

National Disability Authority

Advice paper to the Value for Money and Policy Review of Disability Services Programme

July 2010

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Summary conclusions

Ireland's vision for people with disabilities should be that they are supported to live full lives, of their choosing, in the mainstream community. This vision should underpin all services to people with disabilities, whatever the nature of their disability, be it physical, sensory, intellectual or mental health. Refocusing the current orientation, funding and systems for disability services can achieve better outcomes for people with disabilities. Funding for disability services should be explicitly linked to programmes to support people with disabilities to live the lives of their choice; to support people with disabilities to live in the community as independently as possible; to support people to access mainstream services and facilities and to give people choice about how their support is delivered.

This task is not one for disability services alone - mainstream housing, health, employment and community services, together with specialist disability services, need to provide a coherent framework of support for individual citizens with disabilities.

A higher proportion of people with intellectual disabilities live lives that are apart from their communities. Services for people with intellectual disabilities account for the largest share of disability service funding. So this area needs to be a significant focus for change.

Better value for money can be achieved from existing resources by moving away from over-medicalised and professionalised models of care, by moving to more flexible models of support focused on greater independence of individuals, and by introducing a transparent system of resource allocation. This would result in more efficient use of resources, and better value from the monies invested in terms of individuals' quality of life.

The NDA advises that

- the following values should underpin disability service provision, through being incorporated as conditions for the award of funding, and embedded in mandatory service standards:
 - person-centredness, inclusion, community integration, participation, independence, and choice
 - individuals with disabilities should be supported to live the lives of their choice in the mainstream of the community
- achievement of these outcomes should be supported by enactment of Regulations and mandatory service standards, by registration of service providers, by measurement of a clear set of outcomes under Service Level Agreements and by a robust system of oversight
- there must be a variety of options available if people with disabilities, with diverse needs and preferences, are to get the supports they require
- a new system of resource allocation, framed upon individualised funding, should be introduced, based on assessments of need of individuals, and of their changing needs over time

- this individualised funding - "money follows the person's needs"- should replace the block funding of providers in relation to their person-to-person services
- this will require a robust mechanism to link need to resource allocation. The NDA is undertaking research in this area
- an evidence-based price mechanism should be introduced, established through competitive tendering or an administrative price determination
- innovation, service quality and value for money should be enhanced via competition between alternative registered service providers
- the introduction of any alternative models of funding should be explicitly linked to the achievement of standards
- the model of a single service provider providing for the totality of an individual's needs should be replaced by a system where individuals are free to choose to receive different elements of service from different providers, including mainstream providers
- current models of disability service provision in segregated day or residential services should be replaced by a model that supports the service user in mainstream environments
- people with disabilities should be supported to participate in mainstream community activities rather than segregated activities
- residential care services should be provided in ordinary housing, dispersed throughout the community. A transition towards the closure of residential institutions should be implemented
- therapy supports should be provided via the primary care teams, in line with the primary care strategy and international practice, to provide more efficient resource allocation and equitable access
- to deliver on mainstreaming requires effective cross-sectoral co-ordination based on agreed protocols
- different services (which includes specialist disability services and mainstream services) working with a single individual need to work together to ensure seamless service delivery, and avoid duplication, fragmentation or gaps in service
- a system to co-ordinate different services and community supports, centred on a key worker, is essential to join up the different elements of service for individuals who would face difficulties tying these threads together

The provision, procurement, resource allocation and funding of disability services is a complex area. Implementing reforms in these areas, and moving towards alternative models of service constitutes a challenging undertaking. The HSE will need to develop the skills to effectively commission and oversee delivery of the new model of service. Service providers will face significant challenges in changing their business models. It has proved helpful in other countries to develop an industry plan to manage the transition. Such a plan might address, among other areas, how overhead costs are managed as service users become free to move to alternative service providers.

It will be important to manage the transition period in a way which does not impact negatively on service users. The NDA continues to research and evaluate the learning from transition processes at home and abroad.

The NDA continues to explore system and service innovations and to research and evaluate what is best practice. A report synthesising what the NDA has learned on systems in other jurisdictions will be available in early Autumn.

As the independent statutory advisory body on disability, the NDA is available to advise the Steering Group, the Department and the HSE on further phases of the work of developing and implementing policy change in disability services and collateral supports.

Section I - Background

I. Introduction

The National Disability Authority (NDA) is the independent advisory body to the Government on disability policy and practice. This policy advice paper further develops the NDA's advice to the Value for Money and Policy Review given in a previous paper in December 2009, and in the presentation given by the NDA to the Steering Group on 23 March 2010.

Deliver better outcomes for funