross-sectoral engagement with other agencies, both statutory and non-statutory, who have a role to play in the supporting the individual with a disability in living a full and independent life;
- disability awareness training.

The implementation of the NDS is the agreed focus of disability policy under *T2016*. National disability policy objectives extend to mainstream provision in the field of education, employment and training, public and social services, transport, housing, environmental services.

3.4 Other relevant policy, legislation and developments

A number of other Irish policy and legislative provisions make reference to people with disabilities, including;

- Health Strategy Quality and Fairness 2001
- National Development Plan 2007-2013;
- National Action Plan for Social Inclusion 2007-2016;
- National Children's Strategy;
- The Agenda for Children's Services⁶⁸
- A Vision for Change 2006:
- The Developmental Welfare State⁶⁹ (DWS);
- Equality Act 2004;
- Mental Health Act 2001;
- Office for Disability and Mental Health

These documents are summarised in Appendix 1. Objectives with regard to disability services and people with disabilities or children with disabilities are in accordance with the policies reviewed above.

3.5 International legislation and policy

There are two major instruments under international policy pertaining to disability; the UN Convention on the Rights of People with Disabilities and the Council of Europe Disability Action Plan

⁶⁸ Office of the Minister for Children (2007) *The Agenda for Children's Services: A Policy Handbook*.

⁶⁹ National Economic and Social Council (2005) *The Developmental Welfare State*. The Stationery Office, Dublin.

3.5.1 United Nations Convention on the Rights of People with Disability

The Convention on the Rights of Persons with Disabilities⁷⁰ (CRPD) is an international human rights instrument of the United Nations which aims to “promote, protect and ensure the full and equal enjoyment of all human rights by persons with disabilities”⁷¹. It covers a number of key areas such as accessibility, personal mobility, health, education, employment, rehabilitation, participation in political life, and equality and non-discrimination. The Convention adopts a social model of disability, and defines disability as including “*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*”.

Article 19 of the UN Convention on the Rights of Persons with Disabilities states:

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.⁷²

The Convention marks a shift in thinking about disability from primarily a welfare concern to a human rights issue. Ireland became a signatory to the Convention on 30th March 2007, but has not yet ratified the Convention. States who ratify the Convention will undertake the obligation to have measures that promote the human rights of persons with disabilities without discrimination.

3.5.2 Council of Europe Disability Action Plan 2006-2015

Adopted by the Council of Europe in April 2006, the Disability Action Plan 2006-2015⁷³ seeks to “*translate the aims of the Council of Europe with regard to human rights, non-discrimination, equal opportunities, full citizenship and participation of people with disabilities into a European policy framework on disability for the next decade*”.

The Action Plan contains a number of specific actions, including participation in political, public and cultural life, education, information and communication, employment, accessibility of the built environment and transport. It also draws attention to the needs of women and children with

⁷⁰ United Nations (2006) *UN Convention on the Rights of Persons with Disabilities*. Geneva: United Nations

⁷¹ National Disability Authority, *UN Convention on the Rights of People with disabilities and the Council of Europe Disability Action Plan*. Dublin: NDA. p.5

⁷² United Nations (2006) *UN Convention on the Rights of Persons with Disabilities*. Geneva: United Nations

⁷³ Council of Europe (2006) *Disability Action Plan 2006-2015*. http://www.coe.int/t/e/social_cohesion/soc-sp/integration/02_Council_of_Europe_Disability_Action_Plan/

disabilities, and the severely disabled people in need of a high level of support. Member States are recommended to integrate the actions set out in the Action Plan into their policy, legislation and practice in order to promote the rights and full participation of people with disabilities in society.

3.6 Public Service Reform

A further, more recently developed area of policy is relevant to a consideration of the provision of disability services. As it was only launched at the end of 2008 there has been a limited time frame for implementation or to witness any significant impact on the current delivery of services. However, *Transforming Public Services*⁷⁴ outlines a detailed picture as to how public services should be delivered in the future. As publicly funded services, the reform agenda applies equally to disability services.

3.6.1 OECD Public Management Review

Much of the impetus for the public service reform agenda came from a review conducted by the Organisation for Economic Cooperation and Development (OECD) in 2008. The *Public Management Review*⁷⁵ of the Irish public sector found that accountability systems in the sector are currently characterised by compliance with rules, but to achieve real improvements they need to be more focused on outcomes. An important recommendation was that better policy outcomes could be achieved through performance management.

3.6.2 Transforming Public Services

Following the publication of the OECD report, a *Task Force on the Public Service* was established to develop an Action Plan for the Public Service drawing on the analysis and recommendations of the OECD review of the public service. The report of the Task Force; *Transforming Public Services*⁷⁶ was published in November 2008. The Government adopted the Task Force's report and set out a series of measures to radically transform the public service over a three year time frame (from here on referred to as the Government Statement on TPS)⁷⁷. The actions in the Government Statement on TPS are designed to:

- Achieve improved performance by organisations and individuals;
- Create flexibility in the deployment of people, assets and other resources;
- Identify the precise transforming agenda in each sector and engage and mobilise the necessary actors; and
- Achieve greater efficiency, effectiveness and economy⁷⁸.

Detailed actions are set out in 13 domains, including;

- Clear commitments and keeping promises to the public;

⁷⁴ Report of the Task Force on the Public Service (2008) *Transforming Public Services – Citizen Centred-Performance Focused*. Dublin: The Stationery Office

⁷⁵ Organisation for Economic Cooperation and Development (2008) *Ireland: towards an integrated public service*. Paris: OECD

⁷⁶ Report of the Task Force on the Public Service (2008) *Transforming Public Services – Citizen Centred-Performance Focused*. Dublin: The Stationery Office

⁷⁷ Government Statement on *Transforming Public Services* (2008)

http://www.onegov.ie/eng/Publications/Government_Statement_on_TPS.pdf

⁷⁸ Government Statement on *Transforming Public Services* (2008) Ibid. p.2

- Measuring performance of people and organisations;
- Managing for performance and challenging underperformance
- Engaging and empowering the citizen;
- Better use of information;
- People and leadership;
- Better management of the Public Service.

The measures under *Clear commitments and keeping promises to the public*, describe how the priorities of Government must be clear so that there are clearer expectations as to “*what services are to be delivered and to what standard, and conversely, what activities are to be scaled back or discontinued*”. It is also stated that “*there must be greater clarity about what is expected, greater transparency about how well it is delivered, and a new major emphasis on accountability for the results achieved*”⁷⁹. Essentially, this statement is about defining outcomes and performance management. Particular actions under this heading in the Government Statement were:

- The specification of priority outcomes for all sectors (e.g. Health), together with the relevant performance indicators by which achievement will be assessed;
- Instead of just measuring performance by individual organisations, the government will develop performance indicators that span the efforts of groups of organisations involved in areas such as children and disability; and
- Specific targets will be the basis on which performance of organisations and individuals will be assessed and evaluated.⁸⁰

Further sections of the *Government Statement on Transforming the Public Service* emphasise the use of outcomes and output statements to measure the performance of organisations and to ensure better management of the public service. The recent report of the National Economic and Social Forum⁸¹ also emphasises the need for an ‘outcomes oriented performance culture’ in the Public Service.

Under the action *Engaging and empowering the citizen*, it is acknowledged that “*deeper engagement with the citizen as service user will be essential if we are to realise our ambition of delivering services which are targeted appropriately at particular groups such as... those with disabilities*”, and that “*the citizen, rather than the provider, must be at the heart of our planning and delivery of public services*”⁸².

3.7 Current policy objectives for disability services \

There is a strong coherence in current national and international policy on disability, which places a similar emphasis on objectives such as inclusion in the mainstream community, participation in work and society and supporting the self-determination of people with disabilities in terms of exercising

⁷⁹ Government Statement on *Transforming Public Services* (2008) Ibid. P.7

⁸⁰ Government Statement on *Transforming Public Services* (2008) Ibid. p.7

⁸¹ National Economic and Social Forum (2009) *Implementation of Home Care Package Scheme*. Report 38. Dublin: NESF

⁸² Government Statement on *Transforming Public Services* (2008) p. 10

http://www.onegov.ie/eng/Publications/Government_Statement_on_TPS.pdf

choice and living independent lives. In addition, recent government reform proposals are designed to create a system that will enable the achievement of such objectives.

The objectives in *Towards 2016* pull together the policy objectives concerning people with disabilities in most preceding policy, from *A Strategy for Equality*, to the *Health Strategy Quality and Fairness* and on to the *National Disability Strategy*:

Objective 1: Every person with a disability would, consistent with their needs and abilities have access to appropriate health, education, employment and training and personal social services.

Objective 2: Every person with a disability would have access to public spaces, buildings, transport, information, advocacy and other public services and appropriate housing;

Objective 3: Every person with a disability would be supported to enable them, as far as possible, to lead full and independent lives, to participate in work and society and to maximise their potential;

Objective 4: Carers would be acknowledged and supported in their caring role.

3.7.1 Objectives for disability services or people with disabilities?

It should be noted that these objectives are phrased more directly about people with disabilities and desired outcomes for this group, rather than as objectives for disability services per se. It can be assumed that the objectives specify outcomes which should be addressed by disability services. However, there are few, if any, direct objectives concerning disability services. For example, people with disabilities should have access to health, education and other personal social services (Objective 1), but the nature of these services and how they should operate are not specified. Objective 3 could be considered the key objective in this regard, that people with disabilities will be supported to lead full and independent lives. This is the activity towards which disability services should be focused.

The Comptroller and Auditor General (C&AG) highlighted this issue in his report on *The Provision of Disability Services by Non-Profit Organisations*⁸³. He noted that “*the effective operation of health service delivery... and services to people with disabilities in particular, is dependent upon the relationships between statutory and nonprofit organisations... but systemic thinking about the relationship between the State and nonprofit organisations is still underdeveloped*” (p.16).

The need for greater specificity and clarity in objectives and outcomes for Public Services is recognised in the Government Statement on TPS and actions are detailed as to how this will be achieved. The definition of outcomes and objectives is essential for effective performance management. However, it is clear that policy objectives for people with disabilities have not translated into specific objectives for disability services, nor into desired outcomes for those using disability services.

⁸³ Comptroller and Auditor General (2005) *Provision of Disability Services by Nonprofit organisations*. Value for Money Report No. 52. www.audgen.gov.ie/documents/vfmreports/52_disabilityservices.pdf

3.7.2 Objectives related to current health expenditure

A further issue to consider, in the context of a policy review concerning “all people with disabilities and all services currently funded and provided by the Health Vote”⁸⁴, is the extent to which the T2016 objectives⁸⁵ apply to the ‘health vote’. In this analysis, disability services as currently provided and funded have a direct remit in Objectives 1 and 3 and have a partial remit for objectives 2 and 5. Objectives 1 and 3, and to a lesser extent, 2 and 4 will be considered in the further analysis below.

4. The extent to which existing policies are consistent with delivery of these objectives

None of the policies examined are inconsistent with the delivery of the objectives described in Section 3.7 above. While there are different degrees of emphasis and clarity, none of the policies directly conflicts with the objectives. The consultation undertaken for the VFM review asked about the relevance of the four objectives for the Disability Services Programme. The vast majority (81%) of respondents thought the objectives were significantly still relevant to the needs of people with disabilities, with 15% rating the objectives partially relevant (a total of 96% of respondents).

It is perhaps more useful to examine the extent to which progress has been made in delivering these objectives, as a measure of the effectiveness with which policies have delivered on the stated objectives.

4.1 Objective 1

Objectives 1 and 3 are most directly relevant to the health vote and will be examined in detail:

Objective 1: Every person with a disability would, consistent with their needs and abilities have access to appropriate health, education, employment and training and personal social services.

This Objective contains two important elements; **access** to services and **appropriate** services. It is assumed that appropriate services are those which support the person “to lead full and independent lives, to participate in work and society and to maximise their potential”; i.e. Objective 3. Therefore, detail on the appropriateness of services is dealt with in detail the discussion on Objective 3.

It is more difficult to determine the extent to which people with disabilities have access to health and personal social services as the available information is insufficient to make a definitive judgement. There are approximately 56,000 people with disabilities in receipt of disability services in Ireland (some 26,000 persons registered on the National Intellectual Disability Database (NIDD) and almost 30,000 on the National Physical and Sensory Disability Database (NPSDD)). (These figures have been presented in greater detail in Section 1.1 above). However, estimates from the National Disability Survey⁸⁶, conducted in 2006, would suggest a disability prevalence of 8.1% of the population (approximately 343,000 persons). Two factors largely account for the disparity between these numbers; firstly, many people with disabilities do not require input from specialist disability

⁸⁴ Terms of Reference for Policy Expert Reference Group

⁸⁵ The T2016 objective relating to income for people with disabilities was not included in this analysis as it is completely outside the remit of the review.

⁸⁶ Central Statistics Office (2006) *National Disability Survey*. Dublin: Stationery Office

services, are not registered for such services, and therefore do not appear on the databases. Secondly, the definition of disability in the National Disability Survey was more wide-ranging than that in the Disability Act 2005 thus capturing people with a wider variety of conditions. However, there is an under-representation of people with disabilities on both the NIDD and the NPSDD, as noted in reports from the databases, and there is no estimate on the number of people with disabilities in the population who require disability services but are not in receipt of such services. For this reason, it is difficult to judge whether people with disabilities have adequate access to health and person social services.

The consultation undertaken for the VFM review asked about the degree to which objectives have been met. In terms of Objective 1, 10% of respondents thought it had been met, 53% rated it partially met and 31% said this objective has not been met. This conveys a strong sense that there are some issues in relation to access to health and personal social services.

4.2 Objective 3

Objective 3: Every person with a disability would be supported to enable them, as far as possible, to lead full and independent lives, to participate in work and society and to maximise their potential;

This is perhaps the most important Objective as it gives some specification as to what form supports should take; they should support people with disabilities to **lead full and independent lives** and to **participate in work and society**.

The majority of respondents to the VFM consultation thought that this Objective had been partially (60%) or fully (9%) met, although a significant minority think it has not been met (28%).

4.2.1 “Full and independent lives...”

An examination of those people with disabilities who are currently accessing disability services shows that of the 9,000 people who use residential services, 90% are provided in segregated, group settings, with the remaining 10% in independent settings. Almost 700 people with physical and sensory disabilities were living in full-time residential services in segregated settings. The majority of people with physical and sensory disabilities lived at home with family, although 70% lived in non-adapted housing.

The Day Services Review conducted in 2008 reported 25,302 people with disabilities using day services in 817 locations⁸⁷. Over 90% of these day services are in segregated, group settings.

A recent report of the Irish Human Rights Commission⁸⁸ concluded that *“it remains the case that many of our citizens with an intellectual disability remain accommodated in inappropriate settings, including in or near psychiatric institutions”* (p.26).

There is little detailed information available on people in receipt of disability services with which to judge their overall quality of life or the extent to which they are leading a ‘full life’. A study on a

⁸⁷ Health Service Executive (2009) *National Review of HSE Funded Adult Day Services*.

⁸⁸ Irish Human Rights Commission (2010) *Enquiry report on the human rights issues arising from the operation of a residential and day care centre for persons with severe to profound intellectual disability*
<http://www.ihrc.ie/download/pdf/reporte3.pdf>

representative sample of 300 service users with a mix of disabilities gives some insight into the quality of their lives⁸⁹. Some outcomes⁹⁰ were present for most of the sample (for example, 66% felt they were 'connected to family'). However, the majority of service users had limited opportunities to exercise choice or control over their lives. Only 17% chose with whom they lived; 22% with whom they worked; 22% chose their services and 18% reported 'exercising my rights'.

4.2.2 Participation in work and society

As the data on current disability service provision shows, those who are using disability services are not participating in work or society to any great extent as many are spending their days in segregated, group settings doing activities that they have not chosen to do. In terms of work, the *Day Services Review* reported a small minority of individuals who could be considered to be participating in work; those in open employment with no supports (217, 0.86%), those in supported employment, (1,773, 7%) and external 'work like' work (less than minimum wage)(399, 1.6%). This presents a total of 2,389 (9%) of people with disabilities using day services (from a total of 25,302) who could be considered to be 'in the workplace', and many of these are 'participating in work' for six hours or less per week.

The following indicators on work illustrate that the wider population of people with disabilities (as opposed to those using disability services) generally have much less participation in work than non-disabled people and that the onset of disability significantly affects the probability of being employed:

- In 2004, 37% of people of working age with a disability or long-standing health problem were in work, compared to 67% of other working age adults;
- Between 2002 and 2004 the employment rate for people with disabilities fell from 40.1% to 37.1% despite an overall employment growth of 5.6% over that period⁹¹
- The employment rate of people with disabilities in Ireland is one of the lowest in the OECD at 32% in 2005, compared to an OECD average of 43%⁹²
- People with a disability work less hours on average than the overall population, as well as being more likely to work part-time. Both of these factors affect earnings⁹³
- The onset of disability for adults led to a decline in 20 percentage points in the probability of being in employment⁹⁴
- Persistent disability is strongly associated with unemployment, lower income (largely because of unemployment) and a significant reduction in social participation compared to the non-disabled population⁹⁵.

⁸⁹ Outcomes Network of Ireland (2007) *The Quality of Life of People with Disabilities in Ireland 2007* http://www.outcomestopeople.ie/UserFiles/File/QUALITY_OF_LIFE_2007.pdf

⁹⁰ Personal Outcomes (POMS) was the measure used in the study

⁹¹ Central Statistics Office (2006) *National Disability Survey*. Dublin: Stationery Office

⁹² OECD (2009) *Sickness, Disability and Work: Keeping on Track in the Economic Downturn*, Background paper for high-level forum, Stockholm, May 2009.

⁹³ Gannon, B. and Nolan, B. (2006) *The Dynamics of Disability and Social Inclusion*. NDA and Equality Authority <http://www.equality.ie/index.asp?locID=105&docID=624>

⁹⁴ Gannon, B. and Nolan, B. (2006) *Ibid.*

⁹⁵ Gannon, B. and Nolan, B. (2006) *Ibid.*

There is a very limited amount of information on the quality of life of people using disability services in Ireland. There is also a very limited amount of information on the outcomes for these individuals, that is, what is the effect of the disability services on those who use them? There is a presumption that provision of services leads to better quality of life, but this is not necessarily the case. In fact the available information shows that most of those using disability services do not participate in society in any meaningful way; are not given the opportunity to work or contribute to society. A significant proportion live in segregated settings apart from the general community and live with other people, in some cases many other people (over 4,000 people live in settings with more than 10 beds⁹⁶). Overall, people using disability services have little opportunity to self-determine or to live full and independent lives.

4.3 Objective 2

The provisions specified in Objective 2 are largely outside the remit of the health vote:

Objective 2: Every person with a disability would have access to public spaces, buildings, transport, information, advocacy and other public services and appropriate housing.

The findings from the VFM consultation for Objective 2 showed that just over one third reported it had not been met (35%), 53% believed it had been partially met and 10% that it had not been met.

4.3.1 Information

The VFM consultation also contained questions on the availability, quality and accessibility of information on disability services. Less than one third of respondents were satisfied or very satisfied with the availability of information on services (32%); the quality of information on services (31%) and less than a quarter with the accessibility of information (23%).

4.3.2 Housing

Because of historical patterns of provision, health funds a significant number of residential places for people with disabilities, who are living in segregated, group settings that cannot be considered 'appropriate housing'. As the indicators below show, the majority of people with disabilities live in home settings, usually with their family, which may not be appropriate for all:

- People with disabilities are three times more likely to live in communal accommodation or some form of residential care than other citizens (11% compared to 3% of the non-disabled population)(NDA, 2005)
- The National Intellectual Disability Database (NIDD) for 2008 reported details on 26,023 persons with intellectual disability. Of this total, 16,708 (64%) lived in 'home settings' (i.e. at home with parents, relatives or foster parents), over 8,200 (32%) lived in segregated residential settings⁹⁷ with 950 (3.7%) in independent settings.
- The research carried out by the Congregated Settings Group showed that 4,056 people with disabilities reside in congregated settings, that is, a residence of ten or more beds. The majority of these persons (93%) have an intellectual disability and have been receiving a residential service for over 15 years (73%)

⁹⁶ Health Service Executive (2010) *Report of the Working Group on Congregated Settings*

⁹⁷ Community group homes (3,894), residential centres (3,015) and other services such as psychiatric hospitals, nursing homes and intensive placements (1,381).

- In an Irish study of personal outcomes only one quarter of people with disabilities who received residential services lived in integrated settings⁹⁸

4.4 Objective 4

Objective 4: Carers would be acknowledged and supported in their caring role.

While a range of family support and other services which support carers are funded by health, other supports (such as income) are not within the remit of health. The finding from the VFM consultation on this objective showed that one third (34%) reported it had not been met, 11% believed it had been met and 49% reported it had been partially met.

While there was little in the National Disability Strategy that related specifically to carers, the role of caring was explicitly considered and teased out in T2016, in Section 31 on People of Working Age and section 33 on People with Disabilities. In Section 31 a long-term goal was that *“every person with caring responsibilities would have access to appropriate supports to enable them to meet these responsibilities alongside employment and other commitments.”* The priority actions put forward to realise this goal included continued support for the work of the National Framework Committee for Work-Life Balance Policies; expanding the income limits for the Carer’s Allowance and examination of other benefits for carers; the development of a National Carer’s Strategy that focuses on supporting informal and family carers in the community with appropriate consultation with the social partners. The National Carer’s Strategy is cited as one of the mechanisms for monitoring progress in the achievement of the five long-term goals for people with disabilities (Section 13 T2016).

4.5 Progress in Delivering Policy Objectives

This analysis examined the extent to which progress has been made in delivering on the policy objectives for disability, as a measure of the effectiveness of these objectives. While several areas specified in the objectives are outside of the remit of the health vote, it is clear from the available data that there is still some way to go with regard to achieving the objectives of disability services. More specifically, for those people with disabilities in receipt of services, there has largely been a failure to realise ‘full and independent lives’ for this group, who cannot be said to be participating in work and society in any meaningful way or to any great extent.

5. The sustainability of these objectives

5.1 Changing economic climate

While ‘value-for-money’ or efficiency is the specific context of this policy review, efficiency in the delivery of any publicly-funded service should always be a primary concern. A lack of efficiency results not just in a potential waste of resources, but also in an important opportunity cost, in that inefficiently used resources are then not available to meet some other area of provision. Value for money has received increased focus in the current economic climate.

⁹⁸ Outcomes Network of Ireland (2007) *The Quality of Life of People with Disabilities in Ireland 2007*
http://www.outcomestopeople.ie/UserFiles/File/QUALITY_OF_LIFE_2007.pdf

In common with many other countries, Ireland has been in a 'severe recession'⁹⁹ since 2008. It could be argued that the perceived effects of the recession have been even more marked in Ireland because of the rapid and steep decline from a period of unprecedented growth which saw living standards increase by one-third in ten years¹⁰⁰. This period was also marked by a substantial increase in expenditure on health services; from €5.7 billion in 2000 to €15.4 billion in 2009, and on disability services; from €1.1 billion in 2005 to €1.6 billion in 2008¹⁰¹.

The recession has had a variety of effects. From a historically low level of unemployment; an average of 4.5% in 2007; unemployment has increased to 14.7% by the end of 2010¹⁰². In terms of public finances, a General Government Surplus of 3% was recorded in 2006, declining to an estimated General Government Deficit of almost 12% in 2009. It is estimated that the level of national debt was 65% of GDP in 2009, up from 12% in 2007¹⁰³.

This rapid deterioration of the public finances and other wide-ranging effects of the recession created an urgent requirement for fiscal measures in order to address the deficit. The OECD believes that economic recovery will be weak and a "*protracted period of readjustment will be needed to resolve economic imbalances built up during the expansion*"¹⁰⁴. This will place a continuing requirement on all areas of public spending to generate the maximum value for money from all expenditure.

5.2 Changing demographics

The National Intellectual Disability Database (NIID) provides evidence to suggest that people with intellectual disability in Ireland are living longer¹⁰⁵. Increased longevity in this population is attributed in the research literature to a number of factors which have increased the survival rates among children and young people with severe and complex disabilities and reduced mortality among older adults with intellectual disability, including; improved health and well-being, the control of infectious diseases, improved nutrition and the quality of health care services^{106, 107}.

These factors have led to a steady increase in the proportion of people with a moderate, severe or profound intellectual disability aged 35 years or over, from 38% in 1996 to 48% in 2008, an increase in numeric terms of 1,814 individuals¹⁰⁸.

⁹⁹ Organisation for Economic Cooperation and Development (2009) *Economic Survey of Ireland 2009*. Paris: OECD

¹⁰⁰ Angel Gurria (2009) *Launch of OECD Economic Survey of Ireland 2009*.

¹⁰¹ Department of Health and Children (2009) *Health in Ireland: Key Trends 2009*. Dublin: Department of Health and Children. www.dohc.ie

¹⁰² Central Statistics Office Quarterly National Household Survey
http://www.cso.ie/releasespublications/documents/labour_market/current/qnhs.pdf

¹⁰³ http://www.esri.ie/irish_economy/ These national debt figures are net of the Pensions Fund and Social Insurance Fund

¹⁰⁴ OECD 2009 Ibid.

¹⁰⁵ Doyle, A., O'Donovan, M.A. and Craig, S. (2009) *National Physical and Sensory Disability Database Committee Annual Report 2008*. Dublin: Health Research Board

¹⁰⁶ Doyle, A., O'Donovan, M.A. and Craig, S. (2009) Ibid. p.28

¹⁰⁷ Emerson, E. And Hatton, C. (2004) *Estimating future need/demand for supports for adults with learning disabilities in England*. Institute for Health research, Lancaster University.

¹⁰⁸ Doyle, A., O'Donovan, M.A. and Craig, S. (2009) Ibid. p.28

A high birth rate in the 1960s and 1970s, coupled with low infant mortality rate due to improved obstetric and paediatric care and improved health in the general population, has led to a 'cohort effect' which is evident in the Irish database over time. The 'population bulge' has moved through the services, resulting in large numbers of adults in the older age groups.

The changing ethnic profile of the Irish population may also lead to changes in the prevalence of people with disabilities. There is research evidence to suggest significantly higher prevalence of intellectual disability (and particularly more severe intellectual disability) among people from primarily Pakistani and Bangladeshi ethnic communities¹⁰⁹. While the numbers from this community in Ireland are small, this highlights possible future challenges in terms of provision for people with disabilities.

While such long-term trend data does not exist for people with physical/sensory disabilities, the factors which have increased the survival rates of young people with disabilities and increased the survival rates of older adults with disabilities also apply to this cohort. In addition, there are other factors which influence the absolute numbers of people with physical/sensory disabilities, such as increasing rates of survival among victims of road traffic accidents, who are usually in the young adult age group and survive with significant disabilities.

Data from England predicts similar demographic trends with sustained growth over the next two decades in both the numbers of people with intellectual disability known to services (14% over 2001-2021) and the estimated 'true' number of people with intellectual disability in England (20% over 2001-2021)¹¹⁰. These overall figures mask the changes in age profile which will occur, with for example, very marked increases in the number of people in the 50+ age range in people with intellectual disability known to the services (48% over 2001-2021) and in the estimated 'true' number of people with intellectual disability (53% over 2001-2021)¹¹¹.

5.2.1 Implications for service provision

The greater numbers of people overall with intellectual disability and physical/sensory disabilities will place increasing demands on disability services. In addition, the improved life expectancy of older adults with more severe intellectual disability will place an increased demand on health services. Fewer places (both day and residential) are becoming free over time resulting in increased pressure on the current service model.

The majority of adults with intellectual disability and physical/sensory disabilities live at home with their families. As these caregivers age beyond their care-giving capacity, further supports will be required.

5.3 Changing expectations

There is some evidence to suggest that the expectations of parents of children with a disability are changing in terms of service provision. There has been a distinct change in the age profile of those

¹⁰⁹ See Emerson, E. And Hatton, C. (2004) Response to McGrother *et al.* (*Journal of Intellectual Disability Research*, **46**, 299-309) 'The prevalence of intellectual disability among South Asian Communities in the UK' *Journal of Intellectual Disability Research*, **48**, 201-202.

¹¹⁰ Emerson, E. And Hatton, C. (2004) *Estimating future need/demand for supports for adults with learning disabilities in England*. Institute for Health Research, Lancaster University.

¹¹¹ Emerson, E. And Hatton, C. (2004) *Ibid.* p.9

registered on the NIID over the 34 years of such data collection. There were fewer children and young people (0-19 years) with moderate, severe or profound intellectual disability known to the database in 2008 than there were in 1974, 1981, or 1996¹¹². While this may reflect a declining birth rate between 1980 and 1995 and other factors, there is a suggestion that there may be under-registration of children. This may be due to an increasing number of children with intellectual disability in mainstream services who do not have contact with disability services and are therefore not registered on the database. A reluctance on the part of parents to allow information about their children to be recorded on the database is also noted, particularly in the 0-4 age group¹¹³. This may reflect the changing expectations of younger parents who want their children to remain in the mainstream and are not keen to place their children in segregated services.

Findings from a number of consultations involving people with disabilities show that expectations have changed substantially.

5.4 What people with disabilities want – findings from recent consultations

“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 dystrophy¹¹⁴.

Although the Commission on the Status of People with Disabilities carried out its work and related consultations in the 1990s the above quote captures very well what people with disabilities want and this is reflected in the framing of this policy which views the person with a disability as an equal citizen and focuses on the provision of supports to enable these citizens to live a full life.

A more recent consultation includes that undertaken on behalf of a National Working Group which was established by the HSE to conduct a national review of HSE-funded adult day services in 2007¹¹⁵. The purpose of the review was to reconfigure and modernise these services “in a manner that embraces the principles of person-centredness, access, accountability and quality”.

5.4.1 Consultation for day services review

The report of the main findings of the consultation noted that service users want a day service “where they feel valued and included, and that gives them a structured day, a sense of purpose and a reason to get up every morning. They value the friendships they make, peer support and the sense of teamwork with staff. While many people reported benefits from the day services, others found the experience “unhelpful and negative”, characterised by poor facilities and a limited range of activities that are group-based. In general, service users want to do worthwhile things such as activities and classes as well as work and training opportunities. Families and carers valued the

¹¹² Doyle, A., O’Donovan, M.A. and Craig, S. (2009) NIDD Ibid. p.27

¹¹³ Doyle, A., O’Donovan, M.A. and Craig, S. (2009) NIDD Ibid. p.27

¹¹⁴ 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

¹¹⁵ Health Service Executive (2009) *National Review of HSE Funded Adult Day Services*.

chance for their family member to gain skills, opportunities and a strong sense of self-worth. Other findings of the Day Services Review consultation included;

- “Flexible supports to suit individual needs”
- “...use local services – do ordinary things in ordinary places”
- “Families of service users want to be allowed to play their part in supporting their family member”

5.4.2 Consultation for VFM and Policy Review

A consultation has also been conducted by the Value for Money and Policy Review Group, with 43% of submissions from families or service users, 15% from representative/advocacy organisations and the remaining 42% of submissions coming from service providers or staff in service providers. Findings were grouped under the headings of choice, control, independence and community inclusion¹¹⁶:

Choice

- 73% want to choose to get different elements of service from different providers
- 50% want to get a budget to choose and manage their own services
- 60% dissatisfied with the amount of choice they have over the service received from service providers

In response to a question on the top three changes which would help bring about more CHOICE in the services received by people with disabilities, the most commonly cited changes were:

- The provision of individualised budgets or direct payments;
- Increased consultation with service users in policy, planning, delivery of services (inclusive of involvement in staff recruitment);
- Increased resources in either staffing levels or funding;
- Wider ranges, choices or flexibility in service provision;
- Individualised or person centred planning;
- Greater information on the range and choices of services.

Control

- 68% were dissatisfied with the amount of control people with disabilities have over their lives

In response to a question on the top three changes which would provide more support so that people with disabilities can CONTROL their day to day lives, the most commonly cited changes were:

- The provision of individualised budgets or direct payments;
- Provision of Independent Advocacy Services;

¹¹⁶ 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

- To be listened to and consulted by staff and service providers;
- Increase personal assistant service including to people with intellectual disability;
- Increased resources in either staffing levels or funding;
- Provide more flexible and responsive services;
- Increased access to education and training at all levels;
- Need for rights based agenda/legislation.

Independence

- 61% were dissatisfied with the amount of independence people with disabilities have

In response to a question on the top three changes which would provide more support so that people with disabilities can live an INDEPENDENT life, the most commonly cited changes were:

- Increase personal assistant service including to people with intellectual disability;
- Increase availability of local authority housing;
- Increase the range of independent living options available;
- Provide more accessible transport especially in rural areas;
- The provision of individualised budgets or direct payments;
- Increased access to education and training at all levels;
- To be listened to and consulted by staff and service providers.

Community inclusion

- 53% were dissatisfied with support received from service providers to facilitate inclusion in the mainstream life of the community

In response to a question on the top three changes which would provide more support so as to ensure INCLUSION in the mainstream life of the community, the most commonly cited changes were:

- Promote universal access throughout the environment and services;
- Raise awareness and provide education and training on disability issues;
- Increase personal assistant service;
- Provide more accessible transport especially in rural areas;
- Provision of supports to access mainstream education;
- Promote inclusion and participation in community activity;

Just over half 56% of respondents were dissatisfied with the extent that “funding is targeted at the right services to achieve the best outcome for service users”. Almost half (43%) of respondents were dissatisfied with the quality of services being provided to people with disabilities and just over half (52%) were dissatisfied with the management of services provided for people with disabilities.

5.4.3 Consultation for Expert Policy Reference Group

The NDA commissioned a consultation process on behalf of the Expert Policy Reference Group. This consultation convened 15 focus groups involving 95 individuals drawn from service users with intellectual disability and physical/sensory disabilities, family members, self-advocates and frontline staff. Participants were asked to respond to two vignettes on individualised supports and

mainstreaming. Many of the participants responded positively to the greater choice and control over funding that may be possible with individualised supports, although there was some concern about the capacity of government agencies to effectively deliver on this. Most participants were in favour of greater mainstreaming, provided adequate supports were provided¹¹⁷.

5.5 Conclusion

5.5.1 The relevance and effectiveness of policy objectives

While current policy objectives express desired goals for people with disabilities they do not directly provide specific objectives for the provision or delivery of disability services. The available information shows that disability services as currently organised and structured are not meeting stated policy objectives. Contrary to the T2016 objectives, many of those using disability services do not participate in society in any meaningful way and many are not given the opportunity to work or contribute to society. A significant proportion live and spend their days, in segregated settings apart from the general community. Overall, people using disability services have little opportunity to self-determine or to live full and independent lives. The objectives are, nonetheless, still relevant and reflect the thinking in national and international policy documents. However, the realisation of these objectives has not been evident for most people with disabilities.

The overwhelming majority (95.7%) of respondents to the VFM and Policy Review Consultation agreed that the stated objectives were either significantly or partially relevant, but just one in ten respondents reported that each of the four objectives was met. Respondents who felt that objectives had not been met stated that:

- Many people with intellectual disability do not live full and independent lives, do not have the opportunity to participate in real and rewarding work or the opportunity to maximise their potential;
- There was a lack of acknowledgement and support for carers;
- There was insufficient access to appropriate health and personal social services.

5.5.2 Policy objectives and disability services

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. The additional funding that was available in recent years was focused on providing 'more of the same' in terms of structures and places, rather than addressing individual needs in individualised, flexible ways. These factors have led to a disability service system that is:

¹¹⁷ Weafer Research Associates (2010) *Individualised Supports and Mainstream Services. Attitudes of people with disabilities and other stakeholders to policy proposals by the Department of Health and Children.*

- highly professionalised with attaching high levels of cost;
- not designed to meet policy objectives;
- not designed to meet needs in an individualised way;
- shows little correlation between levels of funding and needs/dependency;
- has a lack of clarity on the association between individual needs, allocated funds and places provided;
- shows little evidence of alignment between required staff competencies and needs;
- reinforces the social exclusion of many;
- shows little recognition of the role of carers;
- presents little choice or control to the service user/family;
- shows wide variation in service design, provision and costs;;
- is not focused on outcomes or amenable to meaningful review;
- is lacking in meaningful, accurate and timely information.

The way the disability system is currently configured creates a conflict of roles for the HSE as commissioner, provider and assurer. 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. In what could be characterised as a perverse incentive, this drives demand for segregated services which are counter to policy objectives. The availability of greater levels of specialist multidisciplinary support was cited as one of the reasons why increasing numbers of students (aged 12+) are moving from mainstream schools to special schools¹¹⁸.

5.5.3 Sustainability of current policies and investment

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. The data on demographics show that there will be increasing demand for disability services into the future. In the short to medium term, the changed economic climate dictates that there will be little or no additional investment for disability services. People with disabilities and their families are looking for more choice in disability services and control over how they access them.

Are current policies and investment sustainable in light of these findings? It can be concluded that **continued** investment at the required level in the disability services programme as it is currently organised and structured is unsustainable. Are current policies sustainable? In light of the legislation

¹¹⁸ Kelly, A. and Devitt, C. (2010) *Why are post 12 year old students with special educational needs who have attended mainstream schools seeking admission to special schools?* Presentation to the National Association of Boards of Management in Special Education Annual Conference 2010

on equality, non-discrimination and the human rights emphasis of international instruments, it is neither possible nor desirable to dilute commitments to people with disabilities. What is required is policy that has clear objectives and outcomes not just on how services are accessed or the lives of people with disabilities, but 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.

It is the changed expectations of service users and families which presents the possibility of a 'new way'. People with disabilities and their families are not necessarily looking for 'more of the same'¹¹⁹. 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 gap is the extent to which these policy objectives and the stated wishes of people with disabilities are met by the current model of disability service provision.

¹¹⁹ 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

Part B: PROPOSED POLICY FRAMEWORK

Based on the preceding analysis of current disability service provision, disability policy and environmental context, a policy framework has been developed to express specific policy objectives for people with disabilities and for disability services, and to support the achievement of these objectives.

6. The life cycle framework

This policy review adopts a life cycle approach and encompasses all age groups; children, adults and older people. The vision and underlying principles and values of the policy apply to all, as does the overall policy framework and recommendations for supports and services. However, there are certain areas where age-group specific issues are considered and these are highlighted in the relevant areas.

Towards 2016 (T2016) adopted the life cycle framework “to address key social challenges by assessing the risks and hazards which the individual person faces and the supports available to them at each stage in the life cycle” p.40. The key life cycle stages were described as Children, People of Working Age, Older People and People with Disabilities. T2016 specifically notes that people with disabilities, in accordance with the policy of mainstreaming, benefit from measures at all stages of the life cycle. Disability describes a characteristic of the person that may present specific needs, but it is the life cycle category that is the primary definition of the person and ensures their ability to benefit from all the measures and services in place for that group. This means that children with disabilities are children first and should benefit from all measures directed at children. Similarly, older people with disabilities should benefit from all measures available to older people. Thus, services for older people should deal with the needs of all older people, including those with disabilities. Older people with disabilities should have access to services for older people if their needs are best met within that service setting. Mainstream services will need to be disability-proofed to support this approach.

The life cycle approach “adopts the perspective of the person as the centrepiece of social policy development” and has therefore been adopted in the framing of this policy review for people with disabilities. It is especially relevant to this policy as mainstreaming is a cross-cutting mechanism within the policy as is cross-departmental and cross-agency working (also specifically referenced in T2016 as an advantage of the life cycle approach).

Ideally, if mainstreaming were fully realised, there would be no need for a separate policy for people with disabilities. However, there is still a way to go to completely integrated policy and fully mainstreamed provision for all. This policy review presents a framework to significantly progress this national goal. T2016 acknowledges that a balance needs to be struck between identifying the needs of specific target groups (such as people with disabilities) “while retaining the perspective of the desired social outcomes for the life cycle cohort as a whole.” P.40

7. Mainstreaming

Mainstreaming is about people with disabilities having access to the same services as the general population (the term ‘universal services’ is also used throughout). 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.”*¹²⁰

While mainstreaming is about people with disabilities having access to the same services as the general population, it does not mean that these services, as currently provided, meet the needs of all people with disabilities. In many cases the contrary is the case. There needs to be a clear understanding and acceptance that people with disabilities may have a range of access issues. Successful mainstreaming relies on a fundamental acceptance of the principle that people with disabilities should access mainstream services and supports in all parts of society alongside all other citizens, and on the provision of the necessary environment and supports to enable people with disabilities to participate fully in society¹²¹.

There are concerns about mainstreaming, particularly fears that services will be diluted¹²² 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. All services (health, education, transport, employment etc.) must adopt an approach of ‘tailored universalism’¹²³ and adjust their services to accommodate people with disabilities. Within a mainstream system, disability-specific supports can be provided where the needs of the individual determine such supports are required. For example, the provision of sign language interpreters in health settings is a specialist support which enables the person to access mainstream health services. The availability of a dentist with expertise in the needs of people with intellectual disability enables those individuals to attend mainstream dental services. Access to other specialist services can be achieved through links and liaison between the mainstream service and the specialist service (particularly in health). Mechanisms to achieve this include the shared assignment of staff between specialist and mainstream services. Such arrangements have the dual benefit of improving access to specialist expertise in a mainstream setting as well as improving coordination between services.

¹²⁰ Quote from a presenter at the *In Control* Conference February 2009

¹²¹ This section draws on the National Disability Authority (2006) *Mainstreaming Position Paper*. NDA, Dublin.

¹²² Disability Federation of Ireland (2007) *Mainstreaming for Me 2005-2006*. DFI, Dublin.

¹²³ National Economic and Social Council (2005) *The Developmental Welfare State*. The Stationery Office, Dublin.

Concerns have also been expressed that the *Sectoral Plans* of many departments¹²⁴ 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, requires all Government departments to commit to this approach. 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. Similarly, accessible buses convey benefits on all the community, such as older people and people with young children, as well as being essential for people with disabilities.

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*. The Sectoral Plans also have a commitment to the policy of mainstreaming. The achievement of an integrated public service is a central objective of the *Report of the Task Force on the Public Service (2008)*.

Mainstreaming is a central mechanism to realise the proposed policy vision. Completely separate services for people with disabilities will no longer be developed. A “whole of government” approach will be adopted so that people with disabilities will no longer be the special and exclusive concern of one Government Department (the Department of Health and Children). There will be an expectation that people with disabilities will live full lives within the general community. This will be the starting point for the development of all supports and services.

8. The importance of attitudes

The attitude of wider society towards people with disabilities may be one reason why mainstreaming has not been more widely embedded throughout services and structures. Attitudes towards this group are complex and often contradictory;

“... most people, if challenged, would deny that they treat disabled people unfairly. They will usually express considerable goodwill towards a group they tend to regard as unfortunate victims who are, sadly, disadvantaged. However, this sympathy and goodwill often conceals a deep reluctance to accept disabled people on equal terms. This is often based on unquestioned, deeply held negative assumptions or stereotypes.”¹²⁵

Both positive and negative attitudes were in evidence in The National Disability Authority survey of public attitudes¹²⁶. Close to one in three of respondents (29%) thought that children with intellectual disability should not attend the same schools as children without disabilities. The rates for other types of disability were 26% (visual or hearing difficulties) and 14% (physical difficulties). One in ten respondents thought that people with intellectual disability should not have the right to a sexual

¹²⁴ National Disability Authority (2006) *Mainstreaming Position Paper*.
[http://www.nda.ie/cntmgmtnew.nsf/0/E51F60A937C22740802571850050BC75/\\$File/mainstreaming_pos_pa p_06_06.htm](http://www.nda.ie/cntmgmtnew.nsf/0/E51F60A937C22740802571850050BC75/$File/mainstreaming_pos_pa p_06_06.htm)

¹²⁵ <http://www.realising-potential.org>

¹²⁶ National Disability Authority (2007a) *Public Attitudes to People with Disabilities*. Dublin: NDA.

relationship, (4% physical disability and 2% vision and hearing disabilities). However, the majority of respondents (71%) knew someone with a disability and these negative attitudes were countered by a broader awareness of unfair treatment and a 'disabling society'. Just over six in ten respondents agreed that it is society that disables people by creating barriers and only 45% thought that people with disabilities were treated fairly in Irish society. Most respondents thought that people with disabilities did not receive equal opportunities in terms of education (52%) and employment (71%), and that buildings and public facilities are not adequately accessible (61%).

The common use of the word 'special' possibly captures this complex and ambiguous relationship and perception of people with disabilities by non-disabled people. It is likely the use of the word special was invoked to create a positive perception of people with disabilities and acknowledge their difference in a positive way. However, it can stand in the way of viewing people with disabilities as citizens;

"The word "special" probably started out as a progressive improvement over another well known word. But these days the word "special" stands in the way of creating strong common experiences and bonds between people with disabilities and other members of our community. We can now see that separate (special) services carry a lot of stigma. Plus, it's hard to find the "special" when you go and visit a segregated, separate, special education classroom or other program based on some sort of special groupings of people away from the larger community."¹²⁷

Essentially people with disabilities are not viewed as valued members of society, but as people who must be cared for, 'minded', and provided for. They are generally not viewed as people with their own needs, wants and desires, or as active citizens with positive attributes and characteristics and the potential to contribute to society.

The negative value attached by others to some personal characteristic, attribute or trait that someone may have, or is believed to have, is also known as stigma. It is important to recognise that stigma can change and be significantly ameliorated. There is evidence of interventions that effectively challenge and serve to lessen stigma. These interventions typically employ education, contact and challenge¹²⁸. A summary of the evidence in this area is provided in Appendix 2.

8.1 The relevance for policy

It could be considered that stigma and attitudes are topics that are outside the consideration of a policy for people with disabilities. However, negative attitudes and discrimination are underlying causes of social exclusion and a significant barrier to social inclusion and participation, an area that is a specific focus of government policy and action¹²⁹. Policy can sometimes serve to reinforce negative attitudes towards people with disabilities;

"We often see the impact of negative attitudes in how one person treats another. But negative attitudes are also the foundation stone on which disabling policies and services are

¹²⁷ Tom Kohler Sept 29th 2009 <http://www.savannahcitizenadvocacy.org/author/tom/>

¹²⁸ Corrigan, P. & Penn, D.L. (1999) Lessons from social psychology on discrediting psychiatric stigma. *American Psychologist*, 54, 765-776.

¹²⁹ National Action Plan for Social Inclusion 2007-2016

built. Harmful attitudes that limit and restrict are institutionalised in policies and services and so maintain the historic disadvantage that disabled people have faced”¹³⁰.

Policy development presents an opportunity to challenge the negative attitudes that can be held towards people with disabilities. This can be done in several ways. Evidence-based interventions and actions have been shown to change negative attitudes towards people with disabilities. In addition, the framing of the policy itself can also serve to cast people with disabilities in a different light. The emphasis throughout this policy is on people with disabilities as citizens with the same rights and responsibilities as all other citizens. 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. Removing the many obstacles in society at large, and providing a varied menu of supports; *“allows people with disabilities to access the basic conditions needed to function as autonomous and responsible individuals – education, work, just remuneration for work, accommodation, justice, equity and the opportunity to participate in civic, cultural and social life”¹³¹.* The implementation of the type of support structures outlined in this policy will enable people with disabilities to access education, employment and social activities on an equal footing with everyone else. This in itself will serve to increase personal contact with the non-disabled population, an action that *“may prove to be the most important and equitable of interventions”* in changing attitudes¹³².]

¹³⁰ Massie, B. (2006) Participation – have we got an Attitude Problem? Paper presented to the NDA 5th Annual Conference.

[http://www.nda.ie/CntMgmtNew.nsf/0/5A19C972AF5A7B93802571E60052A06B/\\$File/conf20064.html](http://www.nda.ie/CntMgmtNew.nsf/0/5A19C972AF5A7B93802571E60052A06B/$File/conf20064.html)

¹³¹ Hannon, F. (2007) *Literature Review on Attitudes Towards Disability*. Dublin: National Disability Authority p.38

¹³² Hannon, F. (2007) *Ibid.* p.46

9. Policy Vision

The vision for the proposed 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.

9.1. Policy Framework

The diagram below (Figure 1) provides an overview of the components of a proposed policy. The policy is rooted in an overall vision and key principles and values and has two overarching goals.

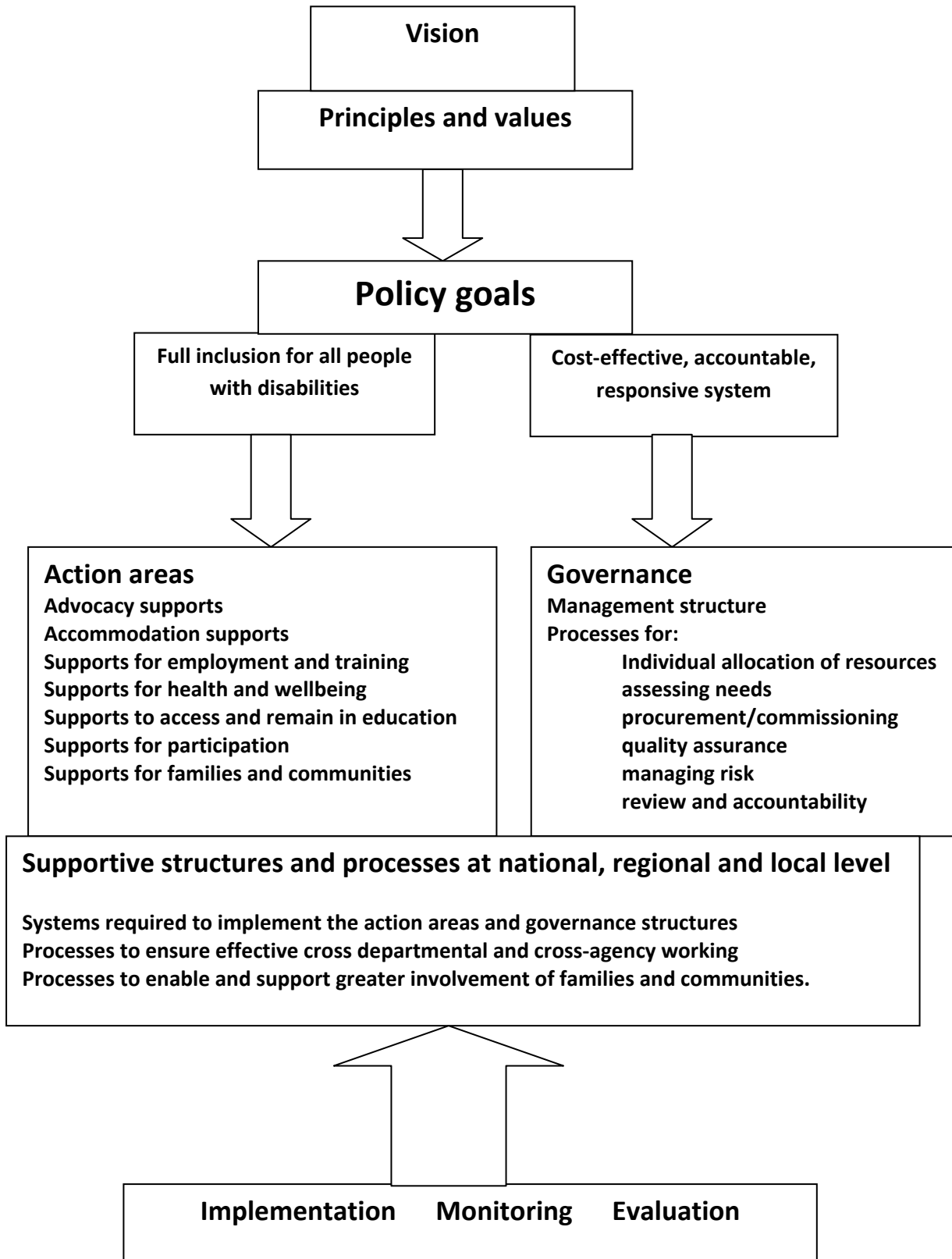
Goal 1: full inclusion and self-determination for people with disabilities

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.

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 the full inclusion and self-determination of people with disabilities.

These proposals take into account the role of the Office for Disability and Mental Health to improve co-ordination and communication across different Government Departments and agencies both in the delivery of services to people with a disability and in the framing of policy initiatives, as well as its policy responsibilities in respect of health policy for people with disabilities.

Figure 1: Proposed Disability policy framework



9.2 Principles and values informing this policy

An understanding of the principles and values listed below is essential to a full appreciation of the content of this policy. If this policy is to bring about real improvements to the lives of people with disabilities these principles and values must inform all actions and decisions arising from this document. In particular, service provision must be characterised by these values which define an overarching ethos to which all stakeholders are expected to ascribe. Services and supports must embody these values and principles to their fullest extent.

Citizenship People with disabilities have the same rights and responsibilities as every other Irish citizen. Opportunities and supports should be available to enable people with disabilities to be active citizens¹³³. The vision and values of this policy flow from this fundamental principle of people with disabilities as equal citizens.

Control All citizens can exercise a degree of control over their lives. People with disabilities should be provided with the necessary supports and services to exercise control over what happens in their lives. Control is closely linked to independent living; “Independent living is not doing things by yourself...it is being in control of how things are done.”¹³⁴

Informed choice Citizens who have control can exercise choice in their lives. People with disabilities should have access to the same choices as everybody else with regard to housing, transport, education, employment, participation and all aspects of living a full life. Alternatives need to be available so that real choice can be made. Information in an accessible format and access to advocacy are pre-requisites to support informed choice.

Self-determination Self-determination means being able to live life on one’s own terms. Viewing the disabled person as a citizen, supported to exercise control and choice, all underpin self-determination.

Responsibility Responsibility accompanies the exercise of control and choice in the context of full rights and citizenship.

Inclusion Inclusion is a sense of belonging; feeling respected, valued for who you are; feeling a level of supportive energy and commitment from others so that you can participate fully in life¹³⁵. Inclusion is not to be confused with ‘located in’ (i.e. the community). Real inclusion is an active contract from both sides; the community and the person with a disability.

Participation One of the rights attaching to citizenship is the right to participate in the structures which run our society. Having one’s voice heard, the availability of forums to facilitate this and voting in elections are all aspects to full participation in society.

¹³³ Report of the Taskforce on Active Citizenship (2007)
[http://www.activecitizenship.ie/UPLOADEDFILES/Mar07/Taskforce%20Report%20to%20Government%20\(Mar%2007\).pdf](http://www.activecitizenship.ie/UPLOADEDFILES/Mar07/Taskforce%20Report%20to%20Government%20(Mar%2007).pdf)

¹³⁴ Judy Heumann from http://www.dublincil.org/il_philosophy.html

¹³⁵ Adapted from definition from Miller, F.A. and Katz, J.H. (2002) *The Inclusion Breakthrough: Unleashing the Real Power of Diversity*. Berrett Koehler Publishers, San Francisco.

9.2.1 Principles and values related to the provision of services and supports

Equity Access to services and supports should be based on need. A distinction is made with equality, where everyone receives the same regardless of need. The provision of, and access to all supports and services will be based the principle of equity.

Person-centred People with disabilities should be supported to live the lives of their choice. The concept of person centredness refers to the process of providing the right support at the right time to enable the individual to lead a life of his/her choosing as an equal citizen. A person-centred approach to service provision is one where services are planned and delivered with the active involvement of the individual and developed around his/her particular characteristics.¹³⁶

Quality Services and supports must be of demonstrable high quality, meeting the necessary standards and regulatory requirements. Standards must be externally validated.

Effective Services and supports should be determined on the basis of the best available evidence and must provide the optimum outcomes in addressing the needs of the person. Services and supports must also be cost-effective, providing the best outcome for the use of resources.

Efficient Services and supports must use all resources to achieve optimum outcomes with no waste. In considering the efficient use of resources we need to be aware of the opportunity cost of using resources inefficiently. For example, using staff to deliver group services which do not significantly improve the quality of life of services users, means the staff cannot be used to deliver individualised services which may achieve better outcomes for service users.

Sufficient People with disabilities should get the supports and services they need, no more and no less than this.

Accountable and transparent Services and supports must have appropriate governance systems in place to ensure optimum outcomes for the individual are achieved and that financial, organisational and professional responsibilities are met.

¹³⁶ HIQA National Quality Standards for Residential Services for People with Disabilities
http://www.hiqa.ie/media/pdfs/National_Quality_Standards_Residential_Services_People_with_Disabilities.pdf

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

10.1 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 the individual to exercise choice and control over the lives. In this model the person is a passive recipient of a pre-determined service rather than an active determinant of an individually tailored service that meets their needs and supports the achievement of their potential.

The move to supports focuses 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).

10.2 Towards a shared language

These policy proposals use new terms to describe the provision of supports and services to people with disabilities into the future. The terms individualised supports and mainstreaming are considered in greater detail below. Other terms are described and defined in Appendix 3. The change required under this policy will not come about by simply using new language. 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 envisages the person with a disability as a self-determining citizen and proposes a range of supports and services required to realise this vision.

10.3 Individualised supports

Individualised supports are a personal social service which includes the 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. This provision

enables people with disabilities to live as full citizens instead of having to fit into standardised models and structures.

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.

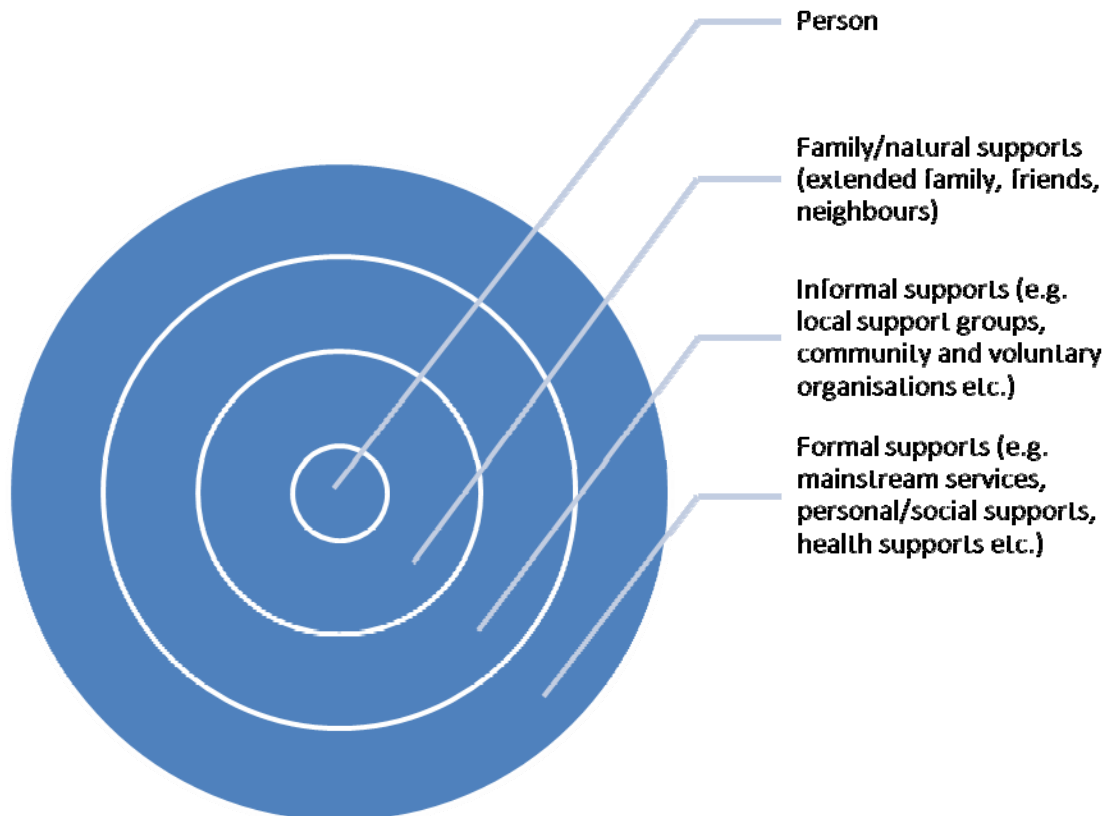
10.3.1 Supports model

A system of individually tailored supports ensures 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 2 below presents a visual representation of these supports, from the family/natural supports, through informal and finally formal supports.

Figure 2: Representation of typical support system¹³⁷

¹³⁷ Adapted from Office of the Minister for Children (2007) *The Agenda for Children’s Services: A Policy Handbook*.



10.3.2 Evidence base for supports model

The American Association on Intellectual and Developmental Disabilities adopted the concept of supports in 1992 in its definition and classification of persons with an intellectual disability¹³⁸. This supports model was based on the premise that appropriate use of supports could reduce the mismatch between environmental demands and a person's capabilities. Supports were defined as *"Resources and strategies that aim to promote the development, education, interests and personal well-being of a person that enhance individual functioning"* (p.151)¹³⁹.

In this model sources of support can be natural or service-based, and support functions include receiving assistance with guidance, building friendships; finances; vocational training; employment; home living; community use and access and so on. The assistance can take various forms including supervision or monitoring; encouragement and reassurance; advice; direct physical assistance or instruction/training to develop new skills and competencies.

The supports model gives practical expression to the social construct of disability, which underpins the definition in the Disability Act, 2005. The social understanding of disability recognises that people with disabilities have a right to participate in, and contribute to society as equals, and that it is societal attitudes and barriers which prevent people with disabilities from reaching their full potential. This view of disability, not as an absolute trait inherent to the person, but as an expression

¹³⁸ American Association of Mental Retardation (AAMR) (1992) *Mental Retardation: Definition, Classification and Systems of Support. 9th Edition*. Washington DC: AAMR

¹³⁹ American Association of Mental Retardation (AAMR) (2002) *Mental Retardation: Definition, Classification and Systems of Support. 10th Edition*. Washington DC: AAMR

of the interaction between the person and their environment, is also central to the World Health Organisation (WHO) conceptualisation of disability. The International Classification of Functioning, Disability and Health (ICF) recognises disability as a dynamic state of restricted function affected by; the person (and their disability); the activities they desire to do; and environmental and personal factors¹⁴⁰.

The adoption of this model of disability leads to the need for a system that is better able to assess the support needs of people with a wide range of disabilities and translate those needs into responsive and individualised service delivery¹⁴¹.

10.3.3 Natural supports

Relatively few people, with or without disabilities are totally self-sufficient but are reliant to varying degrees on a variety of natural supports that exist in every community. The term natural supports, refers to the resources inherent in community environments including *“personal associations and relationships typically developed in the community that enhance the quality of and security of life for people....family relationships; friendships reflecting the diversity of the neighbourhood and community; association with fellow students or employees in regular classrooms and work places; and associations developed through participation in clubs, organisations and other civic activities”*^{142, 143}.

10.3.3.a Valuing the role of natural supports

A person who wants to take part in a sporting activity or community activity generally accesses that directly in their own community, sometimes with friends. The same should be true for people with disabilities. Harnessing the natural supports which most people take for granted can be vital in enabling people with disabilities to live included lives in the community.

However, although most people with disabilities have significant networks of natural supports “we often think of extraordinary measures to incorporate natural supports into the lives of individuals with disabilities, usually after first considering professional, paid supports”¹⁴⁴. This is not only an expensive way of providing supports, it creates barriers that lessen the possible benefits of wider social networks. For example, many services run ‘socialisation/activation programmes’ that often consist of a group of service users going to a social/leisure activity (such as swimming) with members of staff. This is usually a separate class which, while having positive benefits for service users, serves to limit social connections and community integration. An alternative, to use natural supports to do the same activity, enhances the possibility of further social connections being made.

¹⁴⁰ World Health Organisation (WHO) (2001) The International Classification of Functioning, Disability and Health, Geneva: WHO.

¹⁴¹ Schalock, R.L. (1999) A quest for quality: Achieving organizational outputs and personal outcomes. In J.F. Gardner and S. Nudler (Eds.), *Quality Performance in human services*. Baltimore: Brookes

¹⁴² Allen, J.B. *Enhancing recovery through linkage with indigenous natural supports*. www.power2u.org/.../Local_Communities_and_Natural_Support_Systems_2a-Mental_Health.doc - United States

¹⁴³ Lanterman Developmental Disabilities Services Act, Section 4512 of the Welfare and Institution Code, Sacramento, California

¹⁴⁴ Allen, J.B. *Enhancing recovery through linkage with indigenous natural supports*. p. 2 www.power2u.org/.../Local_Communities_and_Natural_Support_Systems_2a-Mental_Health.doc - United States

10.3.3.b Using natural supports in a more structured way

The value of natural supports for people with disabilities has long been recognised by members of the support network and people with disabilities themselves, and efforts to organise these supports in more structured ways include circles of support and microboards.

Circles of support (also called circles of friends) is a group of people who agree to meet on a regular basis to support a friend or family member with a disability. The person who is the focus of the support (the focus person) invites a number of people to contribute within a circle to help them overcome challenges, build friendships, identify and work towards the focus person's dreams and aspirations¹⁴⁵.

A **microboard** is very similar to a circle of support, with the same membership and aims. Essentially microboards are a way of formalising a circle of support, usually with the aim of assisting in administering direct funding to provide the person with the services and supports they desire. This is usually achieved by creating a limited company for this task. The first documented Microboard was formed in Canada in 1984 around a young man leaving an institutional setting. Microboards are now established throughout Canada, in some US states, in Europe and Australia. In their guidelines for bridging service provider gaps, the Disability Service Commission in Western Australia lists Microboards as an alternative service provider model¹⁴⁶. The Microboards Association of Ireland¹⁴⁷ has supported the development of a small number of microboards on a pilot basis, and an evaluation of the project showed positive results¹⁴⁸.

10.3.4 Informal supports

Informal supports usually comprise those supports available in the wide community such as community-based support groups (these may be disability-specific or not), other community groups such as mother and toddler groups, church-associated groups, sporting groups such as the GAA and so on. Community-based volunteers are also an important informal support. The value of a rich community network is such that the terms social capital is used to capture the many benefits of a strongly connected community. Community development initiatives work to build up such connections and strengthen existing ones.

10.3.5 Formal supports - mainstream/universal

Universal services are those which are available to and used by the wider population. Such services include transport, schools, health related facilities such as GP surgeries, clinics and hospitals, and other similar services. The process of mainstreaming, which describes how these universal services are available to all is discussed below.

10.3.6 Formal supports – disability services

Disability services are those specialist services, described earlier, which provide health and personal social services to people with disabilities. This is the overall framework within which disability services fit and gives a context for how disability services should be provided. Disability services should only rarely be the 'first option' for supporting people with disabilities. In order to achieve the

¹⁴⁵ <http://www.circlesnetwork.org.uk/Resources/OxfordCircles.pdf>

¹⁴⁶ www.disability.wa.gov.dscrw/-assets

¹⁴⁷ <http://www.microboards.ie/>

¹⁴⁸ Evaluation of pilot project in Microboards Association of Ireland <http://www.microboards.ie/>

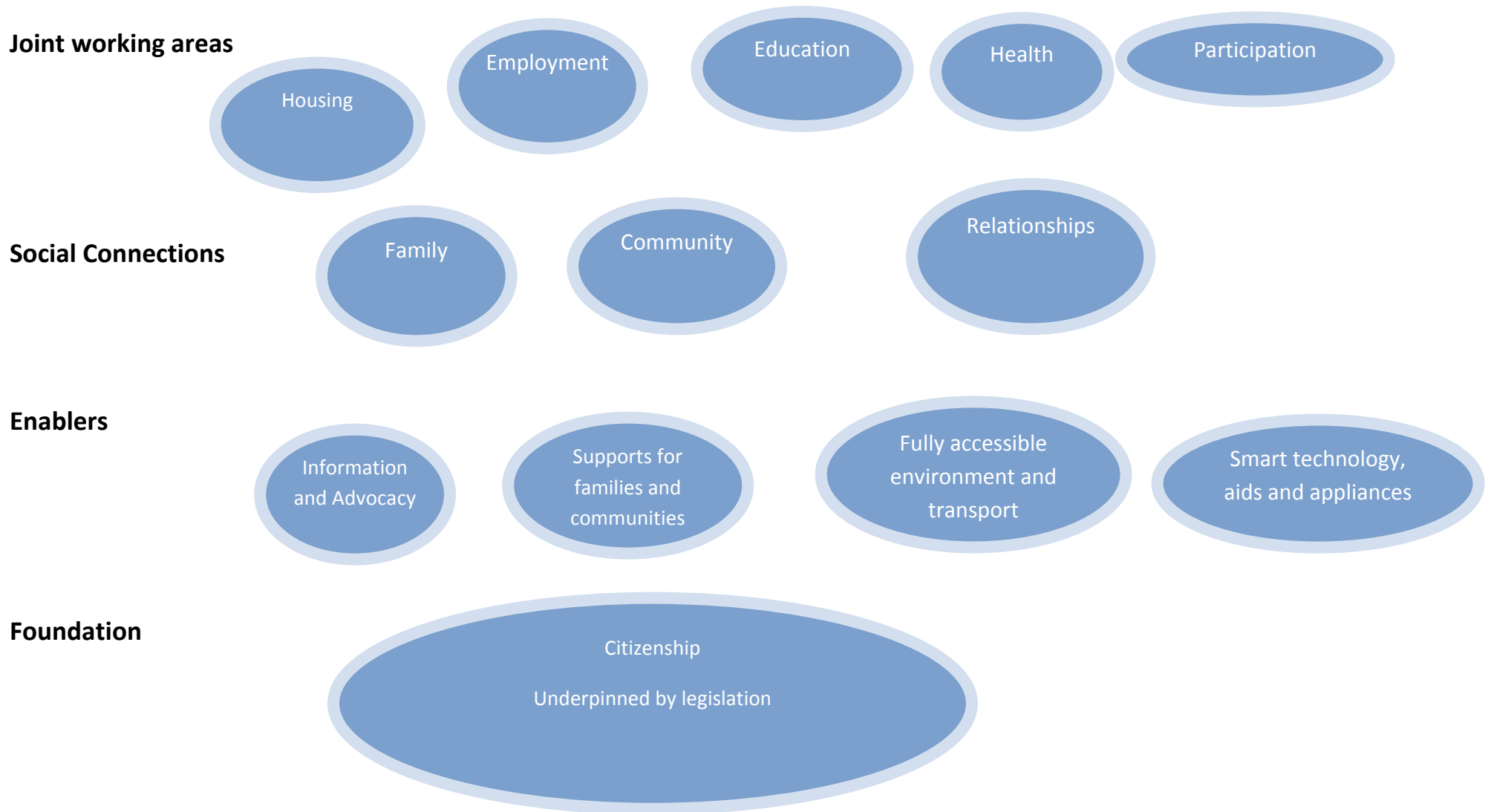
policy objective for people with disabilities of ‘a full and independent life’, the consensus of the evidence is that people with disabilities should be supported to remain in their communities, through the use of all levels of support. Disability services should act as a specialised support to achieve this same aim, not to remove people from their community or to provide services in separate settings.

11 A framework to achieve the goal of full inclusion and self-determination

Figure 3 shows a comprehensive framework for achieving inclusion¹⁴⁹. It is a mainstream model of inclusion and it defines the necessary foundation, facilitators, action areas and social connections to enable full inclusion for all citizens, including people with disabilities. The elements of the framework are explained here.

¹⁴⁹ This framework is based on that of Ager, A. and Strang, A. (2008) Understanding Integration: A Conceptual Framework. *Journal of Refugee Studies*, **21**, 166-191

Figure 3: Framework to achieve inclusion for all citizens



11.1 Foundation

The foundation of rights and citizenship underpins all the other elements. This was well understood by the Commission on the Status of People with Disabilities which placed a great emphasis on rights and the need for legislation to ensure equality and non-discrimination. There has been significant progress in this area and Ireland now has a body of legislation to prohibit discrimination on the grounds of disability and to ensure equality in many spheres. Similarly, legislation on the accessibility of public buildings (for example), is a necessary foundation to facilitate the full participation of people with disabilities in education and employment. The foundational legislation and policy has been fully described in Sections 3 and Appendix 1 and will not be considered further.

11.2 Enablers

Inclusion is often framed in terms of ‘removing barriers’ that inhibit the inclusion of specific groups. In the WHO International Classification of Functioning (ICF)¹⁵⁰, functioning and disability are multi-dimensional concepts relating to the person’s body function, the activities they do, the areas of life in which they participate and the factors in their environment which affect their experiences. Thus if a person lives in an environment characterised by barriers (such as inaccessibility) their performance and participation will be restricted; but if the person lives in an accessible environment this will serve to increase their performance and participation.

The facilitators of inclusion; accessibility; advocacy; supports for communities and families; and smart technology, aids and appliances are considered in detail below. Without an accessible environment and access to information and advocacy, significant action in areas such as employment and education are stymied and these opportunities cannot be maximised by people with disabilities.

11.3 Social connection

Social connections are seen as the processes that provide the ‘connective tissue’ between foundational principles of rights and citizenship and outcomes in areas such as housing and employment. Relationships and social bonds create the connectedness that typifies true inclusion, whereby people with disabilities are truly part of, and not just located in, the community. This has been described in relation to people with mental health difficulties, although it applies equally well to people with other disabilities; “individuals...living outside the [institution] may be described as in the community, but not of it. They may live in neighbourhoods alongside people without disabilities. Their residences may resemble those of their neighbours. Yet many people who are... disabled lack socially valued activity, adequate income, personal relationships, recognition and respect from others, and a political voice. They remain, in a very real sense, socially excluded.”¹⁵¹ Social connections are the bridges which maintain people in the community. They create the social environment which provides opportunities for individual competency to be developed and exercised.

¹⁵⁰ World Health Organisation (WHO) (2001) *The International Classification of Functioning, Disability and Health*, Geneva: WHO

¹⁵¹ Ware, N. Hopper, K. *et al.* (2007) Connectedness and Citizenship: Redefining Social Integration. *Psychiatric Services*, **58**, 469-474.

The social connections of relationships with family and communities are maintained and supported through the supports model described in Section 10.3 above. As specific supports for families and communities are considered in the section on facilitators, social connections will not be considered further here.

11.4 Cross sectoral working to support inclusion for people with disabilities

With the other elements in place; the underpinning legislation supporting rights and citizenship; facilitators such as accessibility, information and supportive communities; and the social 'glue' of connections and relationships; inclusion as expressed by having a home, having meaningful occupation, and having opportunities for learning; can be achieved for people with disabilities.

A very broad understanding of 'full inclusion' has been adopted in this policy. Essentially, 'full inclusion' means that people with disabilities will participate fully in their community in living a full life. The action areas for inclusion were chosen on the basis of domains that were identified by the *Commission on the Status of People with Disabilities*, the domains used by the *Un Standard Rules*¹⁵² and the *International Classification of Functioning (ICF)*¹⁵³, and include housing, employment, education, health and participation. These are considered in greater detail below.

12 Enablers

12.1 An accessible environment

Policy aim

The built environment and public transport services will be fully accessible to people with disabilities.

A fully accessible environment and accessible transport are pre-requisites to the full inclusion of people with disabilities. These elements must be in place if the recommendations under this goal are to be fully realised.

12.1.1 The importance of an accessible environment

The UN Standard Rules¹⁵⁴, the Commission on the Status of People with Disabilities and the International Classification of Functioning¹⁵⁵ all cite accessibility, mobility and transport as vital for the participation of people with disabilities. Employment and educational opportunities cannot be accessed if the built environment is inaccessible or if the person cannot get to their place of work or education. People with disabilities cannot use universal services such as health if the environment is

¹⁵² The Un Standard Rules on the Equalisation of Opportunity for Persons with Disabilities were adopted by the UN General Assembly in 1993 following recommendation of an expert committee which had worked in close collaboration with specialised agencies and NGOs, especially organisations of disabled people. Thus the rules have evolved through a process of consultation with people with disabilities.

¹⁵³ World Health Organisation (WHO) (2001) *The International Classification of Functioning, Disability and Health*, Geneva: WHO

¹⁵⁴ Ibid. The Un Standard Rules

¹⁵⁵ Ibid. World Health Organisation (2001)

inaccessible or if they have no accessible transport to get to the appropriate health service premises. Data from the National Disability Survey suggests that, in spite of significant improvements, there are still accessibility challenges in the built environment, with 27% of people with disabilities reporting difficulties with street crossings and 30% reporting difficulties with footpaths¹⁵⁶.

12.1.2 Accessibility

Accessibility to most people means physical accessibility; ramps to access buildings and similar environmental facilities. However, accessibility is about addressing many more obstacles than environmental ones. Obstacles to full participation include educational, psychological, political, social and institutional obstacles. Removing obstacles and providing a varied menu of supports, “allows people with disabilities to access the basic conditions needed to function as autonomous and responsible individuals – education, work, just remuneration for work, accommodation, justice, equity and the opportunity to participate in civic, cultural and social life”¹⁵⁷.

Obstacles to accessibility for people with disabilities include a broad range of tangible and intangible elements, including, for example:

- communication; where presented in inaccessible formats;
- lack of awareness of the needs of people with disabilities;
- the physical environment such as design, layout, signage, lighting etc.;
- service design, where systems, procedures and practices can present obstacles.

Local audits have shown that many environments and buildings present barriers for people with disabilities. These include undished footpaths, stepped entrances, inaccessible toilets, narrow doorways, lack of lifts and poor signage¹⁵⁸.

12.1.3 Responsibility for an accessible environment

The Disability Act requires local authorities and public bodies to provide a fully accessible built environment by 2015. Accessibility of the built environment in Ireland for people with disabilities is mainly controlled by Part M of the Building Regulations¹⁵⁹. The aim of Part M is to ensure that as far as is reasonable and practicable, buildings should be usable by people with disabilities. In order to promote the use of universal design, which benefits everyone and not just people with disabilities, the NDA has produced a best practice guideline *Building for Everyone*¹⁶⁰ which shows how to design, make and manage buildings and external environments for the inclusion, access and use of everybody. A *Code of Practice on Accessibility of Public Services and Information Provided by Public Bodies* has also been produced by the NDA¹⁶¹.

¹⁵⁶ Central Statistics Office (2006) National Disability Survey. Dublin: CSO

¹⁵⁷ P.44 National Disability Authority (2007) *Literature review on attitudes towards disability*. Dublin: NDA

¹⁵⁸ National Disability Authority (2005) *How far towards equality? Measuring how equally people with disabilities are included in Irish society*. Dublin: NDA

¹⁵⁹ Department of the Environment, Heritage and Local Government (2000) Building Regulations 2000. Technical Guidance Document M. Access for People with Disabilities. Dublin: Stationery Office

<http://www.environ.ie/en/Publications/DevelopmentandHousing/BuildingStandards/FileDownload,1655,en.pdf>

¹⁶⁰ National Disability Authority (2002) *Building for Everyone*. Dublin: NDA

¹⁶¹ [http://www.nda.ie/cntmqmtnew.nsf/0/3DB134DF72E1846A8025710F0040BF3D/\\$File/COPLargeprint.pdf](http://www.nda.ie/cntmqmtnew.nsf/0/3DB134DF72E1846A8025710F0040BF3D/$File/COPLargeprint.pdf)

However, the current regulation of the built environment for people with disabilities via building regulations and the planning system applies only to new buildings and to extensions or material changes of use to existing buildings. There is no legal requirement to adapt most buildings to meet accessibility standards¹⁶². However, a number of Acts provide a legislative framework for organisations to ensure that premises and services comply with minimum accessibility requirements in certain circumstances. These include the Equal Status Act 2000, the Employment Equality Act 1998 and the Safety, Health and Welfare at Work Regulations 1993. This gap in legislation has been somewhat addressed by the requirement for a Disability Access Certificate (DAC) for non-domestic buildings and apartment blocks from 2010 under the Building Control Act, 2007.

12.1.4 Recommendations for Cross Sectoral Working: Accessibility

The Group notes the progress that has been made in improving the accessibility of the built environment and many of the commitments of the National Disability Strategy in this area have been met. A review of the Part M Building Regulations was undertaken and upgraded regulations and technical guidance were signed into law in 2010. The amendments are due to come into operation on 1st January 2012.

The Group recommends that the Office for Disability and Mental Health (ODMH) and appropriate sections in the Department of Environment, Community and Local Government work together to identify appropriate joint actions to improve accessibility for people with disabilities. These actions need to occur at the local level, between local authorities and local health offices. At the Departmental level it will be necessary to identify needs that might be generated by this policy, for example, the presence in the community or more people with disabilities with a wider range of needs than heretofore.

The Sectoral Plan for the Department of Environment, Community and Local Government will be an important mechanism for the alignment of actions in this area and for progressing prioritised actions. It should be noted that other public bodies are also required to meet their obligations on access under Part 3 of the Disability Act to provide accessible public buildings. There is a need to re-energise actions in this area.

12.2 Accessible Transport

12.2.1 The importance of access to transport

Access to transport and specifically access to accessible transport is essential if people with disabilities are to be enabled to take up employment and education opportunities and to participate in many social and leisure activities. One of the strongest findings from the consultation for the *Commission on the Status of People with Disabilities* was that people were ‘prisoners in their own home’, and that ‘even if they got a job they wouldn’t be able to get to it’¹⁶³. Information from the NDA¹⁶⁴ (2004 data) showed that:

¹⁶² Ibid. NDA 2005

¹⁶³ Report of the Commission on the Status of People with Disabilities (1996) *A Strategy for Equality*. Dublin: The Stationery Office

¹⁶⁴ National Disability Authority and tns mrbi (2004) *Social Participation and Disability*. Dublin: NDA

- Almost one quarter of people with disabilities (23%) had no access to transport – i.e. had no car and no public transport, compared to 5% of the non-disabled population
- Less than half of people with disabilities drive a car (46%) compared to 72% of the general population
- Almost half of people with disabilities (44%) cannot access public transport compared to 29% of the non-disabled population.

Following a process of national consultation with key stakeholders, the NDA produced a guidelines document¹⁶⁵ with the aim of achieving a high level of public transport accessibility; *Recommended Accessibility Guidelines for Public Transport Operators*. Recommendations made, are based on the principle of ‘Transport for All’, which focuses on the whole experience of a journey, from the provision of information that is accessible, the accessibility of vehicles and buildings, to disability awareness training for staff, and consultation and communication with people with disabilities.

12.2.2 Responsibility for accessible transport

Public transport accessibility is being progressed in the context of *Transport Access for All*, the Department of Transport’s Sectoral Plan under the Disability Act 2005. The Plan was first published in 2006 and the most recent edition was made available at the end of 2009¹⁶⁶.

Transport Access for All sets out a series of policy objectives and targets for accessible public transport across all modes. Actions are detailed to make trains, buses, taxi and hackney services, as well as air and marine transport, accessible to people with mobility, sensory and cognitive impairments. It also covers parking facilities for motorists with disabilities. *Transport Access for All* promotes the principle of mainstreaming by requiring accessibility to be an integral element of the public transport services.

There have been some improvements in the provision of accessible transport. These include; 100% low-floor wheelchair accessible buses for Bus Eireann’s city fleets in Cork, Limerick, Galway and Waterford; 90% provision of low-floor wheelchair accessible buses in Bus Atha Cliath, improvements in the accessibility of rail and urban rail services and stations and an expansion of the Rural Transport Programme so that it was operational in every county by the end 2008. Disability awareness training is also underway in several transport providers. These are welcome developments. However, it is important that investment is continued to ensure accessibility across the entire rail network.

12.2.3 Recommendations for Cross Sectoral Working: Transport

As transport is a key enabler for many goals relating to people with disabilities, it is essential to work jointly to identify and address challenges in this area. The Group recommends that the ODMH work with the Department of Transport, Tourism and Sport to identify needs that may be generated by this policy and to identify areas of joint working to ensure the availability of accessible transport for people with disabilities. The Sectoral Plan for the Department of Transport, Tourism and Sport will

¹⁶⁵ NDA (2005)

<http://www.nda.ie/cntmgmtnew.nsf/0/CODBA1BA241FB9398025710F004D8EAA?OpenDocument>

¹⁶⁶ <http://www.transport.ie/viewitem.asp?id=12183&lang=ENG&loc=1512>

be an important mechanism for the alignment of actions in this area and for progressing prioritised actions.

The Group also notes that currently, many service providers in the disability sector provide transport services for service users availing of their services, and due consideration will have to be given to the appropriateness of these arrangements in the context of this proposed policy framework.

12.3 Advocacy supports

Policy aim

Advocacy, if required, will be the first support provided to people with disabilities.

It is from this first step of consulting with the person in a meaningful and respectful way that his/her needs and wishes can be determined and addressed appropriately. The provision of appropriate advocacy and of supports to people with disabilities in advocating for themselves, underpins this policy framework.

12.3.1 Why are advocacy supports important?

This policy proposes a very new model of provision for people with disabilities which moves away from the current model of providing 'wrap-around' disability services towards a model of universal/mainstream services and individualised supports. The provision of supports requires the person to be an active part of this process; deciding what he or she needs and wants to do with their life and then being provided with the support to do this. For this reason, the person must have access to advocacy support if required. It is from the first step of consulting with the person in a meaningful way (which may require the provision of advocacy) that a needs assessment can be done and a support plan for that individual can then be formulated. The full implementation of mainstreaming also depends on the person with a disability having the ability/skills to advocate on their own behalf or having access to an independent advocate who can do this.

Any citizen may need an advocate at different times. Not all people with disabilities need advocacy supports as they are willing and able to advocate on their own behalf. However, there may be times, for example in trying to secure entitlements or in dealing with several agencies with a complex matter, that they may require advocacy support. Other people with disabilities may not have the skills to represent themselves and will have a greater need for advocacy supports for more everyday situations, for example participation in needs assessment and in the preparation of a support plan.

It is recognised that many of the staff working with people with disabilities have a strong role in acting as a voice for the individuals they work with, and in representing their needs and wishes. However, the need for an independent advocate is important for the person with a disability who is trying to live their life beyond what can be provided in a service setting.

12.3.2 What are advocacy supports?

An advocate is defined as a trained, independent person who represents and speaks for another. Advocacy has been described as

“... a process of empowerment and can take many forms. It is a way of enabling those who may have difficulty speaking up for themselves to do so and thus can be key to involvement in decision-making. It generally means representing the view of a person or supporting them to exercise or secure their rights.”¹⁶⁷

The term ‘Advocacy supports’ is used in this policy to describe a wide range of supports including;

- Personal Advocates providing a personal advocacy service as described in the Citizens Information Act 2007;
- Community and Voluntary sector advocacy;
- Citizen advocates;
- Support for self-advocacy;
- Statutory and non-governmental organisations which can provide systemic advocacy at a national level.

12.3.2a Personal advocates

Section 5 of the Citizens Information Act 2007 provided for the employment of personal advocates by the Citizens Information Board who would provide a Personal Advocacy Service. Under the Act, personal advocates are trained advocates who provide independent advice and assistance to individuals who apply for such assistance. This would include for example, assistance in making an application under Part 2 of the Disability Act 2005. The independent, statutory nature of the role is important. The Citizens Information Act 2007 also allows for the personal advocate to enter any place where day care, residential care or training is provided for the person and to obtain information on the person they are supporting.

The commencement of the Personal Advocacy Service, which was expected in 2008, has been postponed due to changed economic circumstances. While several of the advocates employed under the projects in the community and voluntary sector (see below) provided a personal advocacy service, they did not have the independent statutory role as described in the Citizens Information Act 2007.

12.3.2b Community and voluntary sector advocacy

The government allocated funding to develop programmes under the heading of Community and Voluntary Sector Advocacy for people with disabilities (including people with mental health difficulties). An evaluation of some 46 pilot advocacy projects under this scheme reported that this service *“has had a hugely positive impact on the lives of people with disabilities”*¹⁶⁸. The evaluation also pointed to changes that could enhance the ability of the service to deliver on its aims, including protecting the independence of the advocate, improving the quality, capacity and level of advocacy and including the voice of the service user in the ongoing design of the advocacy service.

¹⁶⁷ Comhairle (2001) *The Information Process in Citizens Information Centres*, Nua Research Services Report. http://www.citizensinformationboard.ie/downloads/Information_Process_Research_Report.pdf

¹⁶⁸ Citizens Information Board (2010) *Evaluation of the Programme of Advocacy Services for People with disabilities in the Community and Voluntary Sector*. Dublin: CIB

12.3.2c National advocacy service for people with disabilities

Arising from this evaluation of the pilot advocacy projects, a new national advocacy service for people with disabilities has been developed, and was announced by the Minister for Social Protection on 5th October 2010¹⁶⁹. This new service will provide independent, representative advocacy services for people with disabilities and will be in place from January 2011. It will be regionally structured; with five regional teams replacing the existing pilot projects which have provided assistance to more than 5,000 people with disabilities. The five regional teams will be managed by Citizens Information Services in Dublin, Westmeath, Offaly, Waterford and Leitrim.”

Advocacy Support Workers will be recruited to support the provision of an enhanced mainstream service so that more people with disabilities can access and use the general Citizens Information Services while the National Advocacy Service will seek out and respond to more vulnerable people with disabilities.

12.3.2d Citizen advocacy

A citizen advocate is a trained volunteer who freely makes a long-term commitment to a person with a disability to understand, respond to and represent their interests. Citizen advocacy programmes recruit, train and match people with disabilities and advocates and support these relationships over time.

Citizen advocacy is wider than simply ensuring the rights of a person with a disability are met. Citizen advocacy programmes place a strong emphasis on the relationship between the person with a disability and the advocate and on the role of the citizen advocates in helping the person to participate fully in community life. Citizen advocacy is not a service. It has been characterised as “an invitation to people leading full lives in our communities to get to know people who have intellectual disability who have been or who are at risk of being excluded from their community.”¹⁷⁰ Citizen advocates voluntarily enter a relationship which is independent of the formal advocacy services and the disability and health services. A citizen advocate is often a member of the ‘circle of support’¹⁷¹ for the person with a disability and can be closely involved in the development of a person-centred plan for the individual (there are examples of this in several jurisdictions).¹⁷²

12.3.2e Self advocacy

“The aim of advocacy is not solely about the formal representation of others; it is equally about vulnerable people becoming empowered to become advocates in their own lives through training, education and life experience.”¹⁷³

This broad concept of advocacy places the individual in the centre (“nothing about us without us”), with an emphasis on encouraging self-sufficiency and self-determination. It also helps to explain a term that is widely used in the disability sector ‘self-advocacy’. This seems to be a contradiction in

¹⁶⁹ <http://www.welfare.ie/en/press/pressreleases/2010/Documents/pa051010.pdf>

¹⁷⁰ <http://www.uow.edu.au/~bmartin/CAN/intro.html>

¹⁷¹ A circle of support is a group of people who come together to assist a person implement their person-centred plan. There is an emphasis on ‘natural supports’ such as family, friends and unpaid supports, although paid staff can also be part of a circle of support.

¹⁷² <http://www2.citizenadvocacy.org/reallife.html>.

¹⁷³ Forum of People with Disabilities, 2001, p.8

terms, but is widely used to describe the person representing themselves. This can occur through a process of representative advocacy initially, which builds the confidence and skills of the person to the extent that they begin to represent themselves. There are also several courses throughout the country (e.g. in some Institutes of Technology) which provide training to develop the skills of people with disabilities so that they can become their own advocates.

Group advocacy is a form of self-advocacy, when a group of people, with a common cause, act collectively to reach their shared goal. Like self-advocacy, it is seen as enabling people to have a voice, enhancing personal identity and raising self-esteem¹⁷⁴.

Family advocacy describes the situation in which a family member acts as advocate for the individual and can be an important source of support for the person. Family advocacy should ideally supplement self-advocacy so that the wishes of the person are also directly expressed wherever possible. Families may also engage in collective advocacy through various representative organisations and groups, and can become empowered through this process.

12.3.3 Who provides advocacy supports?

The Citizens Information Board (CIB, formerly Comhairle) is responsible for supporting the provision of information, advice and advocacy on a wide range of social and civil services. CIB is governed by the Citizens Information Act 2007, and the Comhairle Act 2000. The mandate of the CIB, as defined by the Acts, is:

- To ensure that individuals have access to accurate, comprehensive and clear information relating to social services;
- To assist and support individuals, in particular those with disabilities, in identifying and understanding their needs and options;
- To promote greater accessibility, coordination and public awareness of social services;
- To support, promote and develop the provision of information on the effectiveness of current social policy and services and to highlight issues which are of concern to users of those services;
- To support the provision of, or directly provide, advocacy services for people with a disability.

The mission of the CIB is *“to ensure that individuals have easy access to high quality, independent information, advice, advocacy and budgeting services on a confidential basis so that they can identify their needs and access their entitlements.”* (CIB Strategic Plan 2009-2012).

Prior to the commencement of the Citizens Information Act 2007, Comhairle (now the Citizens Information Board) commissioned a study in 2004 to identify and examine the components of an advocacy service for people with disabilities that would best fit the policy and legislation in Ireland¹⁷⁵. The report of this study set out three key strands for developing advocacy services in Ireland:

¹⁷⁴ Atkinson, D. (1999) *Advocacy: A Review*. Brighton: Pavilion/Joseph Rowntree Foundation

¹⁷⁵ Goodbody Economic Consultants (2004) *Developing an Advocacy Service for People with Disabilities*. Comhairle, Dublin.

1. A Personal Advocacy Service (PAS), where the CIB will employ professional advocates to deal with complex issues;
2. Community and Voluntary Sector advocacy for people with disabilities (including people with mental health difficulties), funded through the CIB, with priority given to representative organisations where possible;
3. A Community Visitors Programme; a volunteer-based programme to focus on advocacy for individuals in residential settings.

12.3.3a Statutory organisations with a role in advocacy

There are several statutory organisations such as the Office of the Ombudsman and the Children’s Ombudsman which have a role in advocacy in that they can investigate complaints concerning the actions of Government Departments, the HSE and other organisations.

12.3.4 Recommendations for Cross Sectoral Working: Advocacy

The Group notes that there is currently some duplication in the provision of advocacy supports, with some dispersed advocacy within the disability services and wider voluntary group sector. In the interests of optimising the use of resources in advocacy, it is recommended that the ODMH work with the CIB and the HSE to identify areas of common interest and overlap in terms of their respective roles with regard to the provision of advocacy services and capacity building both at the individual and systemic level.

In terms of the provision of individualised supports as described in this policy, part of the process of working with a person to identify their support needs involves an amount of capacity building with the individual in terms of strengthening their skills to self-advocate. However, more systemic provision of advocacy services and capacity building for people with disabilities and families (such as training) is within the remit of the CIB. The commitment to the provision of Personal Advocates with statutory powers under the Citizens Information Act 2007 should be reviewed in light of the development of the new National Advocacy Service for people with disabilities.

12.4 Smart technology, aids and appliances

Policy Aim

The use of emerging and existing technologies to facilitate the independence and participation of people with disabilities will be maximised.

Smart technologies, aids and appliances have significant potential to enable the inclusion of people with disabilities in a cost-effective way.

Smart technology is the term used to describe a range of assistive technologies which have been developed in recent times. Assisted Living Services (ALSs) refers to a collection of technologies which are becoming increasingly available to enable people with disabilities to live in their own homes in

the community and to live richer lives. Five main possibilities in assisted living technologies have been identified which would enable service providers to¹⁷⁶:

- Deliver better and more cost effective social and health care into the homes of older and disabled people – enabling them to live at home longer (**telecare** and **telehealth** services respectively – described in detail below);
- Deliver services which entertain, educate and stimulate social interaction so as to enrich the lives of people with disabilities who live at home (**digital participation** services);
- Provide services which encourage users to get fitter and to adopt healthier lifestyles (**wellness** services);
- Enable people with disabilities to work from home and therefore participate in the economy and in society (**teleworking** services).

12.4.1 Telecare

Telecare services which use assisted living technologies have been in operation for some time now (for example simple pendant alarms to summon help). A typical modern telecare system is described as consisting of¹⁷⁷:

- An alarm hub which, when triggered, dials into a monitoring centre
- A series of wireless sensors which are preset to trigger alarms. They might include a pendant to summon help following a fall, smoke, carbon monoxide sensors, flood sensors, and an extreme temperature sensor (to warn if a cooker has been left on for example)
- A series of monitors e.g. a bed occupancy sensor which sends information to the hub for retransmission to a central server
- A simple voice memo system to remind the person to take keys, turn off gas/electric and issue other reminders before leaving the house.

12.4.2 Telehealth

Telehealth systems are less widely used. Although current telehealth systems are typically designed to manage long-term conditions such as heart failure and diabetes, these systems offer significant possibilities for use with people with disabilities. They usually incorporate a central “communication” station which incorporates a user interface with large screen, large buttons and voice control. This connects to the internet and can be used to help the person communicate with a family member/carer or support worker and supports the independence of the person while helping ensure their safety.

12.4.3 Whole systems demonstrator programme

The Whole System Demonstrator (WSD) programme is a two year research project funded by the Department of Health (UK) to find out how technology can help people manage their own health while maintaining their independence. There is a lack of robust evidence on many of the issues surrounding telehealth and telecare and the WSD programme has been established to provide this

¹⁷⁶ Lewin, D. et al. (2010) *Assisted living technologies for older and disabled people in 2030*. London: Plum Consulting.

http://www.plumconsulting.co.uk/pdfs/Plum_June2010_Assisted_living_technologies_for_older_and_disabled_people_in_2030.pdf

¹⁷⁷ Ibid. Lewin, D. et al. (2010)

evidence. It is believed to be the largest randomised control trial of telecare and telehealth in the world to date with over 6,000 participants enrolled. The provision of health services through telehealth and telecare is envisaged to be an essential part of primary care health services in the UK and the results of this trial will determine the further roll out of these technologies. This type of technology is being used in some US states to support people with disabilities to live independently. For example, Safety Connection in Vermont has developed a support system using this technology (see Section 8.7.5 for more details).

The average cost for telecare units in this UK pilot is approximately STG£500, with installation costing STG£25-50. The cost of monitoring varies from as little as STG£1 per week per user (for 'monitoring only' using a call centre) to STG£15 per user per week for 'monitoring with response' where there is rapid response from the monitoring agency¹⁷⁸.

The costs for telehealth vary more widely depending on the type of monitoring required. For example, simple monitoring of blood pressure or glucose levels is not as expensive as units which use internet and video links for the management of more complex conditions. More definitive costs will be available as the study progresses¹⁷⁹.

12.4.4 Aids and appliances

While telecare and telehealth offer potentially cost-effective solutions to supporting people with disabilities to live independent lives in the community, they are generally underdeveloped in Ireland. Aids and appliances are the chief 'technologies' used by many people with disabilities, particularly physical and sensory disabilities, to live full lives.

The term 'aids and appliances' includes mobility aids, such as walkers and wheelchairs; communication aids such as phones and alternative speech products; appliances to assist in accessing computers such as eye/voice control products; appliances for the visually impaired such as screen readers; appliances for the hearing impaired such as digital hearing aids and a range of appliances to assist in everyday life and activities such as special chairs and stools and adapted kitchen and other appliances.

Aids and appliance are a necessity for people with disabilities and can mean the difference between participating in work and social life or remaining excluded from such opportunities.

Try-it.ie is an on-line library of Electronic Assistive Technology which has been developed by a consortium of Irish disability service providers to enable staff of member organisations to borrow from a wide-range of state-of-the-art devices to trial with their clients and/or for professional training purposes¹⁸⁰. This is a multi-agency and non-disability specific resource, serving individuals with disabilities across the country.

Over 17,000 people on the National Physical and Sensory Disability Database use at least one technical aid or appliance¹⁸¹. However, most of those listed on the database as requiring such

¹⁷⁸ Clark, M. (2010) WSD Network. Personal communication.

¹⁷⁹ Ibid.

¹⁸⁰ <http://www.try-it.ie/Welcome.do>

¹⁸¹ Doyle, A., O'Donovan, M.A. and Craig, S. (2009) *National Physical and Sensory Disability Database Committee Annual Report 2008*. Dublin: Health Research Board.

disability aids have not been formally assessed. Aids and appliances account for about 3% of the total disability budget at present, with spending of about €50m¹⁸². The NDA has advised that consideration should be given to “accelerating assessment for and provision of disability aids. A modest increase in funding in this area could yield a good pay-back in terms of enabling greater independence and quality of life”¹⁸³.

12.4.5 Recommendations for the Department of Health & Children

The new technologies represent important opportunities to support people with disabilities to move from institutional to community settings and to remain in independent settings. It is recommended that the Department, the HSE and the Centre for Excellence in Universal Design, work together to identify actions in this area and will use the information from the UK trial to inform further developments.

12.4.6 Recommendations for Cross Sectoral Working: Smart Technology

The Group recommends that the ODMH and the Department of Environment, Community and Local Government identify areas of joint working so that actions in this area will direct resources to desired policy goals and maximise potential benefits for people with disabilities.

12.5 Support for communities

Policy Aim

Communities and families will realise their full capacity for supporting, connecting with and including people with disabilities as valued members of their community.

Community and families are the key facilitators of full inclusion of people with disabilities in the community.

A central goal of this policy is to support people with disabilities in becoming fully included in their community, accessing whatever services and supports are required in mainstream settings. This level of inclusion, for people who have been traditionally excluded and segregated, requires work on both sides – support for the individual and support for the community. This support often takes the form of community development. Much of the literature on community development focuses on building on the strengths of communities rather than their deficits (this is known as the model of asset-based community development¹⁸⁴).

An important characteristic of involvement in a community is mutual aid – “one of the basic building blocks of community”¹⁸⁵. A focus on mutual aid emphasises the ordinary exchange of support and skills that takes place in many of our interactions in the community. It underlines our mutual dependence in a positive way, as both parties are ‘giving’ something. Many people with disabilities do not have valued social roles and are often viewed as being dependent and having nothing to

¹⁸² National Disability Authority (2010) *Advice paper to the Value for Money and Policy Review of Disability Services*. Dublin: NDA.

¹⁸³ Ibid. p. 25.

¹⁸⁴ Kretzmann, J.P. and McKnight, J. L. (1993) *Building communities from the inside out: A path toward finding and mobilizing a community’s assets*. Evanston, IL: Institute for Policy Research.

¹⁸⁵ Young, M. and Lemos, G. (1997) *The Communities We Have Lost and Can Regain*, London

contribute. Thus a full expression of mutual aid can be missing, which serves to reinforce dependence in an unequal relationship, with one person providing/organising everything and the other as a passive recipient. In this way, people with disabilities can be denied the opportunity to experience the benefits of mutual aid: *“From the engagement in the mutual exchange of community involvement comes a sense of belonging, of safety, of importance and entitlement. And, if people are to take part in this process of mutual exchange, then we have to have an approach which starts from the position of identifying what people can contribute”*¹⁸⁶.

12.5.1 Models of community-based support

This emphasis on mutual aid is one of the key features of the programme; Keyring Supported Living Networks¹⁸⁷ (and a similar organisation in Scotland – Neighbourhood Networks). Keyring works by providing assured tenancies to local authority housing to ten people in a network in a small neighbourhood. Nine flats or houses belong to ‘vulnerable or excluded people’. The tenth property is occupied by Keyring’s Community Living Volunteer (CLV) who supports the network members on a flexible basis. This volunteer is supported by a Keyring Supported Living Manager who also gives direct support to network members around more complex issues. This arrangement enables Keyring to build layers of support around the network members in ‘natural’ community settings. The living support network model provides many benefits – particularly in releasing other resources, such as member’s own skills. The network members provide a mutual support network for each other and their individual skills are available to each other. The Community Living Volunteer supports network members to build healthy links with neighbours, community organisations and agencies like the Police and the Citizens Advice Bureau. Local authorities and other housing providers note many benefits for them as providers and the communities they serve, such as bringing a safe and stable presence to estates and providing exemplar long-term reliable tenancies.

An independent review of the work of Keyring in 2002¹⁸⁸ found that most Keyring members had strong connections in the neighbourhood and make much use of community resources. The Keyring model was seen to be particularly effective in minimising dependency on health and social care workers and encouraging the use of ordinary community facilities. The review also noted a high level of cooperation, with network members being both givers and receivers of help. Network members wanted to be more involved in the selection of Community Living Volunteers and other network members. The maintenance of standards was also seen as a challenge as the organisation expanded.

12.5.2 Community Integration Projects

Inclusion and integration has been described as; *“... something most of us take for granted. We go to work, look after families, visit our GPs, use transport, and go to the swimming pool or cinema. Inclusion means enabling people with learning disabilities to do those ordinary things, make use of mainstream services and be fully included in the local community.”*¹⁸⁹

¹⁸⁶ Poll, C. <http://valuingpeople.gov.uk/dynamic/valuingpeople69.jsp>

¹⁸⁷ www.keyring.org Keyring is a charity which works with health, social and housing services. The organisation has enabled over 600 people to lead independent lives in the community.

¹⁸⁸ www.keyring.org/site/keyring_links.php

¹⁸⁹ Department of Health (2001) *Valuing People. A New Strategy for Learning Disability for the 21st Century*. A White Paper. CM5086, London

A small number of service providers in Ireland have recognised the importance of supporting real community integration, and have employed workers with a background in community development to support service users and communities towards this goal. Some disability services for adults with intellectual disability support service users to access community facilities, activities and social networks so that they depend less on services and instead enjoy a network of friends and associates in their neighbourhoods. There is a subtle but profound difference in this model of support. Instead of bringing people with disabilities in groups, on special transport, to take part in an activity in the community and then back to a segregated setting, service users are supported in an individualised way to participate fully in activities they have chosen, enabling the person to become less dependent on formal supports over time. An additional important function of these workers is building capacity in the community so that community members and providers of mainstream services are more confident in supporting community members with a disability.

This process of community integration and linkage has been described as a four step process by the Grapevine¹⁹⁰ Community Connections Project in England. These simple steps involve; collecting information about people groups and activities in the local community; getting to know the needs and wishes of the person using a person-centred planning tool called identity mapping; connecting them to their local community (with the help of a support worker); and providing support for that connection to grow.

A similar process of supporting community connections has been described by Rans and Green¹⁹¹ who collected and evaluated accounts of four community integration projects in Canada and the US. Three common characteristics of these projects were identified;

- They all centre on identifying the gifts and dreams of each individual isolated person – they do not centre on their needs;
- “Citizen space” is important – citizen space is where connections and associations are made. These are everyday social settings outside of health and social care settings;
- Connectors are key to this process – connectors are “local people who know lots of people” and are good at connecting people in the course of everyday life.

Lessons from the project were that there should be clear boundaries for agencies/service providers who are involved in both services and community connections. These are very different ways of working, and “it is very difficult to mix the two efforts without undermining the connection work”¹⁹². The four projects were all citizen-led efforts and this was identified as a critical success factor in both the success and sustainability of the work. Other lessons from the project were that agencies and services should ask the ‘connectors’ and local leaders how they can help and advising against “bringing in experts” too much, as the provider-client thinking can limit the possibilities of seeing the dreams and potentials that can be contributed by individuals. What the authors advised as;

¹⁹⁰ Grapevine is a charity “run in partnership with people with learning disabilities” which provides support to people with learning disabilities to connect with their local community and have valued social roles.

www.grapevinecovandwarks.org/

¹⁹¹ Rans, S. and Green, M.(2005) *Hidden Treasures: Building Community Connections by Engaging the Gifts of people on welfare, people with disabilities, people with mental illness, older adults, young people. A community building workbook*. Asset-based community development institute: Evanston Il.

¹⁹² *Ibid.* Rans, S. and Green, M.(2005) p. 87

*“Protecting the connectors from the influence of helping systems allows the connection project to remain in citizen space”*¹⁹³. Assistance that was useful from “friendly institutions” was identified as; funding, a staff person, some resources, and advocacy and support for citizens making their own decisions and choosing their own action. A ‘toolbox’ of resources was developed to help others build inclusive communities¹⁹⁴.

This type of work creates social capital by enabling communities to support people with disabilities as full members of their community. Relationships built in communities create the ‘social glue’ thorough which people with disabilities can truly be part of and not just located in their community.

12.5.3 Recommendations for Cross Sectoral Working: Supporting Communities

The Group recommends that the ODMH work with the Department of Community, Equality and Gaeltacht Affairs to identify the range of activities that are relevant to this new direction for disability services. There is an existing framework to support high level joint working (Senior Officials Group on Disability) and opportunities for joint working at the local level should also be identified and supported.

12.6 Supports for children with disabilities and families

Policy aim

Children will be respected as young citizens with a valued contribution to make and a voice of their own; all children will be cherished and supported by family and the wider society; and will enjoy a fulfilling childhood and realise their potential.

Children with a disability are first and foremost children. All children have needs and some children have additional needs such as those associated with a disability. The vision of the “National Children’s Strategy”, which applies equally to all children including children with a disability, is endorsed by the Policy Expert Reference Group.

12.6.1 Children with disabilities

As stated in Section 7, the life cycle approach has been adopted in this policy review and thus proposals relate to all age groups; children, adults and older people. However, there are several issues relating specifically to children with disabilities and in the context of supporting families that merit specific attention and are therefore addressed in this section.

Ideally the needs of children with disabilities should be considered in whatever setting they occur. However, traditionally children with disabilities have always been included in the broader disability sector. There are also specific legislative requirements which need to be considered for some children with disabilities in certain circumstances.

¹⁹³ *Ibid. Rans, S. and Green, M.(2005) p. 88*

¹⁹⁴ <http://www.sesp.northwestern.edu/images/hiddentreasuretoolbox.pdf>

The key principles of the National Children’s Strategy¹⁹⁵ are of equal relevance to this policy:

- **Child centred:** The best interests of the child shall be a primary consideration and children’s wishes and feelings should be given due regard;
- **Family-oriented:** The family generally affords the best environment for raising children and external intervention should be to support and empower families within the community.
- **Equitable:** All children should have equal opportunity to access, participate in and derive benefit from the services delivered and have the necessary levels of quality support to achieve this. A key priority is to target investment at those most at risk.
- **Inclusive:** The diversity of children’s experiences, cultures and lifestyles must be recognised and given expression.
- **Action orientated:** Service delivery needs to be clearly focused on achieving specified results to agreed standards in a targeted and cost effective manner.
- **Integrated:** Measures should be taken in partnership, within and between relevant players across sectors. The strategy stresses the importance also of integrated needs analysis for children.

The National Children’s Strategy applies to all children. Mainstreaming is the mechanism by which children with disabilities will have equal opportunity to access the services they need and the quality supports to enable them to do this.

12.6.2 Child and family centred

In accordance with the principle of child-centredness, the needs and best interests of the child should be the primary driver for the provision of supports and services to children with disabilities. The best place for a child to grow up is in his/her family and a child’s natural place is with his/her family (or an alternative family-type arrangement if this is not possible, such as a foster family). This principle of family-orientation drives the provision of supports outlined here. All supports should be directed at supporting the family in the care of their disabled child, so that the child can remain within their family and avail of universal services such as education in their local school, health with their local Primary Care Team and so on. Consideration of instances where this may not be possible is outlined in section 8.6.5 below.

The principles of minimum intervention and normalisation described in the new draft standards for residential and foster care services for children¹⁹⁶ also apply to children with a disability. Thus, where a family is having difficulty in meeting the needs of a child or young person, supports should be directed at maintaining the child/young person at home rather than directing them towards residential or special settings. Normalisation reflects the importance of mainstreaming for children with a disability so that *“children who need special help should also, as far as possible, have the same experience of growing up as is normal in their society”*.

¹⁹⁵ Department of Health and Children (2000) *National Children’s Strategy*. Dublin: Stationary Office

¹⁹⁶ Health Information and Quality Authority (2010) *Draft National Quality Standards for Residential and Foster Care Services for Children and Young People*.
http://www.higa.ie/media/pdfs/Draft_%20National_Childrens_Standards_Feb2010.pdf

12.6.3 Supports for children with disabilities and their families

The same model of supports to access mainstream services applies to all supports for children with disabilities. Supports under education are detailed in Section 8.10. Most children with disabilities live at home with their parents and additional supports are required for parents and families to provide ongoing care. The provision of supports begins with a detailed assessment (see Section 9.2). Assessments carried out under the Disability Act 2005 for children aged 0-5 primarily determine how the disability is likely to impinge on the child's development, and what interventions and supports may be required in terms of addressing health needs.

12.6.3a Respite services

It is a central recommendation of this policy that families should be supported to care for their child at home. Respite services are one of the key supports available to parents/families of children and adults with disabilities. In order to be most effective, respite breaks should be built around the unique needs of each child and be planned in conjunction with the family and the child. An Irish study supported by the National Parents and Siblings Alliance described eight principles of best practice in the provision of respite care¹⁹⁷:

1. That respite services be person-centred and family-centred;
2. That respite services be provided on a rights basis;
3. That respite be defined as a support service and regarded among a system of support services;
4. That there be a single point of access to respite care services in a given administrative area.
5. That respite services be designed in consultation with families in acknowledgement of their expertise in providing care;
6. That respite be designed to facilitate the service user in building relationships in their community;
7. That respite services be age-appropriate and develop as the service user develops
8. That respite care services have clear goals and that systematic and regular review ensure achievement of those goals.

12.6.3b Current provision of respite services

Figures from the two national databases show that in 2008 4,760 people with intellectual disability and 3,150 with a physical or sensory disability availed of respite services¹⁹⁸ (see table 1 Section 2.1). Respite services account for approximately 4% of the disability services budget. The most common type of respite provision is residential provision, provided in a residential centre on a 24/7, 365 day basis. This model of provision is therefore expensive which results in less than ideal coverage for the full range of families who require respite. This model also effectively provides the same level of support to everybody who avails of it and is therefore an inefficient and inequitable targeting of the resource. The most important shortcoming for families is that the rigidity of a residential model creates a vulnerability to sudden capacity shortages triggered by emergencies (such as the death of a

¹⁹⁷ Merriman, B. And Canavan, J. (2007) *Towards best practice in the provision of respite services for people with intellectual disabilities and autism*. National Parents and Siblings Alliance and Child and Family Research Centre National University of Ireland, Galway.

¹⁹⁸ Figures from NIDD 2008: Kelly, F., Kelly, C., Maguire, G. and Craig, S., (2009) *Annual Report of the National Intellectual Disability Database Committee 2008*; and NPSDD 2008: Doyle, A., O'Donovan, M. and Craig, S., (2009) *National Physical and Sensory Disability Database Committee Annual Report 2008*.

sole carer). The consequence of this is that families and carers have low levels of confidence in the reliability of the service to meet its planned commitments¹⁹⁹. The provision of a residential model of respite creates a focus on the part of families and carers for further residential provision (with its attendant drawbacks) and also orients the family to look outside natural networks of support.

12.6.3c Re-framing the provision of respite support

Needs for respite are as varied as the families and carers seeking such support. They can range from a need for parents to get a night's sleep during the week, to finding time and space to focus on the needs of other children in the family, going on a family holiday, parents needing some personal time together on a weekly or monthly basis, ensuring that the person with a disability gets a break from the family home/change of scene, an opportunity for the person to develop relationships outside of the family, weaning the person from an over-dependence on the presence of his/her parents, building friendships for the person and assisting parents to become more relaxed and confident that their son or daughter is safe when not being directly supervised by them. The fixed response from the disability services of a residential place in a staffed respite house/service offers a single and often poorly focused solution to each of these requirements.

Re-framing the provision of respite requires a move away from the language of burden and relief and a much more specific and detailed identification of the actual need. Thus, instead of a straightforward translation of a request to meet the type of need described above into an offer of a 'place' for a night or a weekend, the provider needs to take time to identify the specific need and then to explore the optimum combination of natural supports and provider supports in natural settings (such as contract or host families) to meet this need. Addressing the need in this way brings all the benefits of promoting inclusion, safeguarding the person's future and widening and deepening roles and relationships.

Working with families and natural support networks creates a variety of options and considerable flexibility. One example of such a model is the host family/shared parenting model where the person with a disability can stay with a host family – for example a trained volunteer's family home or a more formal model of shared parenting. This model operates in other jurisdictions (e.g. US) and some services in Ireland have established this type of provision. Several providers offer 'Home Share' services where a family in the local community has a person to stay with them for a number of days per year to provide respite to the family and a new experience for the person. This arrangement has been further developed in some services to provide 'contract families' where families commit to taking a person for up to 20 days per month to provide respite and an alternative to residential placement.

12.6.3d Information

Families consistently report that accessing information about entitlements, services and other aspects of their child's needs, can be a time consuming and difficult process. This may be even more challenging in the diffuse system of supports and mainstream services recommended in this policy. The provision of timely advocacy supports to parents is particularly important (see Section 8.3 on advocacy). The availability of parent-to-parent support for parents of young children, especially following identification of a disability, may be a useful means of presenting the variety of options to

¹⁹⁹ Broderick, B (2010) Personal correspondence

parents who may not be aware of what is possible. The Citizens Information Board, through its network of Citizen Information Offices, is the national agency for providing information, advice and advocacy on social services.

The Internet represents a valuable and cost-effective resource to make a wide variety of information available to people with disabilities and to families and carers of children with a disability. It can also be changed and updated more regularly and simply than paper-based information. All mainstream services and disability serviced providers should ensure that clear accessible information is readily available on all aspects of their services.

12.6.3e Models for the provision of supports to children with disabilities

A central feature of the UK policy *Aiming High for Disabled Children*²⁰⁰, is a 'core offer' which is aimed at empowering children and young people with disabilities and their parents. This core offer encompasses minimum standards on information, transparency, participation, assessment and feedback to make it clear what entitlements and services children and young people with disabilities and their parents can expect. In addition, Individual Budgets are being piloted to give families and young people with disabilities real choice and control to design flexible packages of services which respond to their needs.

12.6.4 The safeguarding and protection of children and young people with disabilities in out-of-home settings

In accordance with the principle of child and family centred practice, supports should be directed at supporting the family in the care of their disabled child, so that the child can remain within their family and avail of universal services. There are, however, instances when this is not possible for a variety of reasons. There are approximately 300 children with disabilities in residential services, some of whom are in the care of the state and others who are receiving out-of-home residential care.

Children and young people with a disability who avail of residential services (including respite) by virtue of their disability, are not legally the responsibility of the HSE and remain the responsibility of their parents. In contrast, children and young people in children's residential centres, special centres and foster care are all in the care of the HSE which assumes the role of "corporate parent" for them²⁰¹. The HSE has certain responsibilities in relation to those children and young people in its care. These responsibilities are currently laid out in the Child Care Regulations 1995. These may be amended or replaced by regulations developed under the Health Act 2007. For children and young people with a disability in residential care by virtue of their disability, these responsibilities remain with their parents, unless the actions of the parents result in a revocation of their responsibilities (e.g. in the case of abandonment).

It is essential that the children currently in such out-of-home settings receive the statutory protections that are accorded to other children in similar settings; however, residential services for children with a disability should not be part of future service provision. Systems for safeguarding

²⁰⁰ Department for Education and Skills (2007) *Aiming High for Disabled Children: Better Support for Families*. <http://www.dcsf.gov.uk/everychildmatters/healthandwellbeing/ahdc/AHDC/>

²⁰¹ Health Information and Quality Authority (2010) *Draft National Quality Standards for Residential and Foster Care Services for Children and Young People*. p.8

children and young people will need to be formulated on the basis of new models of respite and residential support based on host or 'foster' family settings as described in Section 8.6.4c above.

12.6.4a Current situation

The Child Care Act 1991 describes the function of the health authority in promoting the welfare of children "who are not receiving adequate care and protection". The Act goes on to describe the procedures and protections provided to children in this instance. These include provision for family welfare conferences, care planning, regulations for placement with relative, foster care and regulations for residential centres. Arising from the Child Care Act 1991, *National Standards for Children's Residential Centres*²⁰² were developed by the Department of Health and Children and the Social Services Inspectorate in conjunction with the Health Boards. These standards are used for inspecting all children's residential centres both statutory and non-statutory. However, section 59 of the Child Care Act 1991 specifically excludes 'an institution for the care and maintenance of physically or mentally handicapped children' from the definition of a children's residential centre. Therefore, the protections and benefits of the Child Care Act do not currently apply to children with a disability who are in residential care by virtue of their disability. These centres are not covered by the National Standards, nor are they inspected.

National Quality Standards for Residential and Foster Care Services for Children and Young People, including children with disabilities, are currently being developed by the Health Information and Quality Authority (HIQA). It is envisaged that these standards and their core principles will apply to all children availing of such services, including children with disabilities in residential or residential respite services.

When commenced, specific provisions of the Health Act, 2007 will extend the remit of the HIQA to include statutory responsibility for the registration and inspection of designated centres for people with disabilities, including residential and residential respite centres for children with disabilities. Until such time as these provisions are commenced, there is a significant gap in the oversight of residential services for children with a disability.

12.6.5 Recommendations for the Department of Health & Children: Children and Families

The Group strongly recommends that the family be supported to care for the child, young person or adult family member with a disability at home insofar as possible. If this is not possible, it is recommended that children should be placed in a family-like setting. Children with disabilities should not be placed in institutional settings in the future. In this regard, it will be necessary to develop alternative models of respite provision which support the provision of respite in natural, family-based settings. The provision of respite services within institutional settings must also be phased out as these alternatives come on stream.

Notwithstanding this, the Group notes with concern that centres offering residential or residential respite care to children with disabilities are excluded from inspection under the Child Care Act, 1991. It recommends the commencement of the registration and inspection of such centres upon

²⁰² Department of Health and Children *National Standards for Children's Residential Centres*. Stationery Office, Dublin.

finalisation of the *National Quality Standards for Residential and Foster Care Services for Children and Young People*.

13. Joint working areas to support inclusion

13.1 Housing supports

Policy aim

People with disabilities will be supported to live in ordinary independent settings which are fully integrated into their local community.

A variety of options and models of living arrangements should be available, including secure tenancy to a flat/apartment, home-share arrangements and other evidence-informed supported living arrangements. From a point in time to be specified in the implementation plan, public funds should no longer be used to support residential arrangements which segregate people with disabilities from their local community, or residential settings of more than four people with disabilities.

13.1.1 The importance of housing

Housing is an essential element in supporting people with disabilities to be fully included because *“the way we organise housing may restrict choices, make people dependent on family members or may separate or segregate them from their local community if they are placed in institutional care”*²⁰³. The CSO defined housing as *“the base from which people participate in society [which] can reflect as well as dictate their level of participation”*. This definition captures very well the importance of housing in the process of inclusion and self-determination. The focus on living in the community is not just about providing shelter outside of an institution, but fully realising the national objectives in *Towards 2016*. Where you live can dictate your level of participation therefore supporting people with disabilities to live in natural community settings is a key activity in realising the goals of this policy.

Although most people with disabilities live at home with their families, over 9,000 people with disabilities live in group settings that are largely separate from the community. In considering the 56,000 (approximately) people in receipt of services (i.e. those recorded on the NIDD and NPSDD), approximately 17% are in receipt of residential services but these services account for about half of the Disability Services Programme Budget. This limits the amount of resources available to support those living independently or with their families²⁰⁴. Ireland seems to have a higher reliance on out-of-home residential care than other jurisdictions²⁰⁵. For example, in the US, 26% of adults with intellectual disability live in their own homes, 56% in the family home and 18% in out-of-home placements²⁰⁶ (compared to 32% in Ireland).

²⁰³ Report of the Commission on the Status of People with Disabilities (1996) *A Strategy for Equality*. Dublin: The Stationery Office

²⁰⁴ National Disability Authority (2010) Advice paper to the Value for Money and Policy Review of Disability Services Programme.

²⁰⁵ Ibid. NDA 2010

²⁰⁶ Prouty, Alba and Lakin (2008) Residential Services for persons with developmental disabilities: status and trends through 2007, tables 2.8 and 2.9

13.1.2 What are housing supports?

The first requirement for living independently is appropriate, fully accessible accommodation, of a suitable design and type and in a fitting location. The use of aids and appliances, as well as the use of technology, can play a significant role in making accommodation accessible and safe (see Section 8.4).

Sufficient income must be available to the person to pay rent and other costs associated with running their own home. This income will fall within current entitlements such as disability allowance and rent allowance.

Individualised supports have been described in detail in Section 10.3. For many people with disabilities, the provision of sufficient Personal Assistant hours is the main support required to live independently. In addition, home helps, home care assistants and other home-based supports may also be required. Supported living/independent living involves the provision of a flexible range of supports and services, that are tailored to the needs of the individual, and which enable them to live in their *own* home and to fulfil their goals in life with the support and protection they need. *‘These services support people to live as full citizens rather than expecting people to fit into standardised models and structures’*²⁰⁷. There is an essential separation of the provision of housing and the provision of supports; housing should be in dispersed settings²⁰⁸ in the community (as recommended by the *Report of the Working Group on Congregated Settings*²⁰⁹), with individualised supports to enable the person to be fully included in the community and meet their needs and wishes.

13.1.3 Evidence base

There is strong research evidence from many studies and many jurisdictions which supports community-based, supported living arrangements²¹⁰. 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”*.²¹¹ The evidence also shows that the overall costs for community-based living arrangements are generally the same as institutional residential settings, i.e. community-based living is not a ‘cheaper’ option. However, the *cost-effectiveness* of community-based arrangements is at least the same and usually better as the outcomes for the person are superior to those achieved in institutional settings.²¹²

²⁰⁷ 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.

²⁰⁸ Dispersed housing means apartments and houses of the same types and sizes as the majority of the population live in, scattered throughout residential neighbourhoods among the rest of the population.

²⁰⁹ June 2010 *Report of the Working Group on Congregated Settings*

²¹⁰ National Disability Authority (2010) Advice paper to the Value for Money and Policy Review of Disability Services Programme.

²¹¹ Directorate-General for Employment, Social Affairs and Equal Opportunities (2009) *Report of the Ad-Hoc Expert Group on the Transition from Institutional to Community-based Care*. European Commission.

²¹² 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.

13.1.4 Supports for families

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.

A relatively small amount of the overall Disability Services Programme Budget is used to support families who have a member with a disability living at home (about 4%²¹³). This is largely because of the amount spent on out-of-home placements (i.e. residential services). Ireland is not unique in this regard, although changes are occurring in other jurisdictions. For example, in New Zealand the focus of increased funding has been on providing support for carers. Victoria, Australia, has put funding into individualised support packages²¹⁴.

It is proposed that a person living in the family home should also have access to individualised support packages, although the components may vary depending on the level of input families can make. Specific support for carers such as breaks (respite – covered in more detail in Section 8.6.3) are also key to supporting families.

13.1.5 Models of Supported living/living independently

Some people with disabilities would like not to be dependent on their families or would prefer the independence of living in their own home, either alone or sharing with others²¹⁵ (it should be noted that living independently does not necessarily mean living alone). Policy and service provision in many countries is moving increasingly in the direction of ‘supported living’ or ‘independent living’ for people with disabilities and mental health difficulties and away from the provision of ‘residential care’.

Several studies have described the fundamental principles that determine the success of supported living as:^{216,217}

- *The separation of buildings and support* – level of support should not be determined by the type of building a person lives in but by their needs and choices. Support should follow the person;
- *Access to the same options as everyone else* – as equal citizens, people with disabilities and mental health difficulties should have access to the same housing options as everyone else;
- *Zero Rejection* – nobody should be seen as ‘too disabled’ to live in their own home;
- *Choice and control for the disabled person and their representative* - supports are organised on the principle that the person should have, and be supported to have, as much control over supports as possible;

²¹³ National Disability Authority (2010) *Advice paper to the Value for Money and Policy Review of Disability Services*. Dublin: NDA.

²¹⁴ Ibid. NDA 2010

²¹⁵ June 2010 *Report of the Working Group on Congregated Settings*

²¹⁶ Joseph Rowntree Foundation (1997) *The Early Years of Supported Living*. Social Care Research Findings. Joseph Rowntree Foundation, York.

²¹⁷ Klein, J. (1994) *Supported Living: Not just another rung on the continuum*, TASH newsletter, 20, 16-18.

- *Focusing on individuals* – by moving away from the model of group home and using detailed person-centred planning to provide services that are genuinely individualised;
- *Focusing on relationships* – People’s links (their families, friends and community) are the starting point in designing supports, not an afterthought. Through the use of ‘support tenants’ (who share the home with the disabled person and can provide assistance if necessary) and circles of support, people’s relationships are kept at the forefront.

Supported living arrangements can be provided in singular or shared dwellings. Supported living properties are typically owned by housing associations which provide both the property and housing management services (such as furniture, gardening, heating, lighting etc.) under an assured tenancy²¹⁸. The tenancy of supported living residents ensures their security of tenure. Various funding and contractual arrangements can be in place with local authorities, although in most cases the property is specifically identified as a residential property for supported living. Initial evaluations of supported living suggest that it provides greater opportunities for choice and community participation^{219,220} and is more economical given the lower staffing costs²²¹.

Several models of supported living or housing supports are in place in many countries. For example:

- *Co-tenanting in public and community housing* – this is an arrangement where a person with a disability accessing public or community housing chooses to share his or her home with a non-disabled person (described as ‘support tenants’). This model is used in several states in Australia and has been in place for 15 years in some states. There is evidence of the success of this arrangement, which has been shown to mirror similar arrangements in society. This model is also used to a limited extent in some services in Ireland;
- *Responsive Landlord* – this model²²² provides tenancy support for people with disabilities who are in public housing but require support that is additional to property management. It consists of an inter-agency arrangement between the housing provider, the support provider (provides non-tenancy support) and the ‘responsive landlord’ (an agency which provides specific tenancy support such as budget management, paying rent, maintenance etc.);
- *Housing cooperatives* – a Canadian model is cited as a good example of this arrangement²²³, where a cooperative was formed to run a government housing development. Six people with

²¹⁸ National Disability Authority (2010) Advice paper to the Value for Money and Policy Review of Disability Services Programme.

²¹⁹ Emerson E, Roberston J, Gregory N, Hatton C, Kessissoglou S, Hallam A, Jarbrink K, Knapp M, Netten A, & Walsh PN., (2001). Quality and costs of supported living residences and group homes in the United Kingdom. *American Journal on Mental Retardation*, **106**, 5, 401-15.

²²⁰ Howe J, Horner RH, & Newton JS, (1998). Comparison of supported living and traditional residential services in the state of Oregon. *Mental Retardation*, **36**, 1, 1-11

²²¹ Stancliffe, R., & Keane, S., (2000). Outcomes and costs of community living: A matched comparison of group homes and semi-independent living. *Journal of Intellectual & Developmental Disability*, **25** (4) 281-305.

²²² Department of Disability, Housing and Community Services (2006) *Minister’s Housing Advisory Forum. Housing for People with a Disability: Discussion Paper*. www.dhcs.act.gov.au/__data/assets/word_doc

²²³ Deohaeko Support Network

www.smartcarefoundation.com/docs/pdf/Deohaeko%20Support%20Network.pdf

disabilities were included in this cooperative which had 105 units. These individuals receive the mutual support of the cooperative and are residents with full rights in running the cooperative.

- *Community networks* - Programmes such as *KeyRing Supported Living Networks*²²⁴ in England and *Neighbourhood Networks* in Scotland, emphasise mutual aid as a key feature of their supported living model. KeyRing works by providing assured tenancies to local authority housing to ten people in a network in a small neighbourhood. Nine flats or houses belong to 'vulnerable or excluded people'. The tenth property is occupied by KeyRing's Community Living Volunteer (CLV) who supports the network members on a flexible basis. This volunteer is supported by a KeyRing Supported Living Manager who also gives direct support to network members around more complex issues (see Section 8.5.1).
- *'Home Providers'/Foster homes* - The state of Vermont in the US has no institutional care for people with disabilities since 1993. Currently, most people with disabilities either live with their family (receiving a variety of supports) or live with 'Home Providers'. Home Providers is an individualised model of support where members of the community share their homes with a person with a disability. There is a contractual relationship with a provider agency, whereby tax exempt reimbursement is made to the person sharing their home. Over 40% of people with disabilities in Vermont live in this arrangement. Support for Home Providers is arranged through support managers with a caseload of 8-12 Providers. Support managers provide 24 hour on-call crisis response, frequent monitoring and assistance and respite supports tailored to individual client needs.
- *'Shared parenting'* - this model has been developed in Vermont to provide support to families caring for a child with intensive needs. This offers an alternative for families who otherwise would not be able to keep their children at home. In this model a child may spend alternate weeks or weekdays with a Home Provider. Providers have responsibility to provide 24 hour support and participate as a member of an individualised support team for the person with a disability. Thorough screening is carried out, relevant training is provided and there is careful matching of the two families.
- *'Safety connection'* – Also in Vermont State, a model called 'Safety Connection' has been developed for people with disabilities who are living alone. This model makes innovative use of technology, community members and professional staff to provide support. A variety of monitoring/communication devices are placed in the person's home as appropriate (for example, personal 'alert buttons' that can be worn by the person). Two members of the community monitor these systems for a number of clients from 9pm to 7am. Professional staff ('Responders') are available if required. The monitoring system uses protocols, support plans and medical information to ensure appropriate monitoring and responses.

²²⁴ www.keyring.org KeyRing is a charity which works with health, social and housing services. The organisation has enabled over 600 people to lead independent lives in the community in various locations in England.

13.1.6 Responsibility for housing supports

13.1.6a Housing

Legislation and policy pertaining to housing comes from the Department of the Environment Heritage and Local Government. A cross-departmental housing strategy for people with disabilities is nearing completion and will inform the joint working areas arising from the policy goals.

The Housing Act 1988 specifies the responsibilities of local authorities to provide housing for homeless persons, who are defined under the Act as follows; *“if there is no housing the person can reasonably occupy, or if he or she is living in a hospital...or institution and has no accommodation he or she can reasonably occupy, and is unable to provide accommodation from his/her own resources”*.

Housing associations offer an important mechanism for those interested in providing independent housing options to people with disabilities, including current providers within the disability sector, to offer tenancies to people with disabilities. An Irish Council of Social Housing survey²²⁵ (ref 2007) showed that housing associations are providing more than 2,000 units for people with disabilities, with wide variation in numbers around the country. Just over half of these house people with intellectual disability and one quarter are for people with physical disability. It should be noted that a significant number of these Housing Associations were set up by disability services to address a need in this area and many are still run by disability services.

An important feature of housing associations is the provision of *“...practical and functional supports to tenants which facilitates them to live independently in the community. Health personal and social supports are often as important as the housing provision”*²²⁶. The survey also highlighted challenges raised by respondents which included; the importance of a housing need assessment in providing a gateway to people with special needs to access social housing; funding limits for adaptations including assistive technologies and greater consideration given to lifetime adaptable housing.

13.1.6b Housing adaptations

Assistance with adapting a home can be key to enabling a person to remain in their own home. Under the Department of Environment, Heritage and Local Government (DEHLG) Statement on Housing Policy (Delivering Homes: Sustainable Communities, 2007) a new grant scheme was introduced to address the shortcomings in the previous scheme. People with a disability can now apply to their local authority for a Housing Adaptation Grant or a Mobility Aids Grant (mainly for older people with a disability). In 2007, some 10,393 houses were adapted²²⁷.

13.1.6c Other supports

The provision of other personal and social supports will be addressed by the appropriate authority, such as the provision of personal assistant, home help and other personal social services required to live independently.

²²⁵ Irish Council for Social Housing (2007) *Enhancing Choice for People with Disabilities in the Community*. ICSS Policy and Research Series.

http://www.icsh.ie/eng/services/publications/icsh_publications/enhancing_choices_for_people_with_disabilities_in_the_community

²²⁶ National Economic and Social Council (2009) *Well-being Matters: A Social Report for Ireland*. Dublin: NESC p.283

²²⁷ www.environ.ie

13.1.7 Learning from other jurisdictions

Based on the experience in several countries and a review of the research evidence A European Commission Expert Group has summarised the key challenges in transitioning from institutional care to community-based settings²²⁸. These challenges include;

1. **Over-investment in current institutional arrangements:** For example, a common response to poor quality care in institutions is to improve physical conditions as a short term 'emergency response'. However, this type of response can distract attention and resources from necessary systemic change and make it more difficult to close institutions in the medium term.
2. **Risk of maintaining parallel services:** A build up of alternatives to institutional care without the progressive closure of institutional provision creates an unsustainable situation in several regards; a number of service users remain in institutional care without tangible improvement of their living situation; people with severe disabilities/complex needs can be 'left behind'; 'additional needs' may be generated, where because of insufficient transfer of service users from institutions, new services absorb other potential users who may initially have had little need for them and finally, **long-term** double expenses are economically unsustainable. New allocation models are required so that alternatives to institutional provision can be created and supported while the institutions are closed. It is important to acknowledge that 'hump costs' (initial investment in community facilities to get them underway) as well as double running costs will be required during the transition period. A clear end-point for the transition period must be agreed to avoid long-term double funding. However, many of the accommodation supports described above are not capital intensive. It is important not to create a set of (expensive) mini-institutions but to create tailored individualised supports for each person.
3. **Creating alternatives that are "too institutional":** The experience has been that if service users and their families/advocates are not sufficiently involved in the planning of alternatives to institutional provision, alternatives can be created which are not based on the individual's needs and preferences and therefore are too similar to the institution. They may be too large, they may be based beside or even within the original institution and they often perpetuate an institutional culture. These are often called 'mini-institutions'. The effect is that service users continue to live in segregated settings, with little control over their own lives, little participation in the community and few valued social roles. The language is important as a transition to 'community-based **care**' risks the creation of mini-institutions in the community. What is required is not residential **care** or residential **service**, but individualised supports to enable the person to live in the community in their chosen living situation. This may be on their own, in a 'house share', in a family situation or any variety of options.
4. **Closure without adequate alternatives:** Targets for deinstitutionalisation need to be chosen carefully as take account of the capacity of the authorities to develop appropriate alternatives and to closure as a 'cost-cutting exercise'. Where the driving force is the intention to cut costs sufficient finances are often not available to carry out the process in a

²²⁸ Directorate-General for Employment, Social Affairs and Equal Opportunities (2009) *Report of the Ad-Hoc Expert Group on the Transition from Institutional to Community-based Care*. European Commission.

way that ensures each individual receives adequate, individualised supports. A failure to create a range of alternatives for accommodation supports can also result in those who are 'easiest to place' being moved first, while people with more complex/high support needs can be left behind.

13.1.8 Recommendations for the Department of Health and Children

In accordance with the vision of this policy, the most immediate priority for housing supports is the almost 4,000 people with intellectual disability living in congregated settings (a residence of ten or more beds). To progress this goal, an end date for admissions to congregated settings must be identified and no new congregated settings developed. A closure date for congregated settings must also be identified.

The Group recommends that the development and choice of alternative housing should be based on research evidence on what is most effective. Dispersed, 'ordinary' living situations in community settings are preferable to clustered, 'special' housing. Alternative housing options should have a maximum of four people with disabilities. New housing options should fully embrace the principles of supported living (Section 8.6.5) and should be a separate part of the 'package' of supports which include supports for inclusion and participation.

As the provision of supports should be separate from the provision of housing, it is recommended that in the future, disability services no longer establish and run Housing Associations. It is also recommended that a small working group be established to map the current properties in this category and to determine how they might work in the envisaged mainstream model proposed. The recommendations of this group should be taken into consideration in the implementation planning.

As part of the wider implementation plan for all the policy goals, the Group notes that a detailed implementation plan will be needed for the deinstitutionalisation of congregated settings and the provision of housing.

13.1.9 Recommendations for Cross Sectoral Working: Housing

The Group notes that the Department of the Environment, Community and Local Government is currently finalising a Housing Strategy for People with Disabilities. It is essential that the ODMH work with appropriate sections in this Department to identify areas of joint working and to formulate protocols to ensure the policy goals are realised.

13.2 Employment supports

There has been a long tradition of low expectations in society regarding the possibility of employment for people with disabilities; *“The traditional message sent to people with disabilities, whenever in life that disability is acquired, is that they are unlikely to be economically productive and likely to be economically dependent”*²²⁹. Other factors such as the benefits trap, inaccessible workplaces or lack of transport also restrict the chances of having a job²³⁰. The result is that people with disabilities are far less likely to have a job than others of the same age. The policy goal relating to employment for people with disabilities is based on that expressed in *Towards 2016* and profoundly changes the expectations for people with disabilities in relation to employment for the future:

Policy aim

Every person with a disability will have the opportunity and support to pursue and obtain employment and training in line with their wishes, needs and abilities.

13.2.1 Meaningful occupation

There are approximately 25,000 people currently in adult day programmes funded by the HSE²³¹. There may be others with broadly similar support needs who are currently outside this service framework. When considering this cohort of people, the concept of meaningful occupation is potentially a more useful goal than full open employment (if by employment we mean a 9-5 job in a competitive setting). Meaningful occupation includes all forms of employment but is broader than employment, including jobs with a very limited number of hours (for example two hours per day), volunteering, supported work in the community, job placements and other occupation.

Being at work or engaged in meaningful occupation conveys many benefits to the individual. While an income is an obvious benefit of employment, the intangible benefits of occupation are also very important. For the individual, access to work or meaningful occupation is associated with higher levels of autonomy, health and well-being and social networks. Essentially, being engaged in meaningful occupation provides a valued social role for the person and is an essential element of how the person is viewed by those around him/her and society at large. Participation in work also has wider benefits for the community, contributing to the economic and social development of local communities and the country as a whole. It is for this multiplicity of benefits that providing access to and supports for meaningful occupation, including employment, can be critical for people with disabilities²³².

²²⁹ National Disability Authority (2006) *A Strategy of Engagement: Towards a comprehensive employment strategy for people with disabilities*. Dublin: NDA

²³⁰ Ibid. NDA 2006

²³¹ Health Service Executive (2009) *New Directions: Personal Support Services for Adults with Disabilities*. Dublin: HSE.

²³² Wynne, R., & McAnaney, D. (2004). *Employment and disability: Back to work strategies*. Dublin: The European Foundation for the Improvement of Living and Working Conditions.

13.2.2 What do we mean by employment supports?

The rationale behind all employment supports is to enable people with disabilities to be engaged in meaningful occupation in whatever way suits their capabilities, wishes and needs. The starting point for the provision of employment supports is a holistic assessment of the person's needs, preferences and capabilities. This process is described in Section 9.2 on needs assessment, and it leads to the description of a package of individualised supports which will include employment supports. For example, there are elements of practical assistance an individual may need to access employment, such as Personal Assistant (PA) hours and transport (see Section 8.2.5). Many people with physical disabilities already use these supports to access their jobs. Under mainstreaming, these supports will be provided by the appropriate government department or agency.

The availability of a wide range of options, and flexibility within those options will be essential to ensure people with all levels of disability can participate. Those with more severe disabilities may need a greater level of support both from health and employment agencies. Employment supports programmes should not contain restrictions which in practice exclude people with higher support needs. Some job-readiness or minimum hours criteria restrict their usefulness for many people with disabilities.

A pre-requisite for people with disabilities to taking part in employment and training is that places of work and training be fully accessible. Accessibility means more than just physical accessibility. Information and the means of accessing information (such as Information Technology) must also be accessible. Accessible transport is also needed to get to and from a place of work (more detail in section 8.2.5).

13.2.3 Models of employment supports

An analysis of the type of work and activity undertaken by the 25,000 people currently in adult day programmes provides an indication of what models of support are potentially useful.²³³ The programmes fall into three broad categories; employment programmes (approximately 2,000 service users), work/like work programmes (approximately 6,000 service users) and activity programmes (e.g. educational, training and community integration activities). All 25,000 service users participate in some element of the activities programmes as well as being involved in the more structured employment and work programmes.

Possible forms of employment supports for people with disabilities would come under the following four broad headings:

1. **Supported employment:** enables people with disabilities to access real employment opportunities, of their choice, in an integrated setting with appropriate ongoing support being provided to enable them to become economically and socially active in their communities. Supported Employment provides support to job seekers with disabilities and their employers and co-workers. The support given allows individuals with disabilities to become and remain gainfully employed. People with a wide range of disabilities e.g.

²³³ Health Service Executive (2009) *New Directions: Personal Support Services for Adults with Disabilities*. Dublin: HSE.

physical, sensory and intellectual disabilities as well as people with mental health difficulties, have become successfully employed using the Supported Employment Model²³⁴.

2. **Employment under the wage subsidy scheme:** The Wage Subsidy Scheme (WSS) objectives are to:

- facilitate people with disabilities to enter full-time paid employment in the labour market;
- encourage employers, in both sheltered and mainstream settings, to employ people with disabilities; and
- give people with disabilities the opportunity to experience open labour market employment.

To qualify for the WSS, employees must work for at least 21 hours per week. They must also be subject to the same conditions of employment as other employees²³⁵.

3. **Supported work in the community** (similar to Community Employment Schemes)

4. **Other integrated activities in the community**

13.2.3a Supported employment

Supported employment is a set of methodologies designed to get the best fit between an individual and a job. This process is based on an individualised assessment of the strengths, requirements and interests of a person and matching those to the needs of an employer. One of the ways of matching needs is through various methods of 'customising' a job, such as:

- Job carving – creating a job from one or more but not all of the tasks of the original job;
- Job negotiation – creating a new job from various tasks from parts of several jobs;
- Job creation – creating a new job based on unmet workplace needs;
- Job sharing – two or more people sharing the same job;
- Self-employment – including use of a micro-enterprise.

A seven year study in the US evaluated a customised/supported employment programme²³⁶. Three quarters of the study participants (people with intellectual disability and people with mental health difficulties) achieved employment outcomes, with 73 participants obtaining open employment in jobs which had been negotiated as part of customised employment, 59 in self-employment and nine in open employment using a supported employment approach. The overarching conclusion of this study emphasised the possibility of customising a job in any employment situation;

“Simply put, it is human resource management at its best and most effective. It is not a process driven by disability. Customizing employment ensures a good job match for the individual since it

²³⁴ http://www.iase.ie/pages/about/about_supported_employment.html

²³⁵ Goodbody Economic Consultants (2008) *Review of the Wage Subsidy Scheme*. Dublin: Goodbody. <http://www.deti.ie/publications/labour/2008/review-wage-subsidy-scheme-may08.pdf>

²³⁶ Citron, T., Brooks-Lane, N., Crandell, D., Brady, K., Cooper, M and Revell, G. (2008) A revolution in the employment process of individuals with disabilities: Customised employment as the catalyst for system change. *Journal of Vocation Rehabilitation*, 28, 169-179.

begins with the focus person’s passion. When an individual is engaged in economic pursuits of their interests, there is assurance that both the employee and employer benefit.” ²³⁷

13.2.3b Support for employers

The NDA in its publication on employment²³⁸ emphasised the importance of engaging with employers. One of the ‘strategic pillars of engagement’ is *“Ensuring that both the public and private sectors are aware of the capabilities of people with disabilities and on that basis, implement policies to support the recruitment and retention of people with disabilities”*²³⁹. The following table captures where the change required to move to individualised supports for meaningful occupation.

Table 3: Summary of change required

From	To
Recipient status	Participant status
Passive maintenance	Active support
Dependence	Independence
Labelling as unemployable	Identification of work skills
Disincentive	Incentives to seek employment (and volunteer opportunities)
Insufficient employment supports	Opportunity to develop skills and experience
Insufficient portable benefits and services	Portable benefits and services
Multiple access requirements	Integrated access requirements

Source: NDA – A Strategy of Engagement – Towards a comprehensive Employment Strategy for People with disabilities (2006)

13.2.4 Responsibility for employment supports

13.2.4a Unbundling health and employment supports

Persons currently using HSE provided employment and training services receive their health and social supports and employment-related supports as an unbundled package. For some people this may results in unnecessary duplication of supports already provided agencies such as FAS and its disability-related programmes, Local Employment Services and those provided by the Department of Social Protection, such as job facilitators. The provision of personal social supports will be unbundled from the provision of employment supports so that all people with disabilities can receive supports from the relevant Government Departments and agencies in mainstream settings. Thus the support a person needs by virtue of their disability to access employment, such as a personal assistant, is a personal social support, while support from a job coach is an employment support. However, support arrangements should be made in a way that avoids unnecessary duplication and provision of support from multiple persons during the day, while meeting the needs of the person in the most effective way.

²³⁷ Ibid. Citron, T., Brooks-Lane, N., Crandell, D., Brady, K., Cooper, M and Revell, G. (2008) p.179.

²³⁸ National Disability Authority (2006) *A Strategy of Engagement: Towards a comprehensive employment strategy for people with disabilities*. Dublin: NDA

²³⁹ Ibid. National Disability Authority (2006) p. 22

13.2.4b Welfare benefits

The current structure of the welfare system promotes dependency and “*effectively acts as a passive maintenance mechanism*”²⁴⁰. It encourages economic *inactivity* by making it difficult to move from welfare dependence to economic independence. Some of the factors which influence this include the lack of recognition of the cost of disability (i.e. extra costs incurred such as having to get an accessible taxi if there is no access to accessible public transport), the lack of flexibility to allow for partial capacity to work and the loss (or possible loss) of certain benefits on taking up employment and increasing income.

13.2.4c Monitoring employment of people with disabilities

Under the Disability Act 2005 there is a requirement on public bodies to employ a minimum quota of 3% of people with disabilities. The NDA has reported that in 2007 just over half of public service organisations (51%) had achieved this target, up from 36% in 2006 (ref NDA monitoring reports). Overall, the organisations which responded to the NDA monitoring request had a workforce of 238,833 of which 2.5% were reported as having a disability. It should be noted that monitoring the employment of people with disabilities is ‘fraught with difficulties’ including defining disability, disclosing disability and promoting a positive environment for people with disabilities. The NDA found a direct link between certain proactive activities such as having a specific policy on employing people with disabilities, as resulting in organisations being more likely to achieve or exceed the 3% employment target. The presence of access audits was also found to be strongly associated with the employment of people with disabilities.

13.2.5 Recommendations for Cross Sectoral Working: Employment

High-level leadership and clear procedures are needed to drive collaborative working arrangements and the cultural changes needed to deliver on this policy goal effectively. Local level collaborative arrangements and protocols will be required between FÁS/relevant training agencies and the HSE to ensure that the individual experiences a seamless delivery of the required supports.

The Group recommends that ODMH work with relevant Departments and agencies to identify opportunities for joint working and to develop appropriate protocols at local level and Departmental level to ensure that people with disabilities will have the opportunity and support to pursue and obtain employment and training in line with their wishes, needs and abilities. The Sectoral Plan for the Department of Jobs, Trade and Innovation will be an important mechanism for the alignment of actions in this area and for progressing prioritised actions.

²⁴⁰ National Disability Authority (2006) *A Strategy of Engagement: Towards a comprehensive employment strategy for people with disabilities*. Dublin: NDA

13.3 Health

Policy aim

Individualised supports will be available to facilitate people with disabilities access the mainstream health services most appropriate to their needs. People with disabilities will have access to specialist services as required.

Mainstream health services in this instance include health promotion, primary care, acute services and services for long-term health conditions.

Good health is a fundamental element of wellbeing. There is a complex relationship between health, disability and quality of life. Like everyone, people with disabilities need to use health facilities such as GP surgeries, dentists and opticians, Emergency Departments, out-patient and inpatient hospital services. However, some people with disabilities are more susceptible than the general population to health conditions that are secondary to their disability²⁴¹ (such as respiratory tract infections). As a result people with disabilities may have greater health needs than the general population. For example, 14% of adults with disabilities described their health as 'poor' compared with less than one per cent of non-disabled adults²⁴². Increased longevity in people with disabilities can also result in a greater level of health needs. For example, persons with Down Syndrome are at increased risk of developing Alzheimer's Dementia as they age. The interaction of older age, associated health problems and disability can present more complex needs which will challenge support systems.

13.3.1 Primary health care services

For the majority of people, primary care is the first point of contact with the health services, and the means of accessing other parts of the health services such as hospital-based specialists. The Primary Care Strategy: *A New Direction* states that "primary care is the appropriate setting to meet 90-95% of all health and personal social service needs" and that primary care should be "readily available to all people regardless of who they are, where they live, or what health and social problems they may have"²⁴³.

Primary care is routinely provided at local level to people living in the community and encompasses a wide range of health services delivered by a variety of professions. The provision of primary care is wider than those services available from a GP in a surgery and includes the range of services that are currently provided by others such as public health nurses, social workers, dentists, physiotherapists, occupational therapists, home helps, health care assistant, chiropodists, community pharmacists and others.

Although people with disabilities tend to have greater health care needs than the general population, research from elsewhere has shown that they tend to consume less primary health care

²⁴¹ Kinne, S., Patrick, D. & Doyle, D.L. (2004) Prevalence of secondary conditions among people with disabilities. *American Journal of Public Health*, **94** (3), 443-447.

²⁴² SLAN (2002) National Health and Lifestyle Survey <http://issda.ucd.ie/documentation/slan/slan02-questionnaire.pdf>

²⁴³ Department of Health and Children (2001) *Primary Care Strategy: A New Direction*. Dublin: Stationery Office, p. 7.

services²⁴⁴. While preventative health care is one of the main functions of primary care, for people with disabilities primary care often concentrates on underlying debilitating disorders to the exclusion of preventive health concerns²⁴⁵.

For many people in receipt of disability services, their experience of accessing universal health services is quite different to that of the wider population. Some service providers have a contract with a local GP to provide primary care health services to all those in a residential service, for example. Thus people in receipt of disability services may not be registered with a GP, may not have a medical card (even if they are eligible for one) and may have limited access to the wider preventive and curative services that are provided in the wider primary care network.

In general, people in receipt of disability services have access to a variety of specialist health inputs from multidisciplinary team members employed by the service provider. However, people with disabilities who may require such inputs, but who are not receiving services from a service provider, cannot access these specialist health inputs, even if they live in the same locality.

Thus, for people in disability services, health services tend to be provided as part of the 'bundle' of services from the provider (see Section 2.1.1). This can result in specialist provision for some, with limited access to universal primary health care services, with a corresponding lack of specialist provision for others who may need it.

13.3.1a Accessibility in primary care

People with disabilities interviewed for an Irish study thought that the attitudes of health care staff towards people with disabilities were a major barrier to accessing health information, which resulted in not being given choices about managing their health. Most people in this study saw receptionists as 'gatekeepers' who created a barrier to then accessing that service²⁴⁶. Examples of physical barriers included reception counters being too high or the presence of glass between the receptionist and the person can cause communication problems for people with disabilities. For example, a deaf person who cannot see the receptionist's face cannot lip read. People reported sitting and waiting for their appointment as 'intimidating' and preferred the doctor to come out and bring the patient to their room. Participants said their doctor tended to focus on their disability instead of the ailment they presented with and many spoke of the doctor talking to the person accompanying them instead of directly to them²⁴⁷.

13.3.2 Dental services

Oral health is central to the health and well being of people with disabilities. Good oral health can promote communication, good nutrition, self-esteem and quality of life and lead to a reduction or elimination of pain. Poor oral health – bad breath, overcrowded teeth or unsightly decay – can

²⁴⁴ Fouts, B.S., Andersen, E. & Hagglund, K. (2000) Disability and satisfaction with access to health care. *Journal of Epidemiology and Community Health*, **54**, 770-771

²⁴⁵ D'Eath, M., Sixsmith, J., Cannon, R. and Kelly, L. (2005) *The Experience of People with Disabilities in Accessing Health Services in Ireland: Do Inequalities Exist?* Report to the NDA, Centre for Health Promotion Studies, National University of Ireland, Galway.

²⁴⁶ D'Eath, M., Sixsmith, J., Cannon, R. and Kelly, L. (2005) *The Experience of People with Disabilities in Accessing Health Services in Ireland: Do Inequalities Exist?* Report to the NDA, Centre for Health Promotion Studies, National University of Ireland, Galway.

²⁴⁷ Ibid. D'Eath, M., Sixsmith, J., Cannon, R. and Kelly, L. (2005)

reduce a person's ability to consume nutritious food, affect self image and confidence and cause significant pain, which a person with a disability might not be able to communicate. Good oral health empowers people with disabilities to face the world with more confidence, promoting their participation and contribution²⁴⁸.

An Irish study reported major concerns about dental service provision among parents and carers of people with disabilities²⁴⁹. These concerns centred around a lack of information and support in promoting optimum oral health and a lack of confidence in their ability to access dental services on behalf of their family member. Barriers identified by respondents included a lack of sensitivity to the poor tolerance of waiting times by some people with disabilities; and lack of physical access requirements such as a hoist to transfer mobility impaired persons. The findings of comparatively poor dental health among people with disabilities when compared to the rest of the population "*flag an area where people with disabilities have needs which are no different to anyone else, but where many have been effectively bypassed by the mainstream services. Dental services are unlikely to be unique in this respect*"²⁵⁰.

13.3.3 Secondary health care services

Secondary services are usually provided in hospital settings such as outpatient clinics and emergency departments. However, secondary services are also increasingly provided in community settings such as mental health services and some services for chronic conditions like diabetes. Access to secondary health care services is usually by referral from a GP so limitations on access to a GP can create a barrier to accessing secondary health services.

Experiences of emergency departments were varied with some people reporting positive experiences and others reporting significant difficulties with accessibility (lack of hoists for transfer to examination table), lack of understanding of disability with consequent negative attitudes on the part of some staff²⁵¹. Waiting times in Emergency departments were also an issue as some people with intellectual disability cannot tolerate waiting around for long periods. Others described having to go to a busy A&E for a routine and recurring problem (such as a problem with a catheter) and waiting for hours for a five minute procedure²⁵².

13.3.3a Mental health services

The NDA *Review of Access to Mental Health Services for People with Intellectual Disability*²⁵³ described a poor level of service for people with intellectual disability and mental health difficulties

²⁴⁸ National Disability Authority (2005) *Oral health and disability: The way forward*. Dublin: NDA. [http://www.nda.ie/Website/NDA/CntMgmtNew.nsf/0/4739AF522B1865EC8025707B004C4015/\\$File/NDAOralHealth.pdf](http://www.nda.ie/Website/NDA/CntMgmtNew.nsf/0/4739AF522B1865EC8025707B004C4015/$File/NDAOralHealth.pdf)

²⁴⁹ Taylor-Dillon, F., Friel, S. Sixsmith, J. & Kelleher, C. (2003) *A Review of Oral Health Promotion/Education Activity in the Republic of Ireland and a study of attitudes, knowledge and behaviour of special needs groups towards oral health*. Commissioned by The Department of Health and Children.

²⁵⁰ National Disability Authority (2004) *How far towards equality? Measuring how equally people with disabilities are included in Irish society*. Dublin: NDA

²⁵¹ Ibid. D'Eath, M., Sixsmith, J., Cannon, R. and Kelly, L. (2005)

²⁵² D'Eath, M., Sixsmith, J., Cannon, R. and Kelly, L. (2005) *The Experience of People with Disabilities in Accessing Health Services in Ireland: Do Inequalities Exist?* Report to the NDA, Centre for Health Promotion Studies, National University of Ireland, Galway.

²⁵³ National Disability Authority (2003) *Review of Access to Mental Health Services for People with Intellectual Disability*. Dublin: NDA

in the community, while those registered with a service provider could only access mental health services if there was a psychiatrist within that provider. However, this was a segregated service and people did not enjoy the same range of mental health services that were available to the general population. The national mental health policy *A Vision for Change* recommended that *“The process of service delivery of mental health services to people with intellectual disability should be similar to that for every other citizen”* and that mental health services for this group should be provided by community-based mental health teams with expertise in intellectual disability and available to the population within defined catchment areas²⁵⁴.

13.3.4 Tertiary health service provision

Tertiary health services refer to the provision of care to people as inpatients in hospital settings. A striking finding of the Irish study on people with disabilities accessing health services was that advocates or carers of people with intellectual disabilities were *“required to provide twenty-four hour care to their clients as a condition of their admission to hospital whether the admission was for routine procedures or through the Accident and Emergency department. It was stated that without this commitment from family, and/or carers, a person with an intellectual disability would be denied hospital admission irrespective of their actual support needs.”*²⁵⁵ Communication, attitudinal and environmental barriers were also part of the experience of hospital admission for many.

13.3.5 Disability-proofed health services

Although there is an expectation that health services would be leaders in terms of accessibility, positive attitudes and adaptations for the needs of people with disabilities, this is not generally the experience for some;

*“A health service is not a co-ordinated, inclusive, person-centred service where health professionals will walk away from a person with communication difficulties rather than attempt to communicate with them; where no one has responsibility to ensure that an inpatient who is blind knows that their meals have arrived; where professionals demand that a person with an intellectual disability is accompanied at all times by a carer without regard to the person’s individual need for support and without regard to the impact that tying up a support person may have on other people who share the same support resource. It is also a system that removes from health professionals the obligation to become aware of issues concerning both individuals with a disability and intellectual disability”*²⁵⁶.

These were some of the experiences reported in the qualitative study concerning the experience of people with disabilities in accessing health services in Ireland carried out in 2005. Many of these experiences are not exclusive to people with disabilities and are common to much of the population. There is inadequate provision in many areas for all (e.g. speech and language therapy). Similarly, health services are fragmented for all and many services are more readily available to those who have the means to pay for them. However, the consequences of these deficiencies are much greater for people with disabilities as they are contending with additional disadvantage and these services

²⁵⁴ Department of Health and Children (2006) *A Vision for Change. Report of the Expert Group on Mental Health Policy*. Dublin: Stationary Office

²⁵⁵ Ibid. D’Eath, M., Sixsmith, J., Cannon, R. and Kelly, L. (2005) p. 80

²⁵⁶ Ibid. D’Eath, M., Sixsmith, J., Cannon, R. and Kelly, L. (2005) p. 5

are vital to their optimal functioning and participation in society. Similarly, service fragmentation impacts disproportionately on people with disabilities who may have multiple complex needs.

The degree of fit between people with disabilities and the health service was described as ‘poor’ and a range of adaptations were required to compensate for this. The study found that “the system is generally rendered accessible only with considerable support from friends and relatives and from the informal goodwill of individual health workers who try to personally compensate for the deficiencies, inefficiencies and injustices of the system”²⁵⁷.

13.3.6 Requirements for a disability-proofed health service

Individualised supports, as described in Section 10.3, will be available to support people with disabilities in accessing universal health services. However, fundamental changes are required in how health services are provided to people with disabilities;

“Substantial action needs to be taken by all stakeholders to realise the mainstreaming of provision, reorientation of services towards a social model of disability, and inclusion of people with disabilities not only as active participants in their health care but in strategic decisions regarding the funding and planning of services”²⁵⁸.

13.3.6a Accessibility

In order to access mainstream health services, these services need to be fully accessible. There is a legal obligation on public bodies to make their services and information accessible to people with disabilities (under sections 26, 27 and 28 of the Disability Act 2005). Full accessibility requires not just physical accessibility, but also aids, appliances and adapted equipment. Provision must also be made for people requiring additional supports, such as sign language interpreters. Health information materials must be fully accessible. Health care professionals must be open to the presence of an advocate if that is requested by the person.

13.3.6b Integrated service areas

Services that are decentralised, co-ordinated and provided to people in their local communities are particularly important for people with disabilities in order to overcome access barriers and to ensure service inclusion²⁵⁹. The HSE is in the process of implementing a model of integrated service delivery. In this model, all health services will be delivered in an integrated way within a defined geographical area (an Integrated Service Area). All of the health services required by people with disabilities will be accessed through the Primary Care Team through integrated service areas. The HSE proposes to have a ‘keyworker’ system in place for all those who have complex needs (for example, a person with a disability and an ongoing health problem). This will enable the coordination of the health and social care supports required by that person.

²⁵⁷ Ibid. D’Eath, M., Sixsmith, J., Cannon, R. and Kelly, L. (2005) p.4.

²⁵⁸ National Disability Authority (2004) *Towards Best Practice in the Provision of Health Services for People with Disabilities in Ireland*. Dublin: NDA p.11

[http://www.nda.ie/cntmgmtnew.nsf/0/80BAC50E8A7A749380256E620055944B/\\$File/health.pdf](http://www.nda.ie/cntmgmtnew.nsf/0/80BAC50E8A7A749380256E620055944B/$File/health.pdf)

²⁵⁹ National Disability Authority (2004) *Towards Best Practice in the Provision of Health Services for People with Disabilities in Ireland*. Dublin: NDA

[http://www.nda.ie/cntmgmtnew.nsf/0/80BAC50E8A7A749380256E620055944B/\\$File/health.pdf](http://www.nda.ie/cntmgmtnew.nsf/0/80BAC50E8A7A749380256E620055944B/$File/health.pdf)

13.3.6c Primary health care teams

The Primary Care Strategy proposes a structure of integrated, inter-disciplinary Primary Care Teams providing high-quality accessible services. The HSE's Transformation Programme has placed a significant emphasis on developing primary care services and putting primary care teams and networks in place. Primary Care Teams serving populations of approximately 8,000 people are planned, with Primary Care Networks consisting of three teams and approximately 24,000 people. However, this strategy is not yet fully in place with approximately 246 teams in place around the country by mid-2010 (out of a planned total of 530).

Primary Care Teams and Networks bring together all those health care professionals who previously delivered 'separate' health services within the community, including GPs, public health nurses, home help services, occupational therapists, speech and language therapists and others. Primary Care Teams will be the first point of access for health services for people with disabilities and clear pathways should be in place from the primary care level to the other services at network level and elsewhere.

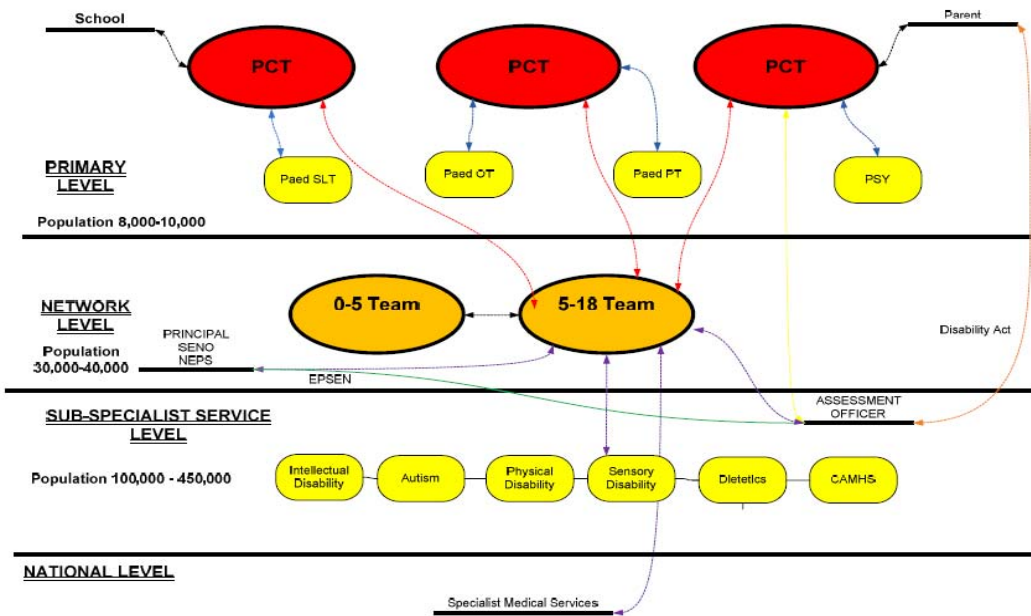
13.3.6d Progressing Disability Services 0-18s

The *Report of the National Reference Group on Multidisciplinary Services for Children aged 5-18*²⁶⁰, recommended an integrated care model that would allow children, whatever the nature of their disability, to be seen as locally to their home and school as possible: at primary care level when their needs can be met there and by a network specialist interdisciplinary team if their needs are more complex. Primary Care Teams and network-level teams will be supported as appropriate by sub-specialist teams with a high level of expertise in particular fields. The Reference Group recommended a realignment of existing statutory and non-statutory resources to achieve this model. Figure 2 below presents a visual representation of this model

Figure 4: Integrated care model for children and young people with disabilities²⁶¹.

²⁶⁰ Health Service Executive (2009) *Report of the National Reference Group on Multidisciplinary Services for Children aged 5-18*.

²⁶¹ Health Service Executive (2009) *Report of the National Reference Group on Multidisciplinary Services for Children aged 5-18*.



A National Coordinating Group has been established by the HSE to progress the recommendations of the Report. The Group’s implementation plan encompasses the ongoing work in coordinating and reconfiguring early intervention services which will closely link with services for school aged children according the same model.

13.3.7 Recommendations for the Department of Health & Children

It is proposed that the supports provided to people in receipt of disability services are ‘unbundled’ and that health services be provided through primary care teams and integrated service areas. Over a phased period, health professionals currently located in service providers should move to primary care teams and networks (either directly or through collaborative service arrangements) so that this resource will be more equitably available to people with disabilities who might need such inputs. Examples of such shared provision between disability services providers and the HSE already exist in some parts of the country. It is essential that a withdrawal of funds in one area (of either service provision or geographic area) is matched with a reallocation of funds to another.

The Group recommends that the ODMH and the HSE work together to promote disability awareness and cultural change in the wider health services so that health services can respond more sensitively to the health needs of people with disabilities, with the person as an active participant in their health care, rather than passive recipient. Actions should be focused on the mainstreaming of the provision of health services to people with disabilities.

It is further recommended that the ODMH should develop a detailed policy implementation plan covering its areas of responsibility. This plan will have identified leadership with responsibility for rolling out the implementation plan, and detailed targets, timelines and desired outcomes (see Appendix 6 for more detail on implementation planning). While this implementation plan will not extend to other Government Departments, it will provide a framework for the ODMH to progress this agenda with other Government Departments and agencies.

13.4 Education supports

Policy aim

Every person with a disability will have the opportunity and supports necessary to receive an appropriate education at all levels from pre-school to third level and through to life-long learning.

This education should take place, wherever possible, in a mainstream environment.

The right to education for all children is recognised in Ireland under Article 42 of the Constitution. A key provision of the Education for Persons with Special Educational Needs Act 2004 (EPSEN Act) is that “*people with special needs shall have the same right to avail of and benefit from appropriate education as do their peers who do not have such needs*”. Current Government policy is to encourage the maximum possible level of inclusion for special educational needs (SEN) students in mainstream schools and to establish the necessary supports to facilitate this development²⁶².

Participation in education is not just important for what is learned, it is in education settings that children play and socialise with their peers. Educational settings can be the first instance in which children can be separated and segregated because of different needs. This can begin with special pre-schools and continue through primary and post-primary settings, with some children with a disability attending special schools for their entire education. This separation not only denies children with a disability the possibility of receiving their education in a fully integrated setting, it also denies other children the possibility of learning with their peers who have disabilities and different needs. It is at this young age that important messages about difference can be conveyed: the inclusion of children with disabilities in mainstream settings presents an opportunity to convey positive rather than negative messages.

Opportunities to stay in education can also be limited for children and young people with a disability. Just over half (50.8%) of people with disabilities aged 15-64 years have no formal second-level education – the corresponding figure for people without a disability is 18.8%. Age at completion of full-time education is an important indicator of future life chances. People with disabilities finished their education earlier than the non-disabled population, with 31% ceasing before the age of 15 years compared to 13% of the non-disabled population.

13.4.1 Current education provision

Table N shows the number of pupils with special education needs in ordinary schools and the number in special schools. For the latest year, almost 7,000 children received their education in special schools.

Table N: National school pupils and classes 2009/2010

Pupils in ordinary	Pupils with special	Pupils in special	Total
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²⁶² Ware, J. et al. (2009) *Research Report on the Role of Special Schools and Classes in Ireland*. Dublin: National Council for Special Education

classes in ordinary schools	needs in ordinary schools	schools	
490,010	9,093	6,905	505,998

Source: Department of Education and Skills²⁶³

Mainstream education for people with disabilities is increasingly being achieved. The proportion of children with disabilities educated in ordinary national schools increased from 49% in 1997/98 to 59% in 2007/08. While comparable figures are not available for second level schools there are indications that lead the National Council for Special Education (NESC) to conclude that there is “a trend towards the greater integration of children with disabilities in mainstream schools”²⁶⁴. However, there is evidence of an increasing trend in the number of students at post-primary level (i.e. aged 12+) moving back from mainstream educational settings to special schools²⁶⁵, in a direction that is contrary to policy. A variety of reasons were cited for this, including the lack of an appropriate curriculum in mainstream educational settings and the availability of a greater level of supports in special schools²⁶⁶.

A review of the role of special schools and special classes in mainstream schools²⁶⁷ concluded that special schools are an important part of the continuum of educational provisions for SEN students. The review identified another important role for special schools in supporting mainstream schools. In some instances, informal links already exist and are highly valued where they exist. However, these links are dependent on goodwill and there is no formal structure to support a two-way collaborative relationship, even though the importance of this type of relationship and links was emphasised.

The review also concluded that special classes in mainstream schools are an important part of the continuum of educational provisions for SEN students and that they have several advantages, including facilitation of inclusion in mainstream schools. While the majority of the participants in the review were in favour of some form of dual placement (where pupils spend some time at a special school and some time at a mainstream school), current policy prohibits dual enrolment and dissatisfaction was expressed about the lack of such an arrangement²⁶⁸. A central role of special schools, as emphasised by the NDA, is their availability as a resource to children and families, to support them in participation in mainstream education²⁶⁹.

13.4.2 Evidence base

While the *Research Report on Special Schools and Classes in Ireland* noted the various benefits of such provision, there was little evidence regarding the outcomes for children in special schools in

²⁶³ http://www.education.ie/servlet/blobervlet/stat_web_stats_09_10.pdf

²⁶⁴ Ware, J. et al. (2009) *Research Report on the Role of Special Schools and Classes in Ireland*. Dublin: National Council for Special Education p. 268

²⁶⁵ Kelly, A. and Devitt, C. (2010) *Why are post 12 year old students with special educational needs who have attended mainstream schools seeking admission to special schools?* Presentation to the National Association of Boards of Management in Special Education Annual Conference 2010

²⁶⁶ Ibid. Kelly, A. and Devitt, C. (2010)

²⁶⁷ Ibid. Ware, J. et al. (2009)

²⁶⁸ Ibid. Ware, J. et al. (2009)

²⁶⁹ National Disability Authority (2009) *Comments on Review of the Role of Special Education Schools and Classes*.

Ireland. Although there are strong, often ideologically-based arguments regarding the provision of education to children with disabilities, there is a strong evidence base supporting the view that, on average, children with disabilities do better in mainstreaming settings, and that children across the spectrum of disabilities have been successfully included in mainstream settings^{270, 271, 272}. However, due to a range of factors, such as individual and family-related factors, school-related factors and disability-related factors, not all children with disabilities and special education needs do better in mainstreaming settings. The evidence base in this area is relatively recent and outcomes studies are particularly difficult to conduct. Given the current evidence base and the current role of special schools in Ireland the approach recommended by the NDA is that all children should be in mainstream classes for the maximum amount of time per day or week that is beneficial to their education and developmental progress; that the ability of mainstream teachers and schools should be continually improved to best support children with disabilities and special educational needs; and that the expertise and resources of special schools should be used to support children with disabilities and special educational needs to participate in mainstream settings²⁷³.

13.4.3 What do we mean by education supports?

Supports to access education should be in place for pre-school age children (approximately 3 years), for children in primary and secondary education, for young adults in third level education and for all adults with disabilities who wish to pursue educational opportunities at any stage. (These supports are the individualised supports described in Section 10.3.) Once in the educational setting, children and young people with disabilities may need additional inputs to be supported in their learning which should be provided in that setting. There can be a fine distinction between ‘health supports’ (such as speech and language therapy) and education supports. It is essential that appropriate protocols exist between education and health agencies to support flexible working and closer links between health services and schools which will benefit children and young people in education.

When relevant provisions of the EPSEN Act 2004 are commenced, the starting point for the provision of education supports for children up to age 18 will be an assessment of the child as set out in the Act (See Section 3.2.2 for description of EPSEN Act). A parent, principal, health board or Council can request an assessment. This can lead to the preparation of an Individual Education Plan (IEP), which is a written document prepared for a named student which specifies the learning goals that are to be achieved by the student over a set period of time and the teaching strategies, resources and supports necessary to achieve those goals.

This should be a collaborative plan involving the student, the parents, the school, the responsible Special Educational Needs Officer and other agencies as appropriate. This collaboration should take place simultaneously (i.e. with the relevant players meeting together) rather than sequentially. This

²⁷⁰ Ruijs, N.M. and Peetsma, T.D (2009) Effects of inclusion on students without special educational needs reviewed. *Educational Research Review*, 4.

²⁷¹ Peetsma, T. et al. (2001) Inclusion in Education: Comparing pupil’s development in special and regular education. *Educational Research Review*, 53 (2).

²⁷² Wagner, M. and Blackorby, J. (2007) *What have we learned, What makes a difference? Influence on outcomes for students with disabilities*, in Office of Special Education Programmes, US Department of Education.

²⁷³ National Disability Authority response to *Research Report on the Role of Special Schools and Classes in Ireland*.

avoids scenarios where the student is assessed several times by separate agencies. At all times the emphasis should be on the needs of the student (and parents), not the needs of the system.

13.4.3a Supports for pre-school, primary and secondary education

The Individual Education Plan must specify the special education and related support services to be provided to the child to enable the child to benefit from education and to participate in the life of the school. Supports must also be provided to enable the child to transition effectively from pre-school to primary and from primary to secondary education. The National Council for Special Education may issue specific guidelines on the type of supports required. This may include the supports currently available such as Special Needs Assistants.

13.4.3b Supports for third-level education and life-long learning

Educational opportunities for people with disabilities should not end at age 18. Follow-on education and training places need to be available for school-leavers with disabilities. A clear pathway should be in place for each school leaver, from secondary education to further education or training and on to employment. The lack of clear pathway can discourage further participation in education and training and can lead to the person being unemployed.

There are a number of support systems for students with disabilities who are undertaking courses at third level in Ireland. Many third-level colleges have a disability or access service which is responsible for giving support and advice to students with disabilities. This may include: an orientation programme; study skills and extra tuition if required; access to assistive technology and training; mentoring. The Association for Higher Education Access and Disability (AHEAD) is an independent non-profit organisation which works to promote full access to and participation in further and higher education for students with disabilities. This organisation provides information to students and graduates with disabilities, teachers, guidance counsellors and parents on disability issues in education.

13.4.3c Pathways and transition points

If this policy is to be truly person-centred, the needs of the person need to take precedence over the needs of the system. This is particularly important at key transition points in the life of a child, for example, from pre-school to primary school, from primary to secondary school and on reaching adult status at 18 years old. Rigidly enforced cut-off points and boundaries are not helpful to children with disabilities, who do not necessarily fit easily into categories that apply to other children.

Similarly, pathways for children through universal services (such as schools) need to be flexible. One way of achieving this flexibility is to have different options available, especially at transition points. The availability of more options, such as dual enrolment (in a mainstream school and a special school for example), or greater support in the secondary school setting (such as a curriculum similar to that developed for the Certificate in Contemporary Living in Trinity college) should enable more children with a disability to remain in mainstream educational settings. The emphasis should be on keeping children in mainstream settings and pathways and systems need to be structured to achieve this.

Characteristics within different systems need to be examined to ensure they do not create barriers to inclusion in mainstream settings. Individual needs should determine access to supports and

services, rather than diagnostic/disability categorisation. For example, access to certain educational supports is based on diagnosis. This can result in an over-emphasis on ‘getting a diagnosis’ which can not only be a resource-intensive activity but may not be in the best interests of the child. A focus on the supports the child needs to access mainstream educational settings and an appropriate curriculum, may offer greater potential to provide these supports without the need for carefully defined diagnostic/disability categories.

13.4.3d Accessibility

For many children, the key to attending mainstreaming education is accessibility. This refers not just to physical accessibility, but the availability of the appropriate materials, aids and appliances to enable the child/young adult to fully participate in their education. The actions related to accessibility are covered in more detail in section 8.2.

A study on the experiences of students with disabilities in second level schools (NDA) made nine recommendations²⁷⁴. These centred on the supports required for schools, teachers and students to make mainstream education a reality and included the need to improve physical accessibility; increase disability awareness; improve access to information and enhance supports in higher education such as Disability Officers. Recommendations also focused on providing access to therapeutic services in mainstream education settings and improving services in the wider community and coordination between services.

13.4.4 Supports for schools and teachers

Teachers are the frontline providers of education to all children in their school and a number of resources have been developed to support teachers in educating children with special education needs;

- The Special Education Support Service (SESS) operates under the remit of the Teacher Education Section of the Department of Education and Science. The aim of the service is to enhance the quality of teaching and learning, with particular reference to special educational provision²⁷⁵. The SESS has produced information and guidelines for schools and teachers to foster inclusion and provide resources for children with special education needs;
- The National Council for Curriculum and Assessment (NCCA) has *Guidelines for Teachers of Students with General Learning Disabilities*²⁷⁶, which were produced on the basis of extensive consultation with teachers, schools and parents. The guidelines can be used in mainstream primary and special primary schools up to Junior Cert., post-primary schools, and other educational settings. They are intended for use by all class/subject teachers and special needs assistants²⁷⁷. The guidelines are also accessible to a range of other personnel directly involved with the student’s education;

²⁷⁴ National Disability Authority (2007) *The experiences of students with disabilities in second level schools*. NDA.

²⁷⁵ <http://www.sess.ie/about-sess/about-sess>

²⁷⁶ http://www.ncca.ie/en/Curriculum_and_Assessment/Inclusion/Special_Educational_Needs/Download_Special_Educational_Needs_Guidelines/Guidelines_for_teachers_of_students_with_general_learning_disabilities.html

²⁷⁷ http://www.ncca.ie/en/Curriculum_and_Assessment/Inclusion/Special_Educational_Needs/Students_with_General_Learning_Disabilities/

- A framework for pre-school education for all children has been produced by the NCCA which is designed to support all adults responsible for children’s learning and development from birth to six years of age²⁷⁸. This has led to *Aistear: the Early Childhood Curriculum Framework* for use with all children in a range of early childhood settings²⁷⁹.

13.4.5 Cross-departmental working in other jurisdictions

In the UK a cross-departmental strategy *Removing Barriers to Achievement*²⁸⁰ has been developed which proposes “a programme of sustained action and review, nationally and locally, over a number of years, in four key areas:

- Early intervention – to ensure that children who have difficulties learning receive the help they need as soon as possible and that parents of children with SEN and disabilities have access to suitable childcare;
- Removing barriers to learning – by embedding inclusive practice to every school and early years setting;
- Raising expectations and achievement – by developing teachers’ skills and strategies for meeting the needs of children with SEN and sharpening our focus on the progress made by children with SEN;
- Delivering improvements in partnership – taking a hands-on approach to improvement so that parents can be confident that their child will get the education they need.

This strategy has been endorsed by the Department of Education and Skills and the Department of Health in the UK.

13.4.6 Recommendations for Cross Sectoral Working: Education

It is the responsibility of educational authorities to provide schooling and educational supports, and the responsibility of the HSE to provide health and social care supports, including therapy supports, for children and young people with disabilities so that they can access education in mainstream settings.

The Group notes the work that has been undertaken under the auspices of the Cross Sectoral Team and recommends that it is essential that the ODMH, the Department of Education and Skills, the HSE and others continue to work closely together to ensure clear protocols are in place that will deliver maximum benefits for each child. Decisions must be made on the basis of what is best for supporting a child/young adult in their education. Specific supports may not fall within neat categories of ‘only educational’ or only ‘health related’, and in such instances, appropriate arrangements in relation to funding and management must be put in place. Protocols on integrated supports are essential in this regard and should be prioritised for continued development. The aim at all times must be for the child/young adult to experience a seamless, integrated mainstream education and for the system to support and facilitate this aim.

²⁷⁸ National Council for Curriculum and Assessment (2004) *Towards a Framework for Early Learning*. (NCCA) <http://www.ncca.ie/uploadedfiles/Publications/ECHSummary.pdf>

²⁷⁹ <http://www.ncca.biz/Aistear/>

²⁸⁰ Department for Education and Skills (2004) *Removing Barriers to Achievement: The Government’s Strategy for Special Education Needs*. http://www.teachernet.gov.uk/_doc/5971/Removing%20barriers%20exec%20summ.pdf

With regard to the inclusion of children with disabilities in mainstream pre-school, the Group notes the cross sectoral working group that was established by the Office for Disability and Mental Health earlier this year to develop and agree a policy framework in this regard. The Group recommends that an appropriate implementation plan be developed on foot of the framework once finalised.

13.5 Supports for participation and active citizenship

Policy aim

People with disabilities will be supported to participate fully as active citizens in their local communities

The achievement of full inclusion for people with disabilities, a central goal of this policy, means ensuring supports are in place so that people with disabilities can live a full life. Living a full life is highly individualistic – the emphasis is put on what is important to the person, which may be very different to what is important for other people. Having friends, doing the things you like doing whether that is being involved in a club or social group, going to the pub in the evening, or just cooking dinner and watching the TV programmes you enjoy are simple activities and choices not available to many people with disabilities.

13.5.1 Describing community inclusion and participation

The New Directions report describes what is encompassed by community participation and active citizenship²⁸¹:

- knowing people in the community who are not involved in providing services;
- living and working in ordinary places;
- being able to access publicly-funded community services such as libraries, public offices and adult education programmes;
- using local services and facilities, such as shops, cinemas and pubs;
- being able to contribute to and be part of specialist community associations for people with disabilities;
- being able to contribute to and be part of mainstream community associations such as residents associations, sports clubs and voluntary bodies;
- volunteering; and
- being able to vote and to influence local planning.

New Directions describes 12 personal supports to enable the person to make choices and plans to support their personal goals, have influence over decisions that affect his or her life, achieve personal goals and be an active, independent member of his or her community. While all of the 12

²⁸¹ Health Service executive (2009) *New Directions. Personal Support Service for Adults with Disabilities*. Report of the National Working Group for the Review of HSE Funded Adult Day Services with a Plan for Implementation 2009-2013.

personal supports enable the person to participate in their community, several are specific to that goal;

- supports for inclusion in one's local community
- support for personal and social development
- support for personal expression and creativity
- support for having meaningful social roles.

13.5.2 Friendships and relationships

One of the most consistent findings of the research on community living for people with disabilities is that loneliness is most often reported as an issue²⁸². This feeling is not confined to community settings as research has also shown that loneliness is also a feature of group settings, particularly in larger settings²⁸³. Many people with disabilities have a limited circle of friends; often the only relationships they have are with paid supporters. This is in part due to the limited opportunities many people have had to make friends as they have lived and spent their days in segregated settings, and also partly due to communities which may be unreceptive.

The emphasis on the provision of supports for participation and inclusion and use of universal services will in itself begin to create more opportunities for people with disabilities to socialise in a wider circle and create friendships outside of service settings. The right of individuals to have relationships of a personal and sexual nature should also be respected. Appropriate information and education on sexuality and relationships should be available to people with disabilities to enable them to make choices and form relationships in an informed way. The individual's capacity to make such decisions can be an issue and the forthcoming capacity legislation will provide a framework within which capacity around specific decisions can be assessed (see Section NN for more detail on capacity legislation).

13.5.3 Being safe in the community

In order to participate fully in the community, people must feel safe and free from threat. Issues of risk and risk management are dealt with in Section 9.5.4. One initiative in the UK, the People in Partnership pack, has been designed with people with intellectual disability, criminal justice and support agencies. The pack contains information and tools for people to know about their rights, how to keep safe, how to access the police and how to report a crime²⁸⁴.

Sufficient supports and strategies must also be in place to address inappropriate behaviours by people with disabilities in the community. Such behaviours present a particular challenge to communities and can feed in a very potent way pre-existing negative attitudes and stereotypes. Agencies will be required to work closely together to provide appropriate interventions which will effectively address these behaviours and reassure the community that they will be safe.

²⁸² Lakin, C. (2010) Gathering and using data to inform public policy. National Core Indicators US. NDA Conference

²⁸³ Ibid Lakin, C. (2010)

²⁸⁴ Department of Health (2009) *Valuing People Now: a new three year strategy for people with learning disabilities*. London: HM Government Department of Health.

13.5.4 Supports for participation

The Individualised supports described in Section 7.5 will include supports for participation. It should be noted that a different set of skills and competencies is required on the part of support staff to work with people in this very different way. Community connectors or coordinators are being employed in different services in Ireland to link service users up with natural support networks and to provide the range of supports to live fully included lives.

13.5.5 Recommendations for Cross Sectoral Working: Participation

The Group recommends that the ODMH work jointly with the relevant Departments and agencies, including the Department of Environment, Community and Local Government, the Department of Justice and Equality, and An Garda Síochána, to ensure that people with disabilities will be supported to be fully included and to participate in their local communities and to be active citizens. In this regard, the Group notes the recent development by An Garda Síochána of a strategy for older people which aims to ensure the needs of older people are being met with regard to policing, security and safety to ensure older people remain active within their communities.

Policy Goal 2: The creation of a high quality, cost-effective, responsive and accountable system

14.1 Introduction

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. The fundamental importance of such a system in promoting citizenship has been acknowledged by the European Parliament:

“Access to well-functioning, accessible, affordable and high quality public services is seen as an important part of citizenship and as a fundamental right”²⁸⁵

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 is defined here 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.”²⁸⁶*

The elements of such a governance framework include;

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

The values and principles described in the policy framework (Section 7.2) point to the type of provision that is envisaged in this policy; provision that is fair and equitable, high quality, accountable and transparent and focused on individual outcomes. A well structured governance system is one which makes a reality of these intangible values and principles and gives them life through policies and processes. Table 4 describes the type of system required, the values driving it and some of the structures and processes that will be required to make the vision real for people with disabilities.

²⁸⁵ European Parliament (2006) *Resolution on a European Model for the Future*. Brussels: European Parliament

²⁸⁶ 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

Table 4: Translation of values and principles into practice through the use of governance structures and processes

Values and principles	...into practice	Governance structures/processes
Fair and equitable	Provision based on needs	Needs assessment process
	Universal access for people with disabilities to local services depending on needs	Structure of delivery system based on catchment areas/integrated service areas
Person-centred	Service user centrally involved in the needs assessment process and in defining outcomes	Needs assessment process Outcomes-focused delivery
	Service user consulted on formulation of standards	Part of process of formulating standards
	Service user aware of the funding available to meet their needs	Part of process of allocating funds
Efficient and effective	Focused on outcomes	Outcomes-focused processes
	Funding allocated on the basis of identified need	Individualised funding model
	Variety of providers	Commissioning model with equal emphasis on cost and quality
High quality	Creation of agreed standards	Inspection, monitoring and review processes based on standards and outcomes to be conducted regularly and results fed back to the system to continually improve practice
	Creation of service-provider and system-wide outcomes, as well as service user-defined outcomes	Information systems are required to capture relevant information to measure and review outcomes
Accountable and transparent	Regular review and monitoring	Inspection, monitoring and review processes based on standards and outcomes to be conducted regularly and results fed back to the system to continually improve practice
	Right of appeal and redress	Develop effective complaints and appeals procedures

14.1.1 A new system of supports and services

The creation of a governance system to deliver the comprehensive system of individualised supports and services described in this policy will require existing structures and processes to be reconfigured. Table 5 summarises the change that is required; the characteristics of the current system and how the new system will look.

Table 5: Defining characteristics of shift from current disability service provision to individualised supports and mainstream services

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

Source: adapted from *The Developmental Welfare State* (NESC, 2005)²⁸⁷

14.1.2 Relationship between needs, cost and governance

Figure 5 shows an idealised ‘rational’ model of the relationship between the population of people with disabilities and their needs, costs and required levels of governance. The total population of people with disabilities is represented diagrammatically by a pyramid. The largest numbers are presented at the bottom of the pyramid; the group of people whose needs are largely met through the use of mainstream/universal services and natural/informal supports. Numbers decrease with increasing levels of need so that the smallest group are those people with multiple and complex needs requiring intensive and long term supports. The hierarchical nature of the model captures the fact that the increasing levels of needs bring additionality of services and supports. Thus, the whole population of people with disabilities can access universal supports and services, but as needs increase and become more complex, additional supports are required.

Needs are fewest and least complex towards the bottom and increase in number and complexity. Ideally, the same should be true of cost, that is, a direct relationship between the resources attached to a person and their needs, and that resources should increase with increasing need. However, there is some evidence that this is not necessarily the case and that there is not a direct relationship

²⁸⁷ National Economic and Social Council (2005) *The Developmental Welfare State*. NESC: Dublin.

between needs and cost²⁸⁸. The third arrow shows the level of governance required, which increases also from low to high depending on the vulnerabilities of the group and the amount of resources they require/being expended on their behalf. The governance system should reflect these interrelationships in how it is structured and how it operates. For example, simpler forms of governance are applied where a person is living with their family or in their own home with largely natural/informal supports. Governance requirements should increase in complexity with increasing vulnerability and increasing levels of resources.

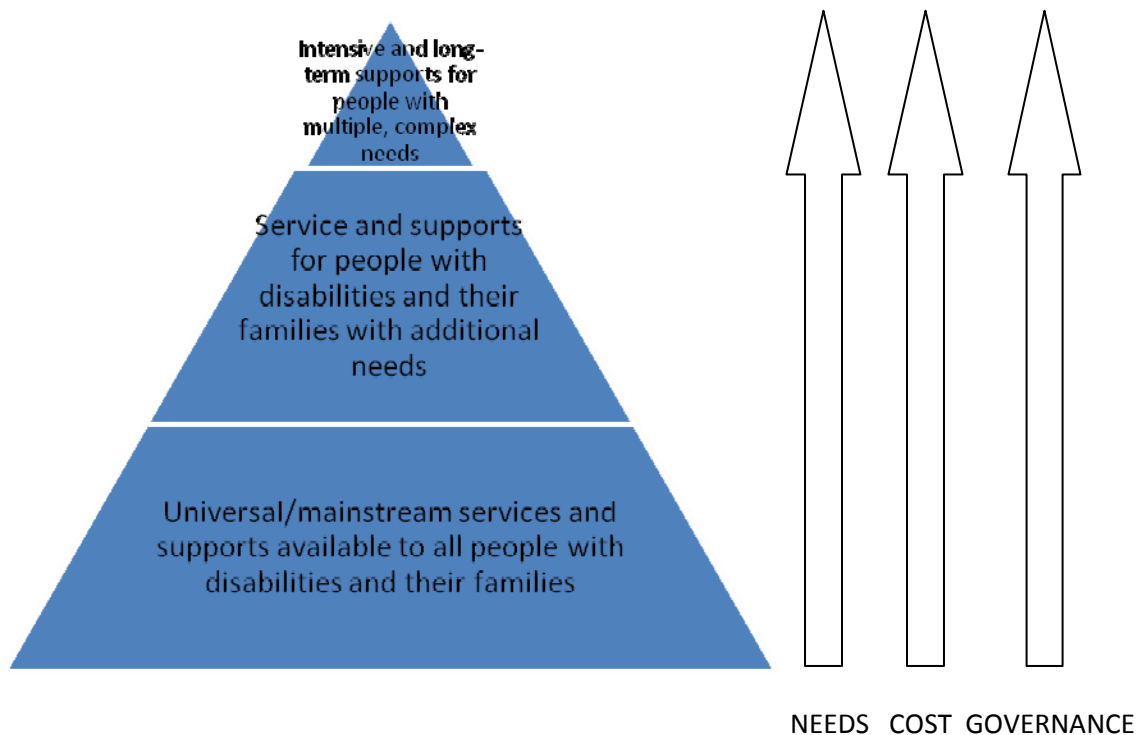


Figure 5: Idealised model of the total population of people with disabilities with corresponding levels need, cost and governance increasing from low to high.

The major elements of the required governance structure are discussed in more detail in the following sections; management structure; funding models; needs assessment; outcomes; quality and risk.

14.2 Processes for assessing needs

The allocation of resources based on need is essential to achieve equity in the provision of supports and services and provision that is fair and transparent. Equity does not mean equality in provision, i.e. that ‘everyone gets the same’. Equity means that access to and provision of service is based on need and implies a bias in provision in terms of those with greatest needs. This is the fairest way to distribute resources in the context of limited resources. The following section considers the benefits

²⁸⁸ National Disability Authority (2010) *Advice paper to the Value for Money and Policy Review of Disability Services*. Dublin: NDA.

of the needs assessment process, describes the current process in Ireland and describes some needs assessment tools.

14.2.1 Why do we need 'Needs Assessment'?

The need for an effective system to assess the support needs of people with a wide range of disabilities and to translate those needs into responsive and individualised service delivery has been recognised for some time²⁸⁹. Although there is often resistance to classification systems, they are important as they serve a number of key functions, for example; tools which identify needs in an objective and standardised manner enable the development of support plans and individualised budgets; and tools for the measurement of outcomes and quality of life²⁹⁰. Importantly, they provide a common language and framework for recording and understanding a wide variety of information, and this has been acknowledged;

"In a perfect world we would prefer to have no classification at all. However, for the purposes of statistics, assessment for services and programs and above all for non-discrimination legislation, we do need to have a definition of who we are and of our situation and we reluctantly accept that this means some sort of classification or analysis of disablement."

Rachel Hurst of Disabled People International (1998) cited in ICF Australian User Guide v1 section 3.2

Historically, people with disabilities were classified and grouped according to their diagnosis and type of disability. The pursuit of a diagnosis has gained particular importance as eligibility for services and income supports is often determined by diagnosis/disability definition. However, the use of diagnosis or disability type as a simple criterion of eligibility has significant drawbacks. People with disabilities need to 'fit with the available service' in order to get a service, which can result in some being under-provided for and others receiving over-provision. Service provision can be fragmented with different disciplines and agencies working in parallel, and gaps and overlaps can occur²⁹¹. Essentially, a simplistic use of classifications such as diagnosis or disability type as proxies for need represents an inefficient way of allocating resources as differences between individuals are not taken into account; rather than the needs of the person determining the allocation of resources, a common label is used instead. Systems based on diagnosis or disability type exist in spite of evidence that coordinated service provision is the most efficient and effective form of intervention²⁹². In essence, resources should be distributed based on what people with disabilities needs rather than on what professionals or agencies choose to provide²⁹³. The influence of environmental or contextual factors in influencing need should also be taken into account.

²⁸⁹ Schalock, R. L. (1999) A quest for quality: Achieving organisational outputs and personal outcomes. In J.F. Gardner & S. Nudler (Eds.) *Quality performance in human services*. Baltimore: Brookes.

²⁹⁰ Parmenter, T.R. and Riches, V.C. (2002) *Assessment and classification of support needs*. Paper presented at Pathways 6 conference, Sydney. <http://www.cds.med.usyd.edu.au/i-can-and-needs-assessment>

²⁹¹ Ibid. p.2

²⁹² Wade, D.T. and de Jong, B. A. (2000) Recent advances in rehabilitation. *British Medical Journal*, 320, 1385-1388.

²⁹³ Parmenter, T.R. and Riches, V.C. (2002) *Assessment and classification of support needs*. Paper presented at Pathways 6 conference, Sydney. <http://www.cds.med.usyd.edu.au/i-can-and-needs-assessment>

14.2.2 Current system in Ireland

Part 2 of the *Disability Act 2005* established a system for the assessment of individual health service needs (in the case of children), or health and educational needs (in the case of adults). This Part of the Act provides a statutory entitlement to:

- an independent assessment of health and education needs. Those who carry out the assessment are statutorily independent, and the assessment itself is undertaken without regard to existing service levels or related cost considerations;
- a statement of the services which it is proposed to provide (known as the Service Statement);
- pursue a complaint through an independent redress mechanism if there is a failure to provide these entitlements.

Part 2 of the Disability Act 2005 was commenced from 1 June 2007 for children aged 0-5 years. Every Local Health Office in the HSE has an assessment officer to coordinate the conduct of Assessments of Need under the Disability Act 2005. When an application is received for an Assessment of Need, the assessment officer conducts an initial, desk-top assessment stage to determine the appropriate team/assessors required to give a picture of the health needs of the child. An assessment report is compiled based on the findings of the assessment(s).

This assessment report must include a determination as to whether the child has a disability as defined by the Disability Act 2005, and if this is the case, a statement of the nature and extent of the disability, the health and educational needs of the child occasioned by the disability, if any, and a statement of the services considered appropriate to meet the identified needs. The assessment must be carried out without regard to the cost of, or the capacity to provide, any service identified as being appropriate to meet the needs of the applicant. The needs of the applicant are recorded in the assessment report in terms of outcomes and goals to be achieved rather than in terms of a specific quantum of service to be provided. The next stage is for a liaison officer to prepare a service statement specifying the health and/or educational services which will be provided to meet the need identified in the assessment report. In the preparation of the service statement the practicability of providing the services identified and the availability of sufficient resources to provide these services must be taken into account (Section 11(7)).

A pre-requisite of needs assessment is that the person is centrally involved, either speaking for themselves or with the support of an advocate and/or family member(s) as appropriate. The involvement of the person is a criterion under *Standards for the Assessment of Need*, developed by The Health Information and Quality Authority.

Six standards for the assessment of need have been described, each with a number of criteria:

1. Person-centred approach
2. Information
3. Access to the Assessment of Need
4. Involving appropriate education and health staff
5. Coordination of the assessment of need
6. Monitoring and review.

14.2.3 Suitability of the current Assessment of Need process

The Assessment of Need under the Disability Act 2005 does not correspond to a ‘needs assessment’ as understood in the wider, international disability sector. Needs assessment generally refers to a highly structured process to gather information on a person’s current abilities, resources, goals and needs. Most needs assessments in other jurisdictions are used to identify what is needed to maximise a person’s independence so that they can participate as fully as possible in their community. Thus all relevant needs are included in context, which may include recreational, social and personal development needs, training and education needs, vocational and employment needs and where appropriate the needs of family and carers²⁹⁴.

The Disability Act 2005 gives the individual with a disability the right to an assessment of **only** their health needs (in the case of children), or health and educational needs (in the case of adults) and by definition, excludes a consideration of the totality of needs of the individual. The provisions and structures that have been put in place to date have flowed from this narrow consideration²⁹⁵, thus the intention of the Assessment of Need process (for the 0-5 cohort) is “to identify the health needs resulting from the child’s disability”²⁹⁶. However, there is no link made between the needs that are assessed and the services that may be provided to address these needs. In fact, under the Disability Act 2005 there is an explicit disconnect between needs and services.

At the moment, there is no specific assessment tool used in the Assessment of Need for children under the Act. Multi-disciplinary assessments are carried out by a variety of health professionals depending on the characteristics of the child and the disability(ies) they may have. While there is a template for the gathering of these assessments, there is no common structure or criteria for how needs are assessed across the different disciplines. As there is evidence that early intervention can have a positive influence on the developmental outcomes for this age group (0-5 years), among children with identified developmental delay, the experience for some has been of assessments across several disciplines,. This approach (i.e. separate, multiple assessments by specialist disciplines) may not be the most effective approach for adults with disabilities. Standardised needs assessment tools are used in many jurisdictions to capture the needs of this group and to design funding and service provision in an individualised way around identified needs.

There is a requirement under the Act that those who carry out the Assessment of Need are statutorily independent. However, in practice, some assessors have been recruited from/are joint appointments with services providers and it is unclear how independent the current assessment process is. It is essential that any needs assessment is independent of the service providers.

The current Assessment of Need process seems to adopt a rehabilitation/medical perspective, rather than an independent living/person-centred perspective (see Table 6). This approach is in conflict with that proposed in this policy; a process which is aimed at enabling the full inclusion of people with disabilities.

²⁹⁴ <http://222.154.236.191/drc/support/service.aspx?id=299>

²⁹⁵ There are some protocols in place to facilitate joint working across different sectors, for example, communication between the health and housing sectors if a housing need is identified in the course of an assessment and protocols for the referral of children to SENOs in the absence of EPSEN but where a possible educational need has been identified by the health system.

²⁹⁶ Health Service Executive *Disability Act 2005 Guidelines to assist assessors*. 16th June 2009.

Table 6: Contrasting the approaches of a rehabilitation/medical perspective and independent living/person-centred perspective

	rehabilitation/medical perspective	independent living/person-centred perspective
The problem is:	Impairment/skill deficiency	Dependence on professionals and others who take control of your life
Located in:	The person	In the environment and services
Solution is:	Professional intervention	Removal of barriers, advocacy, control vested in the person
Person is:	Patient/client	Person/Citizen
Who's in charge?	Professional	Person
Outcomes defined by:	Level of functioning	Living independently and being in control of my life

Adapted from O'Brien and O'Brien 2000²⁹⁷

14.2.4 Proposed needs assessment framework

The system of individualised supports and mainstream services proposed in this policy requires a very different approach to 'needs assessment'. A needs assessment process that embodies an independent living/person-centred perspective should:

- Be driven by the person and family (as appropriate), who are centrally involved in the entire process;
- cover the important domains in a person's life. This means a tool is not just comprehensive, it should also provide a common assessment framework, so that children and adults with disabilities are not continuously undergoing slightly different assessments for different supports (e.g. education, health, accommodation etc.). Excessive duplication results in an inefficient system and is burdensome for service users and their families.
- be sufficiently accessible so that the person and/or their family can be completely involved in the needs assessment process. It has been argued that a professional assessment of need is disempowering, as it does not allow for the possibility of the individual assessing his or her own needs, that it does not necessarily control costs well and that it can limit or discourage family and community support solutions resulting in an over-identification of professionally-met needs thereby increasing costs.^{298,299} However, more recently developed tools are collaborative, with the person and their family participating equally with the professional conducting the assessment (see examples in Section 9.2.5).
- be valid i.e. should measure what it purports to measure. This means that the measure should be meaningful and relevant to the person and reflect their priorities and goals, not the priorities of the professionals or the service provider.

²⁹⁷ O'Brien, C.L. and O'Brien J. (2000) *The origins of person-centred planning: A community of practice perspective*. http://thechp.syr.edu/PCP_History.pdf

²⁹⁸ Duffy, S. And Waters, J. (2005) Resource allocation. In Control. www.in-control.org.uk accessed on 25/02/09.

²⁹⁹ Waters, J. (2007) *Resource Allocation System Discussion Paper*. www.in-control.org.uk accessed on 25/02/09.

- be reliable i.e. should give approximately the same results for people with approximately the same needs. This is essential if the needs assessment is to be used to prepare a support plan and determine an individualised budget for the person.
- Be used easily and quickly for initial assessment and regular review to determine changing support needs and progress.

Arguably, the most efficient and effective way of assessing needs in a way that fits the above criteria is by using a Needs Assessment tool. This tool should have well established reliability and validity for the population for which it is to be used, should result in a clear statement of support needs which should take into account the family and informal supports already available to the person and ways of supporting and maximising these and should also be a positive and empowering experience for the person and their family.

A study on the concerns of people with disabilities and their families in the choice of assessment tools include³⁰⁰;

- The chosen tool must be credible in the eyes of people with disabilities, their families and advocates;
- The tool itself should not dictate the person's choice of services;
- The importance of looking at the whole person rather than limited dimensions of the person's life;
- The tool should be simple to use and understand and should be as brief as possible so that time is not taken unnecessarily on administration;
- The quality of the assessment needs to be assured and accountability in the implementation of the assessment process was also seen to be important, families and guardians should also be involved in the assessment if appropriate;
- If the tool is used to formulate a support plan and individualised budget transparency is important – the link between assessment results and budgets should be clear and explicit.

14.2.5 Needs assessment tools

There is a wide variety of needs assessment tools in use in other jurisdictions, most of which rely on a professional assessment of need. However, some systems use an allocation system based on a self-assessment of need. This model is used in several local councils in the UK to allocate funds to people with disabilities (see section 14.3.4 below).

A number of needs assessment tools are used in the US, most of which focus on people with intellectual disability. Many have been developed by individual States to provide information on the amount of resources needed to support people in the community (e.g. the Connecticut Level of Need Assessment Tool). There are also 'national' assessment tools such as the Inventory for Client and Agency Planning (ICAP)³⁰¹, developed in 1986, or the Supports Intensity Scale (SIS)³⁰², developed in 2004. The SIS has sparked much interest in the US and elsewhere for several reasons; it is a very recently developed tool that is relevant to service plan development; it is one of the only assessment

³⁰⁰ Smith, G. and Fortune, J. (2006) *Assessment Instruments and Community Services Rate Determination: Review and Analysis*. Division for Developmental Disabilities Colorado Department of Human Services

³⁰¹ <http://icaptool.com/index.html>

³⁰² <http://www.siswebsite.org/>

tools to include employment supports; it provides an independent reliable measure of support needs rather than a focus on measuring behaviour; for this reason it appears to be adaptable to use in determining individual funding levels. It is used in several States as part of their resource allocation models.

The Instrument for the Classification and Assessment of Support Needs (I-CAN) has been developed by the Centre for Disability Studies in Australia³⁰³. The I-CAN is:

“a support needs assessment designed to assess and guide support delivery for people with a disability including mental illness. It provides a support services and family friendly holistic assessment, conceptually based upon the internationally recognized WHO ICF framework.”³⁰⁴

The tool is based on the WHO International Classification of Functioning³⁰⁵ and the American Association on Intellectual and Developmental Disability (AAIDD) model of individual functioning, which is an interaction of characteristics of the person, their environment and the supports they receive³⁰⁶. The assessment results in an individual support needs report based on four domains; Health and Wellbeing; Activities and participation; About me (dreams and current life etc.) and My Goals (Appendix 2 has more detail on the I-CAN). The I-CAN has been shown to be a reliable tool for assessing support needs across a wide range of disabilities, and is used in several states in Australia. An on-line version of the tool is available and the support plan can be used to generate an individualised budget.

14.2.6 What is required for a needs assessment process

The assessment of need is the bridge between the individual and the system; it is a process by which the needs of a person are framed in a way that a response can be put in place. The required needs assessment process must be;

- driven and determined by the person with the support of family/an advocate as appropriate;
- independent of the service providers;
- focus on the totality of support needs to live a full and independent life;
- take into account natural and informal supports;
- have nationally agreed methods and standardised instruments/tools;
- be an outcomes-driven process;
- be supported by a quality assurance process;
- be reviewed as required, for example, when the person’s needs change.

14.3 Processes for allocating resources

The system of raising and allocating funds for services for people with disabilities varies across jurisdictions and complex local/state arrangements are often in place. Characteristics of the funding

³⁰³ Arnold, S., Riches, V., Parmenter, T. and Stancliffe, R. *Instrument for the Classification and Assessment of Support Needs (I-CAN)* www.i-can.org.au

³⁰⁴ Ibid

³⁰⁵ World Health Organisation (2001) *The International Classification of Functioning, Disability and Health (ICF)*. WHO: Geneva.

³⁰⁶ Luckasson, R., Borthwick-Duffy, S., Buntix, W. et al. (2002) *Mental Retardation: Definition, Classification and Systems of Support* 10th Edition. Washington DC: American Association on Intellectual and Developmental Disability (AAIDD)

model can have important implications for the shape of services provided; the extent of control offered to the service user, the cost-effectiveness and efficiency of supports, the quality of supports, and the level of accountability in how funds are used.

The current Irish system is analysed and then main funding models in use here and elsewhere are considered.

14.3.1 Current system

In Ireland, centrally raised funds are allocated by block grant to a variety of service providers to provide a range of services to people with disabilities under a service level agreement. In several jurisdictions providers receive central funding to provide a particular service which conforms to agreed standards and regulations, for example, a residential service with a defined number of places. The block grant may be based on standardised rates for specific provision. In several states in the US, standardised rates have been calculated for provision such as a residential place, a day place and so on (ref HSRI). Alternatively, the block grant may simply be based on traditional/historical funding levels. Recurrent provision of funding is usually based on whether standards and other stipulations around provision have been met. Block funding most closely resembles the funding model for most disability service providers in Ireland. An analysis of the Irish model of block funding as currently operated shows that it;

- Lacks transparency about where resources go and on what basis³⁰⁷. While the Service-level Agreements (SLAs) now being implemented across the disability services may address the issues of accountability and transparency, they do not address the central issue of inequitable resource allocation relative to needs;
- Does not have a strong central role in determining and setting unit prices for services;
- Is based on an incremental model of providing 'more of the same' and has not been reviewed in light of increased/improved provision in other settings (e.g. person-centred settings or other mainstream provision);
- Is not based on services achieving policy objectives such as supporting increased independence of service users ;
- Is not linked to individual needs for a large number of service users, and even where this occurred when a person was first taken on by a service, the initial allocation for an individual is not reviewed regularly and/or as needs change, but is rather absorbed into the block allocation year on year. The audit of a sample of disability service providers carried out by the C&AG showed that *"the service costs for persons with similar degrees of disability varied from one service provider to another"*³⁰⁸. An analysis by the NDA of the data on costs per person and dependency ratings showed; *"little correlation between costs per head and the dependency*

³⁰⁷ National Disability Authority (2010) *Advice paper to the Value for Money and Policy Review of Disability Services*. Dublin: NDA.

³⁰⁸ Comptroller and Auditor General (2010) *Report of the Comptroller and Auditor General Accounts of the Public Services 2009. Volume 2*.
http://www.audgen.gov.ie/documents/annualreports/2009/ReportVol2_09_rev2.pdf

composition within centres, and no systematic link between high-cost centres and those with high-dependency residents”³⁰⁹;

- Has an assumed efficiency in the delivery of services to groups, even though the individuals in the group may have quite diverse needs. This assumption is contradicted by the following observation from an American study: *“People often assume that expenditure on services and support provision is strongly influenced by the needs of the individuals serviced. Individuals with fewer self-care skills , more challenging behaviour, or more serious health problems are through to need, and are assumed to receive, more staff support and so require greater per-person expenditure to provide appropriate services. Studies have reported widely varying relationships between expenditure on services and characteristics of recipients.”³¹⁰*
- Is expensive compared to other jurisdictions. The analysis in Table 7³¹¹ shows that Irish spending on disability, using a calculation of per head of total population of people with disabilities, is significantly higher than other jurisdictions. Table 8 shows differences between Ireland and other countries in the cost for a group home place, where there is also a substantial difference. While the calculations in Tables 7 and 8 do not take into account difference in the standard of living in the different jurisdictions, every effort was made to include comparable costs in these calculations in terms of services provided. Allowing for this proviso, and given that pay costs account for about 80% of the Disability Services Programme Budget, it is likely that inter-country differences in pay costs account for much of the difference in costs between different jurisdictions.

Table 7: Specialist disability health service spending per head of population

	All disability	ID
	€	€
Ireland	359	219
England	149	110
Scotland	179	131
New Zealand	81	54
Victoria	126	n.a.

Source: NDA Advice Paper³¹²

³⁰⁹ National Disability Authority (2010) *Advice paper to the Value for Money and Policy Review of Disability Services*. Dublin: NDA. Page 11

³¹⁰ Stancliffe, R.J. and Lakin, C.K. (2005) Context and Issues in Research on Expenditures and Outcomes of Community Supports, in Stancliffe, R.J. and Lakin, C.K. Eds. (2005) *Costs and outcomes of community services for people with intellectual disability*. Baltimore: Paul H. Brookes Publishing Co.

³¹¹ Ibid. NDA 2010

³¹² National Disability Authority (2010) *Advice paper to the Value for Money and Policy Review of Disability Services*. Dublin: NDA

Table 8: Average group home cost per person across four jurisdictions

Jurisdiction	Average cost per service user
Ireland (group home) - 2004	€71,283
Ireland (institution) - 2006	€115,000
England - 2009	€63,570
Australia	€63,000

Source: NDA Advice Paper³¹³

While a block grant system is relatively simple to administer, it is clear that there are strong inefficiencies in a system which identifies a flat (i.e. single) cost for a unit of service, e.g. €80,000 for a residential place. Such a system assumes everyone needing a ‘residential place’ needs the same and that the cost will be the same for all. This works against the principle of equity as no effort is made to provide resources based on need; and also works against the principle of sufficiency, since some will receive more than they need and others will not receive enough. The use of unitary service costs which are not tied to individual needs assessment meet neither the needs of the person (for an individually tailored support) nor the system (which needs to use limited resources as efficiently as possible).

14.3.2 Required processes for individualised resource allocation

The current system of resource allocation in Ireland (primarily block funding) is neither effective in achieving policy goals nor efficient in how it operates. A very different model will be required to support the individualised provision of supports and services described under Policy Goal 1. In order to realise the goal of inclusion and self-determination for people with disabilities a process for allocating resources on an individual basis will be required which;

- is based on a comprehensive, standardised, individual **support needs assessment** in which the person and family as appropriate are centrally involved (this means that the person and the family are core (not discretionary) participants in the assessment process and that the person and family get copies of the needs assessment etc.;
- the results of which are used to prepare a **support plan** – a statement of supports and services required by the person based on their needs and goals. The person and/or family as appropriate is at the centre of the process to define the support plan and the plan considers all forms of support; those available within the family, other natural supports and formal supports;
- results in an **‘individualised budget’** – a sum of money that attaches to the person and is used to provide the supports and services they need. This sum is subject to resource availability and considerations of equity;
- results in more control for the service user - at a minimum they will know the amount allocated to them to provide the supports and services they need to at a maximum having full control over their funds in the form of a direct payment;
- considers mainstream/universal services as the first level of provision, unless a specialised, disability-specific alternative is indicated by the person’s needs

³¹³ Ibid. NDA (2010)

- is cross-sectoral and represents a ‘one-stop-shop’ – the funding for specific supports may come from different departments or agencies but this process of negotiation is done in preparing the support plan – the person does not have to negotiate the different components.

An important requirement of a system of individualised funding is appropriate capacity legislation. The Mental Capacity and Guardianship Bill 2008³¹⁴ and the Scheme of Mental Capacity Bill 2008³¹⁵, which expands the original Bill, should address the gap in capacity legislation in Ireland when the Scheme of Mental Capacity Bill is commenced.

14.3.3 Individualised funding

There are several mechanisms which can be used to provide funding which is more directly linked to the needs of the person and provides varying levels of control to the person. The most widely known is perhaps direct payments. Two other models are proposed here which offer varying degrees of control to the service user. All three models depend on a standardised, independent needs assessment process, through which the needs of the person are carefully established, although direct payments are usually used for a narrower range of supports. This results in an identified budget or monetary amount for the person, from which their supports and services are provided.

Direct payments – individualised cash payments made directly to people with disabilities *instead of* services usually provided or arranged by social care services (such as Personal Assistants). These payments enable the person to employ, either directly or indirectly, individuals to assist them with their everyday tasks. In this model the person has direct control of their funding and assumes responsibility for providing all their own supports. Direct payments operate in a number of EU countries including Britain, Sweden, Austria, Finland, Belgium, Holland and Germany. While some people who receive a direct payment take on all the associated tasks and responsibilities (such as becoming an employer), the experience in most jurisdictions where direct payments are available, is that the majority of eligible individuals use some form of intermediary arrangement (such as a co-operative) to help them manage their fund and/or be the employer for PAs etc. For example, in Sweden only 4% of the 14,000 people who receive direct payments for PAs employ their PA directly. The experience in the UK is that direct payments are typically used to support the individual to engage in community activities and cannot currently be used to purchase permanent residential care, local authority provision or health care (ref NDA doc). Further detail on direct payments in the UK, Sweden and the US are in Appendix 1.

Individualised support budget paid to a broker – the main difference between this model and direct payments is that the person has indirect control over the budget, which is allocated to a broker or intermediary who administers the funds and sources or commissions supports and services on the person’s behalf. Thus, supports may come from a variety of providers depending on the needs and wishes of the person. A standardised, independent needs assessment process is conducted, through which the needs of the person are carefully established. This results in an identified budget or monetary amount for the person, from which their supports and services are provided. A wider

³¹⁴ <http://www.oireachtas.ie/documents/bills28/bills/2008/1308/b1308s.pdf>

³¹⁵ http://www.justice.ie/en/JELR/Pages/Scheme_of_Mental_Capacity_Bill_2008

variety of supports and services can be included in this model, and not just personal assistants, as is the case with direct payments.

Individualised budget paid to a serviced provider who is nominated by the person– this is a refinement of the block funding model. A standardised, independent needs assessment process is conducted, through which the needs of the person are carefully established. This results in an identified budget or monetary amount for the person, from which their supports and services are provided. The service provider receives this funding to provide the documented supports and service to the person, in ongoing consultation with the person. The individual amount of funding is known to the person and the service provider administers this budget on their behalf.

14.3.3a Consumer control

There are several benefits to giving the person more control over their funds. From the point of view of the person, having some control over their funds or budget is the embodiment of the principle of control. It gives expression to self-determination as it enables the person to exercise choice over the supports they receive. There are also benefits from the point of view of the system; chief among these is the promotion of the economic concept of consumer sovereignty.

Balancing the demand from service users with the resources available to meet that demand is an ongoing challenge for funding bodies. In economic terms demand assumes that the best people to decide on the values to be attached to various goods and services are normally those who will benefit from them (i.e. the consumers)³¹⁶. It is assumed that consumers are the most knowledgeable and best placed to make the appropriate judgements about what services they need and how much they are willing to pay for them. This belief, that the individual is the best judge of his/her own interest, is not only central to the economic principle of consumer sovereignty; but also underpins the argument of many people with disabilities that they should have greater control over their funds and determining how they should be used. Thus, systems which give greater control to consumers align the needs of both consumers and the system; the consumer gets greater choice and control over the supports and services they need and the system gets a means to balance demand with resources.

14.3.4 Developing a disability-specific resource allocation model

The term resource allocation is generally used to describe a procedure for distributing resources between competing claims in order to achieve certain pre-specified goals³¹⁷. A report on resource allocation prepared by a team in Dublin City University goes on to describe the function of resource allocation;

“Resource allocation is an essential function of any government that is providing public services; in particular, it has become a major focus of work in health service planning in many countries. Active RA is driven by the need to achieve efficiency and equity in healthcare provision, regardless of the mechanisms by which these services are provided. The goal is to develop a sustainable and defensible method of distributing resources between areas. The

³¹⁶ Mooney, G. H. (1986) *Economics, Medicine and Health Care*.

³¹⁷ Dublin City University (2010) *Towards the development of a resource allocation model for primary, continuing and community care in the Health Services. Volume 1.*
<http://www.dcu.ie/news/2010/jan/ResourceAllocationDCUreport.pdf>

two central questions to be posed when considering any resource allocation process are: what is to be allocated and what purpose is intended to be achieved as a result of the allocation?”(p.1)³¹⁸

Resource allocation models have also been developed to allocated resources to specific areas such as disability. In this context, resource allocation models are designed to establish the amount of funding that may be authorised to deliver an individual’s support plan. These models prospectively determine the total amount of funds available and are designed to promote flexibility and individual choice in the selection of services and supports to meet the needs of the individual. Within the amount of an individual’s resource allocation, support plans are developed by selecting supports and services and determining the amount of each support or service that will be received.

The different resource allocation models have a number of key steps;

1. independent needs assessment
2. determination of a support plan based on needs assessment and the supports currently available to the person such as family and other natural/informal supports
3. use of resource allocation model to determine the resources assigned to a person. In some US states the person is assigned a low medium or high band of funding on the basis of their assessed needs and the service provider is funded accordingly. More sophisticated funding models cost the different elements of the support plan to formulate an individualised budget for the person (see Section below, determining rates for supports and services). With these systems there is inbuilt flexibility so that the “ money follows the person” if they move from one provider to another

Examples of this process from other jurisdictions are considered here.

UK example: *In Control*³¹⁹ has developed a resource allocation system based on a self-assessment of need to identify how much money the person might reasonably expect to have in their individual budget. The person completes the self-assessment questionnaire. Each area of need is scored according to the level of support required to address that need and is also weighted and has associated outcomes so that it is clear what will result from funding allocated. Completing the whole questionnaire gives an individual profile of needs and an individual points total. It is this points total that is used to offer an indicative budget allocation. A range of allocation levels are linked to points from the individual’s self-assessment questionnaire. The result is a table of actual monetary amounts for total points from the needs assessment (e.g. 8 points receives £1,500, 52 points receives £24,644). This is an indicative amount which is then negotiated with a case manager.

US example: Systems to link payments for services to the assessed needs of service users developed in the US in the early 1990s and have developed rapidly in response to changing patterns of service provision (e.g. the closure of institutions and greater use of community services) and changes in how services for people with disabilities were funded (the shift of more funding to Medicaid through

³¹⁸ Ibid. p.1

³¹⁹ In Control is a social enterprise company which has been working since 2003 on helping to transform the present social care system into a system of Self-Directed Support (SDS). They are currently on version 5.0 of their resource allocation model designed to support SDS.

waiver programmes). Several States use the Supports Intensity Scale (SIS) as the first step in determining individualised budgets. For example, in Colorado, six levels of funding were determined following a data collection exercise. As the levels increase from 1 to 6 the overall support needs increase, as do the dollar amounts. The level of funding received by the person is based on their SIS results. These models work for the large majority of individuals requiring support. Allied systems are put in place to provide support to individuals with exceptional support needs (approximately 7% of those requiring support in the experience of the States using this method).

Determining rates for supports and services: An essential part of a resource allocation model is the determination of rates. Rates (i.e. the costs of supports and services) need to be normalised or standardised to take account of two sources of information; firstly, the 'usual and customary' service consumption patterns of persons who have similar characteristics/support needs; secondly, rates need to be freed from 'legacy biases'. These can take several forms; for example, different providers may be paid different rates for the same service – the differences caused either by a rate negotiation process (with some providers better negotiators than others) or perhaps the time period when providers started delivering services (whatever rate was in effect when services began are the rates that will always be paid, with newer providers receiving higher rates), or because providers were paid some sort of flat amount per service user, regardless of the amount of services that were delivered to any individual service user. In order to ensure portability of the resources for the person and to ensure fairness of the system, the biases must be removed before a resource allocation model can be developed.

Findings from other jurisdictions suggest that a well designed resource allocation system creates a strong alignment between the needs of the person and the system. The person gets an individually tailored budget which addresses their needs, is reviewed based on outcomes that are meaningful to that person and is therefore responsive to their changing needs. For the system, this process creates a performance-related budget which lends itself to individual and system-wide accountability.

14.4 Processes for procurement and commissioning

Systems in use in other jurisdictions for procuring or commissioning disability services generally fall into two categories; the procurement of services through a competitive tendering process or the use of standard rates of payment which are determined and set by the commissioning body and registered providers offer services at those rates.

14.4.1 Tendering

A number of procurement processes for social services have been identified which are compatible with the European Union (EU) procurement framework:

- open tendering;
- restricted tendering;
- negotiated procedure with a call to competition;
- competitive dialogue;

- framework agreements³²⁰.

Tendering for services is a potentially useful approach as it helps to establish the appropriate price for services which build in specific quality criteria and can also enhance innovation, service quality and value for money³²¹. The NDA has advised that the procurement of service through a competitive tendering process has the potential to ultimately benefit service users by increasing the level of choice, enabling people to source services that meet their needs and deliver better value for money³²².

14.4.2 Commissioning framework

Personal social services are significantly different to other goods and services which may be procured by public bodies. Learning from other jurisdictions has shown that a comprehensive commissioning framework is required to ensure the needs of the person are met, the desired outcomes achieved and that service are provided to the highest standards. Such a framework must include;

1. **Outcome-based standards** for a wide variety of service provision models and settings (i.e. standards that are not just for residential or day settings but are appropriate to a variety of community settings. Procurement must achieve positive outcomes for service users.
2. **Personalisation** – social care procurement must take account of the need to deliver personalised services providing choice and control through building individual, family and community capacity, with attention to consistency and continuity, performance improvement and the delivery of agreed outcomes.
3. **Involvement** – service users and carers must be active partners and citizen leaders in both defining their needs and the outcomes of the support they require to realise their potential and influencing the design of services.
4. A rigorous standards-based **registration system for service providers**
5. **Best Value** – services must be developed to meet the needs of service users and carers and achieve best value, balancing quality and cost with regard to economy, efficiency, effectiveness, equal opportunities, attention to risk, and sustainable development.
6. **Benefit and Risk** – strategic decisions concerning social care procurement must be based on careful benefit and risk analysis of the potential effects on: service users and carers; the quality and cost of services; and partnership working with service providers and workforce issues.
7. **Procurement Rules** – social care procurement must comply with the EC Treaty principles of equal treatment, non-discrimination and transparency and the requirements of the Public Contracts (Scotland) Regulations and Scottish public procurement policy.
8. **Training** for both commissioners and providers in the desired approaches
9. An **oversight system** for service providers to assure quality and standards

³²⁰ Scottish Executive (2010) Guidance on procurement of social care for consultation.

<http://www.scotland.gov.uk/Publications/2010/01/13125045/0>

³²¹ National Disability Authority (2010) *Advice paper to the Value for Money and Policy Review of Disability Services*. Dublin: NDA.

³²² National Disability Authority (2002) Submission to Consultation on Towards Better Regulation

10. **Partnership** – there must be collaboration between agencies across the public, private and voluntary sectors to make the best use of the mixed economy of care.

Within a commissioning framework for Irish disability services, it is likely that the current statutory framework under which Section 38 and Section 39 agencies operate will need to be reviewed.

14.5 Quality assurance systems

All services and supports must be of high quality. There are many definitions of quality and in reality quality is an overarching term that overlaps with other areas such as effectiveness and efficiency, person-centredness, risk management and so on. In essence a high quality system is one which provides the required supports and services focused on the outcomes of the person and does this in an effective, efficient and safe manner. The NESF report on delivering quality public services (ref) emphasised the centrality of meeting the service users outcomes in defining quality and their ‘working definition’ of quality was; *“The extent to which service delivery and/or service outcomes meet with the informed expectations and defined needs of the customer”* p.3 NESF

14.5.1 Service user focused quality

In this definition, quality is determined by the service user based on their needs and expectations. Research with service users and service providers in the UK (ref) has identified characteristics of service delivery for those services which seem to work well and increase the social participation of service users; which include;

- individually tailored approaches
- multi-agency working
- joining up and customising services
- making services more accessible through one-stop shops and flexible opening hours
- common objectives for all target groups
- providing alternative environments for service delivery.

For service user-centred supports and services to be effective, they must be³²³:

- **Focused on priority needs:** the priority areas that need to be tackled should be identified in good time;
- **Accessible/inclusive:** all supports, services and information should be fully inclusive;
- **Timely:** supports and services should be available when people need them;
- **Holistic:** the whole needs of the person should be assessed and met;
- **Flexible:** supports and services should adapt flexibly to people’s needs over time, i.e. the life-cycle approach;
- **Responsive:** outcomes should be evaluated to ensure that services meet users’ needs and the lessons learned should be incorporated into the design and delivery of supports and services in a process of continuous improvement.

The adoption of a comprehensive needs assessment process would create a framework within which the assurance of quality could be located. The needs assessment process would objectively define

³²³ National Economic and Social Forum (2006) *Improving the Delivery of Quality Public Services*. NESF: Dublin

the needs of the person, based on their own input and that of family/carers as appropriate. The measurement of these needs over time would establish the extent to which they have been met or not, and how they have been met. Framing quality in this way corresponds with the increasing use of outcomes-oriented standards instead of standards which set a minimum performance target. The State of Victoria, Australia, has established an outcomes standards regime and plans are underway in New Zealand to develop outcomes-oriented standards. Scotland's National Care Standards for care in the home capture outcome and performance dimensions of each standard and present these in a service user focused way. The essential difference between minimum performance standards and outcome-oriented standards has been described as follows³²⁴;

- Minimum performance standards set out minimum actions to be taken or levels of performance to be achieved on the part of the provider of a service
- Outcome-oriented standards are essentially statements of required outcomes for the user of a service or support.

Further consideration of outcomes is in Section 14.6.

14.5.2 Regulation and quality assurance

As well as defining what is meant by quality, systems are required to assure the quality of the supports and services that have been delivered and there is a variety of processes to do this. A review of the evidence on regulation and quality improvement has shown that the focus of regulatory activity in the health care sector is on institutions, the professions and the healthcare market³²⁵. Sutherland and Leatherman summarise the views on the purpose of regulation by describing three central purposes as follows³²⁶;

- To improve performance and quality
- To provide assurance that minimally acceptable standards are achieved
- To provide accountability both for levels of performance and value for money.

However, these three purposes are not necessarily compatible. There is evidence that regulation and review are generally perceived to be a tool for control and risk management, with less appreciation of the possible role in service improvement. In fact, there is evidence that the emphasis on functions of control and risk management can act as a disincentive to innovation³²⁷.

Consideration and understanding of the tensions between these functions, and the trade-offs that may need to be made to achieve them is essential in the development of a regulatory programme that best fits the desired purpose. For example, if the main priority is to provide assurance, standards are set at a minimal level. This will not necessarily improve performance and quality. This requires the setting of ambitious standards and targets which can be used to challenge the system and help organisations identify areas for development. If the primary purpose is accountability, methods are required that enable regulators to compare performance in a meaningful way.

³²⁴ NDA advice doc

³²⁵ Sutherland, K. & Leatherman, S. (2006) *Regulation and quality improvement: A review of the evidence*. Quest for Quality and Improved Performance. The Health Foundation. www.health.org.uk/QQuip

³²⁶ Ibid.

³²⁷ Office of Public Services Reform *Inspecting for improvement: Developing a customer focused approach*. <http://archive.cabinetoffice.gov.uk/opsr/documents/pdf/inspecting.pdf>

Three components involved in the regulation of healthcare organisations/institutions are described;

1. Direction: the communication of expectations and requirements to the regulated organisations and other stakeholders
2. Surveillance: assessment of the level of performance or extent of compliance on the part of regulated organisations
3. Enforcement: the use of regulatory powers to bring about change.

In practice, these different components are often used together. External oversight models (such as inspection) are often used alongside directive approaches such as standard setting (direction). Powers of enforcement often result in tandem with surveillance and direction. Figure 6 describes clearly the focus of the regulatory activity and its relationship to other such activities.

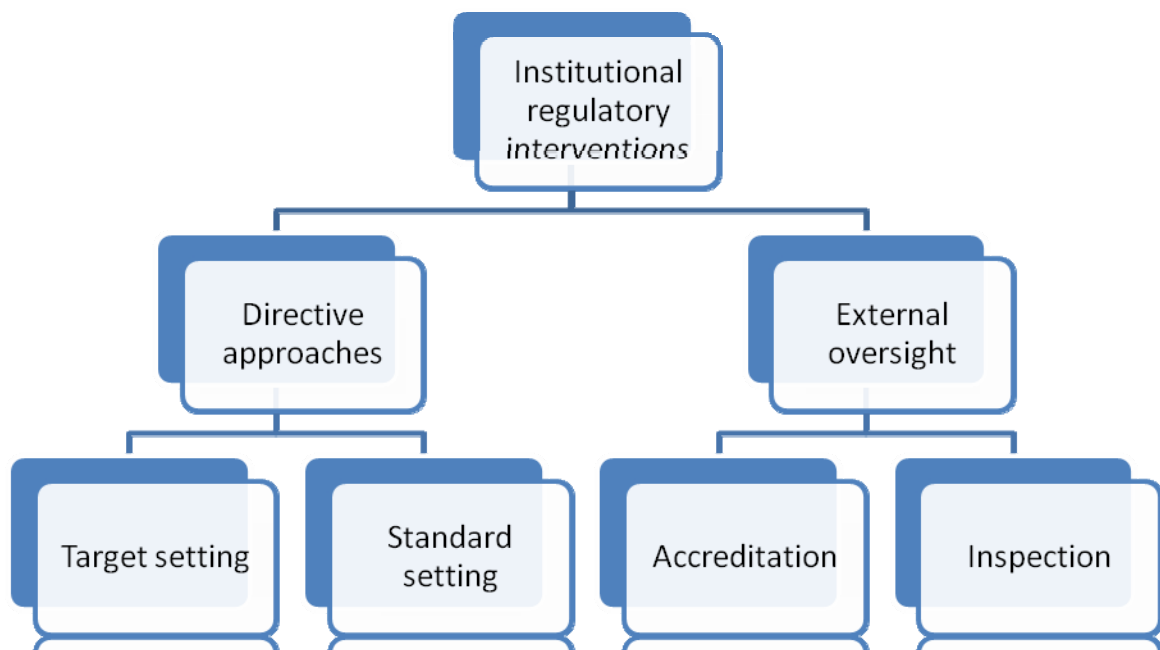


Figure 6: A taxonomy of quality enhancing regulatory interventions aimed at institutions³²⁸

In practice, these different components are often used together. External oversight models (such as inspection) are often used alongside directive approaches such as standard setting (direction). Powers of enforcement often result in tandem with surveillance and direction. Figure 1 (p.59) describes clearly the focus of the regulatory activity and its relationship to other such activities.

14.5.3 Current standards

The Health Information and Quality Authority (HIQA) has developed *National Quality Standards for Residential Services for People with Disabilities* (HIQA, 2009). These standards were developed following extensive consultation with representatives of those who use the services, their families,

³²⁸ Sutherland, K. & Leatherman, S. (2006) *Regulation and quality improvement: A review of the evidence*. Quest for Quality and Improved Performance. The Health Foundation. www.health.org.uk/QQuip

advocates and support groups, and with service providers. In order to be registered, residential services must meet standards across seven areas:

- Quality of life
- Staffing
- Protection
- Health and development
- Rights
- The physical environment
- Governance and management

Each standard has a number of criteria by which it will be measured. Regulations may also attach to certain standards. The Social Services Inspectorate within the HIQA will carry out inspections to ensure that residential services comply with standards and regulations.

While these standards have been developed for residential services (the provision of which in congregated settings will cease following the full implementation of this policy), there are many elements which are relevant to the provision of support in any setting. These standards will contribute to the development of appropriate standards for the system of supports and services proposed in this policy.

The assurance of standards within a diverse and diffuse system will be a considerable challenge. An effective and efficient way to ensure standards are 'built into' the delivery system is to require all providers to be registered. A registration system can stipulate the standards that are required and these must be met before a provider can be registered. For example, it may be a requirement of registration as a provider of day supports that such supports are provided on an individualised basis. Other jurisdictions have found that the use of self-reports of compliance that are assessed by a central authority (for example the Health Information and Quality Authority) is an effective way of ensuring standards are maintained.

Due consideration should be given to 'light touch regulation' which has been found to be effective in other jurisdictions if all other systems (such as registration) are sufficiently robust. Flexibility should be built into the delivery system so that a balance can be achieved between, for example, workers rights to health and safety, and a person's right to their private home being treated as such - we have to be careful a person's private home does not become a setting for inspection. Figure 1 (p.59) captures this gradation of governance, with requirements for regulation and inspection at their lowest for most people with less complex needs, who are less vulnerable, and who will receive the bulk of their supports and services in mainstream settings from natural and informal supports. Governance requirements are more rigorous for those who are most vulnerable and those who are receiving the bulk of their supports and services in non-family settings from service providers.

The structures and processes that are put in place to assure quality must emphasise that quality is about how supports are delivered and is the responsibility of everyone within the system. There is a significant role for training among staff and service providers in this regard and the encouragement of processes that make quality a part of everyday work, rather than the responsibility of a separate department or person. The same approach is essential for the management of risk, where everyone

has a role in their everyday work to be aware of risk and safety and to work in a way that manages this on an ongoing basis.

14.5.4 Safety and risk

All services and supports must be provided in a safe manner and in accordance with all the relevant legislation, policy, regulations and guidelines. However, many people with disabilities have vulnerabilities which bring a consideration of safety and risk to the centre of the governance system. These vulnerabilities can range from people who are not accustomed to articulating their views and wishes (although they have the capacity to do so) to individuals who have no verbal communication, no mobility and limited capacity and are completely dependent on others to voice their wishes and concerns and to provide continuous support and assistance.

14.5.4a Individualised approach to risk

A consideration of safety and risk needs to take this broad diversity of vulnerabilities and needs into account. A central tenet of this policy is an individualised approach to the design and delivery of supports and services to people with disabilities, with the goal of full inclusion, while locating control as much as possible in the person themselves and their family as appropriate. This approach is also relevant to safety and risk; enabling self-determination and independence in a safe manner. It must also be acknowledged that risk is a significant part of life for everyone, including people with disabilities. Choosing to be involved in a full life that involves risk and the need to address or 'manage' risk are both important parts of service planning in the provision of disability services and supports³²⁹.

In the context of planning and delivering supports and services to people with disabilities there are many areas in which risk is a consideration either explicitly or implicitly. These include;

- Clinical interpretation of risk
- Accountability demands
- Occupational health and safety requirements
- Contractual obligations to 'manage risk'
- Funding frameworks that manage risk through bulk funding
- Multiple value systems, including a public that expects the government to 'protect' people with intellectual disability and keep them 'safe'³³⁰.

The recent Report of the Expert Group on Resource Allocation notes that in the type of disability system proposed in this policy, change will be required in the understanding of duty of care;

"international best practice in disability services... is to move away explicitly from a medical model of care to a social model of support, with the emphasis on maximising self-determination, community participation (inclusion) and equal citizenship.... This change in orientation and relationship in the

³²⁹ ³²⁹ Bonardi, A. (2009) *The balance between choice and control: risk management in New Zealand Intellectual disability services*. Fulbright: New Zealand

³³⁰ Ibid. p.v

*area of disability services requires fundamental change in the understanding of the duty of care that is typically held, where the client is viewed as a dependent and passive recipient of services.*³³¹

14.5.4b Balancing safety and risk

These pressures can impose a 'risk-averse bias in service delivery', and a concern with safety above all else. Difficulties can arise when the requirements of these areas have conflicting perceptions of, or approaches to handling risk. For example, the wishes of a person with an intellectual disability to pursue their interests in the community (in accordance with them living an ordinary, fully included life) may conflict with the values of the local community which perceives people with an intellectual disability as individuals who must be 'minded' at all times, and may conflict with the accountability demands of the organisation providing support to that person who are 'responsible' for their care and well-being. A workable approach to risk firstly requires all issues and concerns around risk and safety to be fully explicit, as implicit concerns and perceptions of responsibility where none exists can prove to be real barriers to people with disabilities living full lives. When all issues are explicit, there may need to be a re-negotiation of the approach to risk on an individual basis.

The HSE guidance document on risk management in mental health services emphasises the dynamic and multi-dimensional nature of risk and the potential gains as well as the hazards of risk-taking³³². The guidance document adopts this wider view of risk; "*where the process of managing risk is not just focused on eliminating risk, but on realising the potential benefits, while reducing the likelihood of harms occurring as a result of taking risks*" (p.5)³³³.

This approach is echoed by Titterton, who describes the dangers of a 'safety first' approach that³³⁴:

- Denies the right to choice and self-determination,
- Can lead to loss of self-esteem,
- Supports a form of institutionalisation with the loss of individuality, volition, and an increase in dependence, and
- At its worst... can lead to the abuse of vulnerable people.

Moving from a 'safety first' to a 'risk taking' environment recognises that in ordinary life, people balance opportunities against risk all the time. A system that supports people with disabilities must be able to achieve this as well³³⁵. This is described as a 'risk-taking' approach which³³⁶:

- Celebrates the taking of risks as a way to enhance people's lives,
- Recognises the importance of psychological and emotional needs, as well as physical needs,
- Promotes choice and autonomy for the person and their family, and
- Promotes the rights of vulnerable people and their carers, while accepting that these will sometimes be in conflict.

³³¹ Report of the Expert Group on Resource Allocation (2010)...

³³² Health Service Executive (2009) *Risk Management in Mental Health Services*. HSE and Clinical Indemnity Scheme.

³³³ Ibid. p.5

³³⁴ Titterton, Mike (2005) *Risk and Risk Taking in Social Welfare*, London: Jessica Kingsley Publishers

³³⁵ Bonardi, A. (2009) *The balance between choice and control: risk management in New Zealand Intellectual disability services*. Fulbright: New Zealand

³³⁶ Titterton, Mike (2005) *Risk and Risk Taking in Social Welfare*, London: Jessica Kingsley Publishers

14.5.4c Guidelines for approaches to risk and managing risk

It is proposed that the overall approach to risk should be the application of general guidelines based on best practice approaches to safety and risk, on an individual basis according to the needs of abilities of each person. There is no ‘one-size fits all’ approach to risk. The adoption of such an approach results in some individuals being ‘over-protected’, with a resultant denial of their right to be participating members of the community and to be fully included. The effective management of risk, which includes the identification, analysis and mitigation of negative outcomes, is an important element of ensuring the quality of supports and services for people with disabilities.

Research has shown that well-designed systems of risk management must include^{337, 338};

- The person’s (and family as appropriate) assessment of risk (can be included in a comprehensive needs assessment although this can lead to an focus on deficits)
- Leadership that values and supports risk-taking (with appropriate safeguards)
- Effective communication protocols and information systems that inform providers of factors that place people at risk of harm
- A workforce that is skilled at facilitating choice and negotiating ‘risk dilemmas’ and has been trained in risk management
- A proportionate approach should be taken in formal inspection and regulation relating to risk and safety
- A collaborative approach between the person, their family and staff in recognising the obligations on all to minimise risk.

The HSE has issued a *Quality and Risk Standard*³³⁹ that describes a framework to manage risk through the implementation of an integrated quality and risk management system, and has adopted the *Australian New Zealand Risk Management Standard*³⁴⁰ which describes a process for risk management. This outlines the required processes for integrated risk management through the identification, assessment, treatment and monitoring of risk in the relevant context;

“The balance between choice (flexibility) and control (safety) will be best achieved through well-considered attention to the role of risk and risk management in [the provision of] supports”³⁴¹ p.vii

14.6 Processes for performance management, review and accountability

In 2008 the Organisation for Economic Cooperation and Development (OECD) carried out a *Public Management Review*³⁴² which found that accountability systems in the Irish public sector are currently characterised by compliance with rules, but they need to be more focused on outcomes. It recommended that better policy outcomes be achieved through ‘performance management’.

³³⁷ Ibid.

³³⁸ Health Service Executive (2009) *Risk Management in Mental Health Services*. HSE and Clinical Indemnity Scheme.

³³⁹ HSE (2007) *Quality and Risk Standard*. Office of Quality and Risk.

³⁴⁰ AS/NZS 4360: 2004

³⁴¹ Bonardi, A. (2009) *The balance between choice and control: risk management in New Zealand Intellectual disability services*. Fulbright: New Zealand

³⁴² Organisation for Economic Cooperation and Development (2008) *Ireland: towards an integrated public service*. Paris: OECD

14.6.1 Inputs ,outputs and outcomes

There has traditionally been a strong focus on inputs in the health system and the wider public sector services. **Inputs** can be defined as ‘anything a system uses to accomplish its purposes’³⁴³. This includes money, staff and processes (with process defined as the actual treatment or service delivery). A focus on inputs means there is a detailed tracking of money spent, staff and types of inputs/services. This helps ensure financial accountability. However, an excessive focus on inputs can often result in a failure to recognise the results these inputs are to achieve; that is, the outputs and outcomes.

Outputs are ‘anything a system produces’ (for example a number of school places or residential places) while **Outcomes** are ‘results, impacts and accomplishments’ (the effect of these places on the lives of those using them)³⁴⁴. Efficiency is usually associated with outputs, and effectiveness with outcomes.

Performance management is about how better outcomes can be achieved. In this case, we are interested primarily in better outcomes for the person (defined by them and including meaningful measures of quality of life and independence). However, better outcomes for the system in terms of greater efficiency and better value for money, are also essential.

14.6.2 Outcomes and accountability

This policy aims to have an explicit link between the vision and high level goals and the outcomes to be achieved. To arrive at a long-term positive outcome, it is necessary to create a thorough, strategic plan to focus efforts and evaluate progress. Ideally there should be a chain of outcome planning, with output statements as a mechanism to link policy goals with departmental strategies and with service plans to achieve the optimum outcomes/personal goals for individual service users³⁴⁵.

The OECD report recommends that output statements should:

- Have a limited number of clear, precise, measurable, high level and strategic goals;
- The strategic goals would be broken down into several operational goals which anticipate the actions needed to achieve the high-level goals;
- These operational goals should be quantified so that progress is measured and reported;
- The operational goals should also be expressed as outputs, not inputs and processes;
- They should be reported on regularly.

This template has been used to define the different levels of outputs and outcomes for this policy. These build from individual outcomes, which are defined in the needs assessment process and monitored and reviewed locally, to service provider outcomes and finally to system-wide outcomes. Guidance for the definition of outcomes is given here and possible service provider and system-wide outcomes are suggested. It is essential that the description and measurement does not become the end in itself. Outcomes are a means to clearly identify goals and activities to be undertaken and measure progress.

³⁴³ Martin, L.L. and Kettner, P.M. (1996) *Measuring the performance of human service programs*. Thousand Oaks, California: Sage

³⁴⁴ Ibid. p. 4 and 6

³⁴⁵ OECD 2008

14.6.3 Individual outcomes

The use of a comprehensive needs assessment tool should result in an individualised set of needs and goals, which can then be measured as outcomes. Goals are a record of what the person and his/her family as appropriate are aiming for over the next few months; what the person hopes to achieve in a short time period which may be an end in itself or may be building towards a more complex goal. Outcomes are the results of activities undertaken to achieve the goals. Individual goals and outcomes should be;

- **Defined by the person and their family** as appropriate. The necessary support should be provided for the person to do this
- **Specific not ‘fuzzy’** – clear, specific goals are unambiguous statements of what behaviour and activities are expected of service users, staff and others³⁴⁶. ‘Fuzzy’ statements are vague and open to misinterpretation; they tend to be ‘generic’. For example, a fuzzy, generic goal is “develop competency in domestic tasks” compared to a specific goal which is “load the dishwasher twice a week and Hoover the bedroom once a week.
- **Measurable** – a primary function of defining outcomes is to measure whether, and to what extent they are achieved or not. This does not mean that goals that cannot be measured (for example, expressed wishes and dreams) should not be recorded in the person’s plan. Goals and outcomes are the small steps that are required to work towards the person’s ultimate dreams and wishes
- **Achievable** – the outcome can be achieved within the time frame but progresses what has previously been achieved
- **Relevant** – takes the person’s context into account
- **Time limited** – there should be a target associated with each outcome, probably aligned with the review of the person’s plans, for example, six months.
- **Associated with the supports or services** which will enable the person to achieve that outcome. These do not have to be formal supports or services but can be family or informal supports.

14.6.4 Service provider outcomes

Service provider outcomes will reflect several functions; measuring the achievement of the outcomes for individual service users; measuring the various standards and regulations defined by regulatory authorities and those departments who fund the organisation or service; and measuring outcomes that the organisation may have defined for itself – the achievement of its own mission and goals.

The definition of outcomes will depend on these functions. Thus, aggregate reports of outcomes achieved for individual service users may be prepared.

14.6.5 System-wide outcomes

The system wide outcomes need to be defined on the basis of the desired impacts from the stated goals of the policy:

³⁴⁶ Arnold, S., Riches, V., Parmenter, T. and Stancliffe, R. *Instrument for the Classification and Assessment of Support Needs (I_CAN)* www.i-can.org.au

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

Goal 2: The creation of a cost-effective, responsive and accountable system to support the full inclusion of all people with disabilities

Possible outcomes for the goal of *full inclusion* may include, for example;

- % of people with disabilities living in ordinary community settings
- % of people with disabilities in employment/meaningful daily activity

Possible outcomes for the goal of *effective system* may include, for example;

- Comprehensive, objective needs assessment tool used to assess the support needs of people with disabilities
- Funding for supports and services based on assessed needs.

The explicit statement of outcomes in this way is useful in several regards. It can highlight where there are conflicting goals which hinder implementation. For example, if a service provider's outcome is to provide congregate residential care for people with disabilities, this service provider cannot support a person whose desired outcome is to live independently in the community. Similarly, if a stated national outcome is that people with disabilities live independently, funding given to this provider will not help achieve this goal.

14.7 Information systems

Comprehensive, real-time information systems will be required to ensure efficient monitoring and review of the various processes within the governance system, from individualised needs assessment, through to the preparation of a support plan; the formulation of an individualised budget; the coordination of required actions and supports; the identification of outcomes; and the monitoring and review of needs, supports and resources as required. While the existing databases provide an infrastructure which can be built on, it is essential that information will be input on a real time basis so that individualised data can be acted upon and aggregated to provide useful management reports. In view of the systemic changes proposed in this policy review, the functioning of the existing databases will need to be reviewed.

Essential requirements for such a system will be a unique identifier for each person and the ability to link records across sites. A comprehensive system will require significant investment in both IT infrastructure and in staff time and training.

14.8 Management structure

Section 2.1 described how the current configuration of many disability services is in the form of 'wraparound' service provision where all services and supports (such as health services, residential services and day services) are provided by one provider for an individual in a way that is often expensive and does not necessarily meet that person's individual needs or support 'a full life'.

It is clear from the description of the various supports and services required to achieve inclusion and self-determination for people with disabilities (under Policy Goal 1) that a wide variety of providers, both universal/mainstream and 'specialist disability' are required to meet the range of individual

needs. At the moment, almost all the needs of those people with disabilities in receipt of services are met within the health system, through block funding to disability services. The consequences of this system of service provision have been outlined in section 14.3.1.

Our disability service system is not currently configured to support the inclusion and self-determination of people with disabilities. Most services are provided in segregated, group settings and offer little opportunity for choice or self-determination. It is proposed that the model of a single provider meeting all of the needs of the individual should be replaced by a model which supports service users to access the services and supports they need from a variety of providers, both disability providers and mainstream/universal providers. This is echoed in the NDA advice paper;

“the model of a single service provider providing for the totality of an individual’s needs, often in a segregated setting, should be replaced by one where individuals are free to choose to receive different elements of service from different providers, including mainstream providers.” (p.28).

An appropriate management structure will be required to support this type of provision.

14.8.1 Management of health and personal social supports

It is proposed to separate out or ‘unbundle’ the central elements of services and supports so that provision more closely matches the individual needs of service users. There are three distinct inputs that people with disabilities currently receive from disability services funded by the health system;

1. **Clinical inputs** - which address the health needs of an individual, providing specific treatments to cure/ease specific symptoms and disorders. These inputs are provided by medical and therapy professionals, usually in disability service settings in the current model
2. **Therapy inputs** - which are aimed at increasing of sustaining functioning in various ways. These inputs are largely provided by therapy professionals and usually in disability service settings in the current model
3. **Personal social services** – to support people in activities of daily living (for example self care and accessing facilities in the community), with inputs from appropriate staff (such as personal assistants).

It is recommended that the provision of health services (e.g. clinical and therapeutic services) and the provision of personal and social supports should be managed separately.

14.8.2 Health management structure

There is already a structure in place for the provision and funding of health services for all citizens. This is based on provision by primary care teams and hospital services as appropriate, within integrated services areas. However, the provision of primary care teams is still underway and many of the therapy services required by people with disabilities are located (both physically and financially) within specialist disability providers. (It is estimated that about half the budget for therapy services for people with disabilities is allocated to voluntary disability agencies, who employ specialist therapists such as speech and language therapists, occupational therapist,

physiotherapists, psychologists, psychiatrists and others)³⁴⁷. Only individuals who are attached to a specific disability service can access these therapists, which results in considerable inequities for other people with disabilities.

The provision of health services for people with disabilities within the universal health structure must ensure that there is equitable access to mainstream and specialist therapies and other health inputs for all people with disabilities within a specific catchment area/integrated service area. This will require;

- Multidisciplinary early intervention teams to be in place throughout integrated service areas;
- Primary care teams to have access to the therapies that are currently located within disability providers (this can be achieved in a variety of ways depending on local circumstances);
- The availability of accessible primary care and other health services;
- Processes to ensure the services of private practitioners (such as GPs and dentists) within a catchment area are also available to people with disabilities. For example, every person with a disability who is entitled to a medical card should have their own individual card (this is not always the case at present, for example, group homes may have a 'group card'). In this way, the person can register with the medical practitioner they choose.

14.8.3 Personal social service management structure

The provision, funding and management of personal social services is currently embedded within the health service structure. This is the case for disability services and even outside of disability services, personal social services such as home helps come within the management and funding structures for all health services.

An appropriate management structure for personal social services should be put in place to ensure the delivery of such services to all people with disabilities (and other users of personal social services such as older people). A national director for personal social services will be required to head up such a structure with an appropriate, ring-fenced budget.

This management structure may remain within the HSE or may come under a different agency/department which has a remit for personal social services. An example of how this might work is where a person moves from a residential setting provided by a disability service. The provision of housing will be separate from the provision of health services and from the personal social services required to live independently. Thus, the person (if he/she is eligible) will have an assured tenancy on a home (through a Local Authority or a Housing Association), will receive health services from his/her local Primary Care Team and will receive Personal Assistant hours and other personal social supports from a registered service provider.

14.8.4 Linking up the services and supports

While the comprehensive wraparound service from one provider often serves to isolate the person with a disability from being fully included in their local community and from mainstream provision,

³⁴⁷ National Disability Authority (2010) *Advice paper to the Value for Money and Policy Review of Disability Services*. Dublin: NDA.

the advantage of such a model is the 'joined-up' nature of services. Thus there is little need for coordination of services across sectors. The proposed model of a variety of support providers, both specialist and mainstream, and the separate provision of health and personal social supports will require a greater degree of liaison and coordination across sectors. This will include personal social services such as transport and housing which come within the remit of other Government Departments.

At the individual level it will be necessary to have a single service coordination point, for example a key worker, link worker or 'support broker' so that the experience for the person with a disability is of the seamless, integrated provision of the appropriate supports and services. This will require;

- The provision of link workers and a single service coordination point (there is already potential within Part 2 of the Disability Act for such structures);
- The development of processes across departments and agencies to support a seamless, integrated service. For example, a commitment that service users are not 'passed around' to different departments, but that the initial point of contact that is made by the person has an obligation to find, and provide the contact details of, the most appropriate person within the relevant department/agency. This type of customer-friendly working process is envisaged in Transforming Public Services;
- At the system level a structure is required to streamline implementation of this new model and to ensure provision is not overly fragmented. The whole-of-government disability strategy already provides such a structure.

14.9 Recommendations

The group recommends that the processes for assessing the support needs of people with disabilities be reviewed taking into account the requirements for a needs assessment process as described in section 14.2.6.

The group recommends that the necessary actions be taken to put in place a system of individualised funding for people with disabilities. This system should include a range of options for the administration of individualised funding and should take into account the required processes for individualised resource allocation in Section 14.2.6.

The group recommends that a comprehensive commissioning framework for disability services be developed so that a range of service and support options will be available to people with disabilities.

It is further recommended that the current statutory framework governing Section 38 and Section 39 agencies be reviewed in light of the proposals around commissioning in this review.

The group recommends that a quality assurance system be put in place that is based on outcomes-based standards and has a focus on continuous quality improvement. Such a system should support an individualised approach to risk and should create a realistic and reasonable balance of regulation and risk based on the individual in context.

The group recommends that a management structure and operational processes be developed to support the model of provision recommended in this review and that within such a structure the

provision of health services (e.g. clinical and therapeutic services) and the provision of personal and social supports should be managed separately.

The group recommends that an appropriate information and data management system be developed to support the individualised funding and provision of supports and services for people with disabilities.

14.10 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 OECD³⁴⁸) will be essential. Implementation must focus on the achievement of specific outcomes and goals that are derived from the proposals set down in this policy review. Further details on the requirements for effective implementation are in Appendix 6.

³⁴⁸ Organisation for Economic Cooperation and Development (2008) *Ireland: towards an integrated public service*. Paris: OECD

Appendix 1

Other relevant policy and legislation

A number of other Irish policy and legislative provisions make reference to people with disabilities:

Health Strategy *Quality and Fairness*: Health policy for all members of society, including those with disabilities, is guided by the principles of Equity, People-centredness, Quality and Accountability which were set out in the Health Strategy – *Quality and Fairness – A Health System for You* (2001)³⁴⁹.

The four goals of the Strategy are; better health for everyone; fair access; responsive and appropriate care delivery and high performance. Quality and Fairness emphasises the importance of mainstreaming; *“that specific services for people with disabilities should be the responsibility of those government departments and state agencies which provide services for the general public”* (p.141). People-centredness was one of the four underpinning principles of the strategy. A people-centred system is one which identifies and responds to the needs of the individual; is planned and delivered in a coordinated way; and helps individuals to participate in decision-making to improve their health. The policy principle in *Quality and Fairness* pertaining to people with disabilities is *to enable each individual with a disability to achieve his or her full potential and maximum independence, including living within the community as independently as possible”* (p.141).

National Development Plan 2007-2013: This Plan outlines the investment under the People with Disabilities Programme and reaffirmed support for the continuing rollout of the NDS and for mainstreaming as provided for under the National Disability Act 2005. Investment in other sub-programmes, such as the special needs sub-programme under Education is also described in the Plan.

National Action Plan for Social Inclusion 2007-2016: This strategy for social inclusion is based on the lifecycle approach as outlined in *Towards 2016*. The strategic framework proposed in the plan facilitates greater coordination and integration of structures and procedures across Government at national and local levels as well as improved monitoring and reporting mechanism. The Action Plan describes several high-level goals for specific groups. The high level goal for people with disabilities focuses on employment and participation, with targets specified to increase the overall participation rate by people with disabilities in education, training and employment. Goals in relation to housing, health, community care and income support are also relevant to people with disabilities.

National Children’s Strategy : This strategy sets out a series of objectives to guide children’s policy over ten years (2001-2010). The emphasis in the Strategy is on listening to children and acting more effectively for children. Several national goals are recommended, including the statement that *Children will receive quality supports and services to promote all aspects of their development*. The National Children’s Strategy applies to all children. The vision and goals of the Strategy are endorsed by *Towards 2016*.

³⁴⁹ Department of Health and Children (2001) *Health Strategy: Quality and Fairness – A Health System for You* Dublin: Stationery Office

The National Children's Strategy³⁵⁰ sets out a series of objectives to guide children's policy over ten years (2001-2010). Objective J of the Strategy is specific to children with disabilities. It states that "children with a disability will be entitled to the services they need to achieve their full potential". Specific actions include:

- Supports necessary to enable children with disabilities to obtain a quality education will be developed, and participation of students with disabilities in third level education will be promoted through an access fund.
- Mainstreaming of disability services to provide for inclusion and equality for people with disabilities in accessing public services.

Many of the actions proposed have been implemented, such as the development of the NDA, the enactment of the Equal Status Act and the development of the EPSEN Act.

The Agenda for Children's Services:³⁵¹ is a more recent document which sets out the strategic direction and key goals of public policy in relation to children's health and social services in Ireland. The key messages of existing policies in relation to children promote; a whole child/whole system approach to meeting the needs of children and a focus on better outcomes for children and families. The Agenda draws together the various outcomes in children's policy:

*The Seven National Service Outcomes for Children in Ireland*³⁵²:

1. Healthy, both physically and mentally
2. Supported in active learning
3. Safe from accidental and intentional harm
4. Economically secure
5. Secure in the immediate and wider physical environment
6. Part of positive networks of family, friends, neighbours and the community
7. Included and participating in society.

A Vision for Change 2006: This document set out government policy on mental health. The policy describes a comprehensive framework for building and fostering positive mental health across the entire community and for providing accessible, community-based, specialist services for people with mental illness. Recommendations on mental health services for people with intellectual disability are also included in this policy.

The Developmental Welfare State³⁵³ (DWS): While the DWS is not a policy document, it has had a strong influence on shaping government policy since 2005. This report states that *the task of the social policy system should, first and foremost, be to support and facilitate the development of each person, enabling them to reach their full potential*. The report is also clear on the need for change within a value for money context, and notes that Ireland is being challenged to *revise systems that embody low expectations and achieve low outcomes for a minority, to support its population more*

³⁵⁰ Department of Health and Children (2000) *National Children's Strategy*. Dublin: Stationary Office

³⁵¹ Office of the Minister for Children (2007) *The Agenda for Children's Services: A Policy Handbook*.

³⁵² Office of the Minister for Children (2007) *Ibid.* p. 12

³⁵³ National Economic and Social Council (2005) *The Developmental Welfare State*. The Stationery Office, Dublin.

adequately in changed times, and to institutionalise wholly new standards of participation and care for its most dependent and vulnerable members. In many instances, additional resources do not guarantee the outcomes sought. New ways of working, new policy instruments and institutional innovations are required if additional resources are to be effective in significantly improving on social outcomes.

Equality Act 2004: This Act promotes equality, prohibits discrimination across nine grounds (including disability) and allows for positive action measures to ensure full equality in practice. The Equality Act amended the Employment Equality Act 1998 and the Equal Status Act 2000. The Employment Equality Act 1998 is based on the principle of equal treatment between persons with and without a disability. Employees, trainees, job seekers and workers have a right not to be discriminated against, when compared to workers without a disability. Employers have an obligation to reasonably accommodate workers with a disability.

Mental Health Act 2001: This Act replaces legislation that regulated involuntary admission to mental hospitals (Mental Treatment Act 1945). The Mental Health Act 2001 has two main functions; to promote the establishment and maintenance of high standards in the delivery of mental health services and to protect the interests of those detained in mental hospitals. The Act led to the establishment of the Mental Health Commission, the Inspectorate of Mental Health Services and Mental Health Tribunals to review detentions. The definition of mental disorder in the Act includes significant intellectual disability with specified co-occurring characteristics.

Office for Disability and Mental Health

In January 2008, the Government announced the establishment of the Office for Disability and Mental Health to support the Minister for Disability & Mental Health in exercising his responsibilities across four Government Departments: Health & Children, Education & Science, Enterprise, Trade & Employment and Justice, Equality & Law Reform.

The Office brings together responsibility for a range of different policy areas and State services which directly impact on the lives of people with a disability and people with mental health issues. The stated aim of the office is *“to bring about improvements in the manner in which services respond to the needs of people with disabilities and mental health issues, by working on a cross-sectoral basis to develop person-centred services, focussing on the holistic needs of clients and service users and actively involving them in their own care”*³⁵⁴.

Among the key priorities for the Office for Disability and Mental Health are³⁵⁵:

- supporting the implementation of the Health Sectoral Plan under the Disability Act 2005. The Office will focus in particular on facilitating the delivery of integrated health and education support services for children with special needs, by further developing existing mechanisms for co-operation and co-ordination between the health and education sectors, both at national and local level; and

³⁵⁴ Speech by John Moloney, TD, Minister for Equality, Disability and Mental Health, June 2008

<http://www.dohc.ie/press/speeches/2008/20080624.html>

³⁵⁵ Ibid.

- developing an appropriate continuum of training and employment support services for people with a disability by working together with the Dept. of Jobs, Trade and Innovation, FÁS and the HSE.

Regular meetings are held with the Secretaries General of the relevant Departments and the Director of the Office to progress the priority areas. The Office for Disability and Mental Health creates a tangible structure to enable 'joined-up government' to happen, and generates a more coherent and integrated response across Government Departments and agencies to the needs of people with disabilities and mental health issues.

Appendix 2

What works in combating stigma?

Presenting stigma as problems of knowledge, attitudes and behaviour, helps to frame problems in ways that lead to action and makes interventions more manageable, i.e. to develop effective interventions in at least one of these domains. Actions designed to tackle stigma typically employ education, contact and challenge³⁵⁶. These areas are similar to those recommended by the NDA in the 2004 report *Strategic options for influencing public attitudes towards people with disabilities in Ireland*; 1) contact with people with disabilities, 2) giving information and 3) providing experiential learning opportunities as three major ways for changing public attitudes to disability.

1) Education

Educational programmes that work typically target specific audiences, support local activity, and involve people with first-hand experience of discrimination. For example, a public education programme for local residents beside a community-based group home (for people with mental health difficulties) resulted in these residents being three times more likely to visit the group home than others who had not received the education programme³⁵⁷. Disability awareness training has also been shown to be effective in challenging and changing negative attitudes and stereotypes of people with disabilities in a variety of settings³⁵⁸.

Contrary to popular perception, media campaigns alone are not an effective means of changing attitudes or addressing stigma^{359, 360}. However, the media can be important in determining attitudes to and knowledge about disability. The NDA BCI guidelines are designed to address this...

2) Contact

The positive effects of contact in changing attitudes and reducing stigma have been noted in several contexts^{361, 362}. Research has shown that contact works well, particularly under the following conditions;

1. Under conditions of equal status
2. In situations where stereotypes are likely to be disproved
3. Where inter-group cooperation is required
4. Where participants can get to know each other properly
5. Where wider social norms support equality.

³⁵⁶ Corrigan, P. & Penn, D.L. (1999) Lessons from social psychology on discrediting psychiatric stigma. *American Psychologist*, 54, 765-776.

³⁵⁷ Social Exclusion Unit (2004) *Mental health and social exclusion*. London: Office of the Deputy Prime Minister

³⁵⁸ National Disability Authority (2007b) *Literature Review on Attitudes Towards Disability*. Dublin: NDA.

³⁵⁹ Brown, P. (1996) A review of mass media campaign as a form of health education. *Journal of International Health Education*, 2, 34.

³⁶⁰ Crisp, A.H., Gelder, M.G., Rix, S., Meltzer, H.I., Rowlands, O.J. (2000) Stigmatisation of people with mental illnesses *The British Journal of Psychiatry* 177: 4-7

³⁶¹ Hewstone, M. (2003) Inter-group contact: Panacea for prejudice? *The Psychologist*, 12 (7), 352-355

³⁶² Desforjes, D.M., Lord, C.G., Ramsey, S.L. *et al.*, (1991) Effects of structured cooperative contact on changing negative attitudes toward stigmatized social group. *Journal of Personality and Social Psychology*, 60, 531-544.

Contact between disabled and non-disabled people seems to “work more than any other method [in changing attitudes] – more, for example, than big communications campaigns”³⁶³.

A ‘hidden’ advantage of the provision of services in community-based settings is the increased visibility of people with disabilities and increased opportunities for contact in ordinary, everyday settings such as the local shop or local pub;

“As more people with disabilities participate in all aspects of ‘mainstream life’, the general population will become increasingly informed and this should help them to abandon stereotypes based on ignorance.”(p.46)³⁶⁴

3) Challenge

The disability-inclusion model has been recommended as very useful for reducing discrimination, as the issue is framed in a way that emphasises that; “individuals have legal rights to particular benefits, rather than be assessed as ‘worthy poor’ to receive discretionary charity”³⁶⁵. It has also been recognised that within the EU “there has been a paradigm shift from a charity-based to a rights-based disability policy”³⁶⁶. This creates a legal framework within which people with disabilities can exercise their legal entitlements using disability discrimination laws. The presence of legislation has a powerful additional function in sending a message that discrimination is wrong in law and wrong in wider society.

The role of disabled people

The presence of negative attitudes among certain groups of people with disabilities towards others with different disabilities has been named by Deal, a professional with a disability³⁶⁷. He has noted that collaborations between organisations of people with disabilities have been rare and that much can be gained by working together;

“If minority groups can work in unison, such coalitions based on the demand for social change can be much more powerful than working in silos. Each minority group, whilst respecting the uniqueness of their agenda, can gain greater influence by finding those areas of commonality³⁶⁸”.

The evidence shows that interventions aimed at changing stigma or its components parts; ignorance, attitudes, and behaviour; need to be multifaceted and wide-ranging. Legislation creates a legal framework for the pursuit of rights and outlaws discrimination; education challenges negative attitudes and stereotypes; and contact provides the most direct challenge to negative attitudes and stigma.

³⁶³ Massie 2006 citing Hewstone 2003

³⁶⁴ National Disability Authority (2007b) *Literature Review on Attitudes Towards Disability*. Dublin: NDA.

³⁶⁵ Oliver, M. and Barnes, C. (1998) *Disabled People and Social Policy*. London: Longman

³⁶⁶ Thornicroft, G. (2006) *Shunned: Discrimination against people with mental illness*. Oxford University Press p.241

³⁶⁷ Deal, M. (2006) *Attitudes of Disabled People towards other Disabled People and Impairment Groups*. Doctoral Thesis, City University London (Health Care Research Unit, School of Nursing and Midwifery

³⁶⁸ Deal, M. (2006) *Ibid*. p.453

Appendix 3

Towards a shared language

Independent living

Independent living is a policy concept about supporting disabled people to live their lives as full citizens and have choice and control over the way in which their care is delivered³⁶⁹. It is much broader than simply where a person lives; it is about how a person lives. A widely used definition is:

“Independent Living” means that disabled people have access to the same life opportunities and the same choices in everyday life that their non-disabled brothers and sisters, neighbours and friends take for granted. That includes growing up in their families, being educated in the local neighbourhood school, using the same public transport, getting employment that is in line with their education and skills, having equal access to the same public goods and services. Most importantly, just like everyone else, disabled people need to be in charge of their own lives, need to think and speak for themselves without interference from others.

Jane Campbell, Chair of the Independent Living Expert Panel.

Supported living

Supported living is a term generally used in the UK to encompass a range of services designed to help people with disabilities retain their independence in the local community.

A definition in the US describes supported living as “A group of individually determined services designed and coordinated in such a manner as to provide assistance to adult clients who require ongoing supports to live as independently as possible in their own homes, to be integrated into the community, and to participate in the community life to the fullest extent possible.”

http://www6.miami.edu/futureplanning/residential_def.html

Supports

The term supports is used as an adjunct to services (as in ‘services and supports’) to denote the interventions a person with a disability may need to live independently. The use of the term supports indicates an active role by the person in determining the assistance/supports they need. This is in contrast to ‘service’ where the person is in a more passive role using the services that are provided. Supports include assistance provided by others, whether in the form of personal or nursing care, communication or advocacy support, learning support, therapeutic interventions, aids and equipment, adaptations to the physical environment, and so on. The term supports is used throughout this policy document to indicate the range of assistance and interventions required to fully realise independent living for people with disabilities.

³⁶⁹ Hurstfield, J., Parashar, U. and Scofield, K. (2007) The costs and benefits of independent living. Office for Disability Issues. Leeds, Her Majesty’s Stationery Office.

Supported employment

Supported Employment enables people with disabilities to access real employment opportunities, of their choice, in an integrated setting with appropriate ongoing support being provided to enable them to become economically and socially active in their communities. Supported Employment provides support to job seekers with disabilities and their employers and co-workers. The support given allows individuals with disabilities to become and remain gainfully employed. People with a wide range of disabilities e.g. physical, sensory and intellectual disabilities as well as people with mental health difficulties, have become successfully employed using the Supported Employment Model. http://www.iase.ie/pages/about/about_supported_employment.html

Universal services: Services that are available to all members of the population, i.e. those provided by Government Department, state agencies and other publicly funded services.

APPENDIX 4

Direct payments

Direct payments in the UK: In the UK, persons eligible for direct payments are those assessed by Health Trusts as needing personal social services, who are over 16 years and are ‘willing and able’ to manage Direct Payments alone or with support. Direct payments can be used for any personal social service (except for permanent residential care) and are also available to disabled people older people who get services from a Health Trust, disabled parents, parents of disabled children and other carers. Direct payments are essentially cash payments instead of Trust services. The individual uses the payment to arrange their own support. Over 1,100 people in Northern Ireland currently receive direct payments. The direct payments system in Northern Ireland is administered by the Centre for Independent Living (CIL) in Belfast, which also provides support to individuals receiving direct payments through Independent Living Advisors. Funding for the Belfast CIL is provided by the trusts.

An analysis of the experience of local councils in the UK (CSED doc) provided recommendations to ensure the cost-effective implementation of direct payments. This research concluded that in order to be cost-effective, direct payments must be embraced as a core component of delivering support, not as an exceptional or incremental process. In this way, the savings from traditional provision could be realised. There were initial costs in setting up an effective direct payments support service, but once fully operational, direct payments should be cost-neutral. For some Councils there were opportunities to make savings on the basis of significantly reduced costs associated with procurement and payment systems for service providers. These savings were dependent on flexible redeployment of staff and systems. An important conclusion was that direct payments should be measured by outcome as well as cost; simplistic comparisons of the price of an hour’s delivered care were not appropriate. A focus on cost control during the move to a direct payment system was important. Examples of this included ensuring that any outsourced services (e.g. direct payment support services) were cost-effective and considering a ‘light touch’ audit and review of direct payment users.

Direct payments in Sweden: The system in Sweden followed the introduction of the Personal Assistant Act in 1994³⁷⁰. Sweden is the only EU country which confers a right in law to a personal assistant without regard to cost. This Act allows for PA cover for all assessed needs, is not means tested and includes a payment to cover the administrative costs associated with direct payments. There is one centralised source of funding for all PAs – the National Social Insurance Fund. Approximately 14,000 people are entitled to PAs currently. Most users (55%) buy their services from local government (municipalities) who traditionally provide a home-help type service, 12% manage their service through cooperatives while another 30% used commercial companies to provide their PA service. Only 4% act as direct employers to their personal assistants.

³⁷⁰ *ibid*

A cost analysis of different forms of services and supports to people with extensive functional impairments was carried out. The study was prompted by concerns over the continued increase in both the number of people eligible for assistance and the average number of hours of assistance granted, since the inception of the scheme in 1994. The Swedish National Audit Office proposed that the target group for personal assistance should be limited on the basis that people with reduced autonomy should be living in group homes. This was based on the belief that group homes were less expensive than personal assistance.³⁷¹

The costs of personal assistance and group homes were compared very carefully, for people with major functional impairments in JAG (include note to explain what JAG is) and four group homes. This cost analysis highlighted instances of inefficiencies that can occur in inflexible settings where, for example, three employees spent six hours of one afternoon per week with no service users in the house as they all were in activities on that day.

The results of the study showed that supporting a person with extensive functional impairments in a group home is often more expensive than the cost of personal assistance. The provision of personal assistance leads to additional benefits such as greater flexibility and freedom of choice for the person thus leading the authors to conclude that personal assistance was more cost-effective. There was a marked difference in the quality of support; *The staffing of the group homes is not tailored to provide continuous individual support, but is instead based on the users either managing independently for some of the time, or being able to “wait their turn” if everyone on the staff is busy* (p.18, 2006¹⁰⁴).

Consumer directed services in the US: A national review of the implementation of consumer-directed services (CDS) for people with intellectual or developmental disabilities in the United States examined the extent to which states have implemented both individual budgets and consumer control over services for Home and Community Based Services (HCBS) recipients with intellectual disabilities.³⁷² Consumer control was defined as both individual budgets and decision-making authority over the budget. This study found that CDS have been implemented to a variable extent across the states. Thirteen states had state-wide availability of individual budgets and consumer control for at least some HCBS recipients with IDD. A further eleven states had a consumer-directed option available as a pilot to a limited number of people or available within a limited geographic area. Eight states were in the final stages of development of a consumer-directed option and 18 states had not established individual budgets and consumer control and did not anticipate doing so. The number of CDS participants ranged from 15 individuals in a small pilot in Oklahoma to 4,000 individuals enrolled in the consumer-directed option in Oregon.

Although many states have not yet formally evaluated the impact of CDS, these options were reported to be highly successful and satisfactory to those who use them. Findings on cost are variable, with some states reporting significant savings, others reporting cost neutral and others reporting CDS as being more expensive. These are initial findings and formal cost-effectiveness

³⁷¹ National Audit Office (2004) *Personal Assistance for people with functional impairments*. Riksrevisionen, Sweden.

³⁷² Policy Research Brief (2009) *Implementation of Consumer-Directed Services for Persons with Intellectual or Developmental Disabilities: A National Study*. Research and Training Centre on Community Living. University of Minnesota.

studies are required. It is recommended that costs are assessed within the service system as a whole to assess impacts on other cost areas (e.g. possible decreases) and that wider benefits also need to be taken into account. This review also recommended that adequate information, training and support 'needs' be provided to the individual and their family, and that a separate broker role should be formulated to assist families in administering the payments. Different levels of assistance are also recommended so that some individuals can choose to completely administer their budget while a variety of supports are available to others depending on their needs. Significant changes need to be made to information technology systems to support this different way of allocating funds. Much more complexity is involved in making 100 separate payments to different individuals compared to one contract payment to provide a service to 100 individuals. Monitoring and quality assurance systems also need to be modified for the same reasons, as do the systems ensuring accountability and equity. Finally, many states reported a loss of flexibility when they moved from pilot level to state-wide consumer control options. The administration and monitoring systems described above need to become more formal when this increase in scale is achieved.

Appendix 5

I-CAN support Needs Assessment

I-CAN has four Domains:

1. Health and well-being

- Physical health
- Mental and emotional health
- Behaviour of concern
- Health and support services

2. Activities and participation

- Applying knowledge, general tasks and demands
- Communication
- Self-care and domestic life
- Mobility
- Interpersonal interactions and relationships
- Lifelong learning
- Community, social and civic life.

3. About me – my dreams and aspirations, current life situation and support network.

4. My goals

The ratings for frequency of support range from Never – no support needed, through occasionally, monthly, weekly daily to constant (support required a number of times per day or consistently throughout the day). Ratings for the level of support range from Independent (the person does not need any support) through managed, minor, moderate, extensive, to pervasive (person requires the direct support of two or more people due to this health need or to complete this activity).

Appendix 6

Considerations for formulating an implementation plan

Too often the challenges involved in turning a policy idea into effective outcomes, and the skills and effort required to do so, are not fully appreciated. Too often the results fall short of expectations. Yet we know that defects in implementation rob the community of the full benefits of a new policy and waste community resources. (p.i)³⁷³.

1. Introduction

The evidence-based factors which characterise successful implementation are presented in this Appendix. These factors provide a guide to essential activities, tasks and roles to ensure effective implementation. An initial framework for developing an implementation plan is also proposed, with a focus on achieving specific outcomes.

The final implementation document should outline a 7-10 year plan to bring about inclusion and self-determination for people with disabilities and to create a system of support to achieve this goal. The overall aim of the implementation plan is to reconfigure the disability service system away from the delivery of segregated services in group settings and towards a system of individualised supports which have the express objective of achieving inclusion and self-determination for the individual with a disability. It is also essential to ‘future-proof’ the new system of individualised supports and to create a disability support system which will not just meet the needs of those people with disabilities currently in receipt of services, but also those who, in the future, may acquire a disability, and children who will be born with a disability.

The need for a change in how people with disabilities are supported has already been outlined (ref the policy overview paper). The proposed policy will require a substantial timeframe to be fully implemented; at least 7-10 years. The policy and action steps proposed here are based on practices and policies that have been successfully implemented elsewhere³⁷⁴. There are several possible courses of action that may be taken, including no change or minimal change ‘at the margins’ in an attempt to improve efficiency. However, it should be recognised that a lack of action will have serious negative consequences for people with disabilities and for the service system itself. People with disabilities will continue to receive services in segregated settings, in groups and services which do not necessarily work to increase integration and self-determination. A costly, inefficient system will also remain in place, using all available resources and therefore presenting an opportunity cost to those not yet in receipt of any services. Similarly, minimal changes to achieve marginal improvements will not bring about the long-term sustainability and efficiency which is required, nor

³⁷³ 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

³⁷⁴ Illinois paper

will it address the wishes and concerns of people with disabilities and their families. What is required is a challenging and complete system change in the way disability services are organised and managed, and how resources are allocated. Without this level of change, the desired policy objective of inclusion and self-determination for people with disabilities will not be fully achieved.

2. Evidence-based implementation

There is broad agreement that implementation is highly complex, and that *every aspect is fraught with difficulty, from system transformation to changing service provider behaviour and restructuring organisational contexts*³⁷⁵. The need for specific skills and competencies in implementation is not often acknowledged³⁷⁶. In commenting on the progress in Ireland in modernising public services, the OECD noted that *significant capacity building in terms of deepening project management and implementation skills is still required*³⁷⁷.

A systematic review of the wider implementation literature has indicated that *effective implementation is synonymous with coordinated change at system, organisation, programme and practice levels*³⁷⁸. It is essential that evidence on what has worked well in terms of implementing policy elsewhere is used to inform the implementation process for the proposed Disability Policy. Several factors that have characterised successful implementation in other jurisdictions have been identified³⁷⁹. It is acknowledged that the reality of implementation is considerably more complex than the rational order proposed by these factors. However, there are essential tasks and activities that need to take place in a certain order to increase the chances of effective implementation of a policy. These tasks and activities occur in three broad stages, the policy formulation process, the implementation process itself and monitoring^{380,381};

2.1 Pre-implementation: Policy formulation process

1. *Make implementation an important consideration during policy design* – this includes identifying different means of achieving policy objectives and identifying barriers to implementation. The inclusion of experienced implementers at the policy formulation stage can be important in assessing the feasibility of proposals. A consideration of risks, challenges and specific aspects of the policy that may impact on implementation should also be considered at this stage^{382,383}.

³⁷⁵ Fixsen, D. L., Naoom, S.F., Blase, K.A., Friedman, R. M. and Wallace, F. (2005) *Implementation Research: A Synthesis of the Literature*. University of South Florida, Tampa, Florida.

³⁷⁶ Mental Health Commission (2009)

³⁷⁷ OECD (2008) *Public Management Reviews: Ireland Towards an Integrated Public Service*. OECD: Paris

³⁷⁸ Fixsen, D. L., Naoom, S.F., Blase, K.A., Friedman, R. M. and Wallace, F. (2005) *Implementation Research: A Synthesis of the Literature*. University of South Florida, Tampa, Florida.

³⁷⁹ This section draws substantively from a publication by the Mental health Commission (2009) and from publications by the WHO and the Australian Government

³⁸⁰ World Health Organisation (2003) *Mental Health Policy, Plans and Programmes*. Mental Health Policy and Service Guidance Package. WHO, Geneva.

³⁸¹ 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

³⁸² Ibid. Department of the Prime Minister and Cabinet (2006)

³⁸³ Harvard Business School (2003) *Managing Change and Transition*. Harvard Business School Publishing, Boston.

2. *Involve as many stakeholders as possible in policy formulation process* – including and consulting with stakeholders serves to inform the policy and also the implementation of the policy. It also facilitates other tasks such as the dissemination of the policy and the generation of support.
3. *Disseminate the policy* – all stakeholders need to know about the new policy. A rolling programme of communication, using different media and engaging with different stakeholders creates awareness and understanding of proposed changes and also helps to generate support.
4. *Generate political support and funding* – active stakeholder participation and communication activities are important in achieving this. Political leadership and support can be crucial in ensuring implementation.

2.2 Implementation

5. *Appoint a leader and an implementation team* – the WHO reports that a multidisciplinary team to implement policy has proved successful in several countries. The leader and team members should be individuals with the appropriate skills, time and decision-making responsibility to ensure effectiveness³⁸⁴.
6. *Establish an implementation structure* - This national team should be echoed regionally and locally with, at a minimum, a regional leader and local leaders of the process. These local leaders and teams should be individuals with the appropriate skills, time and decision-making authority to ensure effectiveness.
7. *Provide the necessary resources*– sufficient skilled attention to identifying the appropriate funding for implementation is identified as a key success factor. This includes *an appropriately crafted budget, including managing contingency funding and financial risk*. It is also strongly recommended that *appropriately skilled and experienced financial management personnel should be part of the implementation team*³⁸⁵. The type of *long-term strategic budgetary frameworks* suggested by the OECD³⁸⁶ would provide a mechanism to allocate and manage the resources required to implement the new policy.
8. *Prepare a plan* - Systematic and structured implementation planning is essential. *A level of management experience and skills commensurate with the sensitivity, significance and impact of initiatives should be applied to the development of implementation planning. It is important to avoid the assumption that this is a low level technical task*³⁸⁷. An implementation plan should provide a map of how the policy will be implemented and should deal in sufficient detail with:
 - a. Timeframes, including the different phases for implementation
 - b. Roles and responsibilities of those involved in implementation
 - c. Resources, including funding and human resources
 - d. Risk management, including how any potential barriers to implementation will be addressed

³⁸⁴ Ibid. World Health Organisation (2003)

³⁸⁵ Ibid. Department of the Prime Minister and Cabinet (2006)

³⁸⁶ OECD (2008) *Public Management Reviews: Ireland Towards an Integrated Public Service*. OECD: Paris

³⁸⁷ 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

e. Monitoring and reporting requirements.

In implementing a complex, multi-layered policy, it may be necessary to have an overall plan for the complete policy and sub-plans or strategies which deal with specific complex tasks within the plan. These strategies should have the same format, with sufficient detail on timeframes, roles and responsibilities, resources, risk management and monitoring. The importance of implementation planning is recognised by the Task Force Report on the Public Service³⁸⁸, which contains an implementation strategy, with identified leadership and a leadership team (a proposed Programme Office), defined accountability, and dedicated resources to achieve the implementation.

9. *Communicate* –the need to *communicate relentlessly*³⁸⁹ throughout any change process has been highlighted. Policy implementation represents an extensive and complex change process, underlining the importance of communication. Communication is critically important to implementation because it is *an effective tool for motivating employees, for over-coming resistance to an initiative, for preparing employees for the pluses and minuses of change and for giving employees a personal stake in the process*³⁹⁰. For communication to be effective, especially during a change or implementation process, it must be ongoing; a single ‘big bang’ announcement will not produce significant benefits. This is even more important when other changes are also taking place in the organisation, and when there are other adverse events that need to be managed, such as financial cuts. Effective, ongoing communication is also essential for building and maintaining trust among staff. One business leader who turned around a failing company changed the communication policy, from “don’t tell anybody anything unless absolutely required” to “tell everybody everything”. He realised that *cultivating honesty, trust, dignity and respect becomes the job of the leaders. It may even be their most important job*³⁹¹.
10. *Include stakeholders and promote stakeholder interaction* – Stakeholder management is a key aspect of implementation. The purpose of stakeholder inclusion in the implementation process must be clear so that the right stakeholders can be identified. For example, is their inclusion to obtain support, to provide a communication channel or to test the design or roll-out? Multiple interactions between different stakeholders need to take place at different levels. For example, between the Department of Health and Children and the HSE; between management and mental health professionals within the HSE; between service users and the HSE.
11. *Support interdepartmental coordination* – several departments outside health provide services for people with disabilities. An overall coordinating role is essential to ensure all relevant departments are implementing actions within their remit of responsibility³⁹². Where cross-agency implementation is necessary, the likelihood of effective implementation is greater where there is a high-level implementation plan involving the relevant agencies.

³⁸⁸ Task Force Report

³⁸⁹ Harvard Business School (2003) *Managing Change and Transition*. Harvard Business School Publishing, Boston.

³⁹⁰ Ibid. Harvard Business School (2003) p.60

³⁹¹ Brennerman, G. (1998) Right away and all at once: How we saved Continental. *Harvard Business Review*, 76, no. 5.

³⁹² World Health Organisation (2003) *Mental Health Policy, Plans and Programmes*. Mental Health Policy and Service Guidance Package. WHO, Geneva.

The need to *think about the Public Service as an integrated “system”* has also been emphasised by the OECD³⁹³, and is an underpinning principle of the Report of the Task Force on the Public Service³⁹⁴.

2.3 Monitoring

12. *Put in place a governance structure* – governance arrangements are required to ensure adequate reporting and review mechanisms. Monitoring is essential to determine if the desired outcomes are being achieved and also to identify risks to implementation so that corrective action can be taken. *Monitoring and review is more effective when it is performed by personnel with skills and knowledge specific to the implementation being undertaken*³⁹⁵. Timely and relevant information also needs to be readily available.

3. Implementation framework

A number of action areas have been identified which will focus on achieving specific outcomes through a number of specific actions.

Action areas: *(note these are initial suggestions and can be refined with further discussion)*

1. Support people with disabilities in the most integrated setting possible

Publicly-funded supports and services for people with disabilities must be provided in the most integrated setting possible. For example, residences should not have more than 4 people and should not be located in campus settings...etc.

2. Support people with disabilities in an individualised, person-centred way to achieve valued outcomes

Supports should be based on an individualised assessment leading to the development of a plan by the person and their family as appropriate, and with the necessary support. Services and supports themselves should be provided in an individualised, flexible way so that the person can achieve their desired and valued outcomes. Services and supports should promote outcomes such as personal self-determination and independence, employment/meaningful activity and community inclusion.

3. Expand and develop a wider range of integrated settings and supports and providers of same

A wide range of supports and services will be required to address the varied needs of people with disabilities which is not generally available throughout the country. Providers should be encouraged and supported to provide a wider range of supports in that comply with and support the policy objectives.

³⁹³ Ibid. OECD (2008)

³⁹⁴ Task force report

³⁹⁵ 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

4. Develop a system of individualised funding

Individualised funding has been identified as the key mechanism by which people with disabilities can achieve greater self-determination and also the mechanism by which the flexibility and wide range of individualised supports can be provided.

5. Design support and service coordination and management from the point of view of the service user, with one point of access and 'support brokers'

The model proposed here will be more diffuse and dispersed than was previously the case (i.e. people with disabilities will no longer have to receive all their supports from one provider). It is essential that the service user experiences a single 'point-of-entry' system and that the coordination and management of the variety of supports and services is carried on in the background and is not the responsibility of the service user. An effective, adequately resourced and independent coordination system (such as a support broker) should be put in place to do this.

6. Measure and monitor performance and quality

The achievement of valued outcomes for individuals should be monitored. Quality assurance systems must be in place to ensure the safety of persons using services and supports and to assist in balancing safety, risk and individual self-determination.

7. Promote efficiency and value for money in the provision of supports

This means creating an emphasis on using public funds in the most effective and efficient way possible to achieve desired outcomes, using lower cost services and supports that can achieve desired outcomes, building on informal supports such as those available in families and communities to achieve greater inclusion and self-determination.

For each of these action areas, a number of outcomes and actions need to be developed. For example, under Action Area 1, *support in integrated settings*, the whole of the congregated settings report and its actions will be brought in to address accommodation in more integrated settings, changes to how day supports are provided will be another large area which will need its own set of actions, full mainstreaming is another area which will need an action list, and so on for each action area. Table 1 below presents a possible framework for addressing this.

In addition, there are a number of key issues which may be relevant to each action area, and specific actions can be grouped or categorised according to these issues;

- Legislative changes
- Resource allocation
- Required management structure
- Manpower issues
- Developing service user, provider and community capacity.

For example, the implementation of Action Area 4 Individualised funding, will require legislative changes, will involve training and supporting service users, and will require the expansion of support options. This also highlights the inter-relatedness of the different Action Areas, and will require a complete and carefully sequenced implementation in order to achieve the changes required which will result in the efficiencies required to create a sustainable disability support system.

Table 1: Outline implementation framework for each action area

ACTION AREA 1: Support people with disabilities in the most integrated setting possible				
SPECIFIC ACTIONS:	Timeline	Key dependencies	Responsible person/agency	Outcome monitoring/ Targets
Implement recommendations of <i>Congregated Settings</i> report 1. Action... 2. Action... 3. Action... 4. Etc.				
Implement recommendations of <i>Day Services Review</i> report 1. Action... 2. Action... 3. Action... 4. Etc.				
Etc...				

Notes:

Key dependencies should include issues such as the removal of legislative and policy barriers to a specific action, the achievement of actions under other Action Areas so that sequencing can be managed etc.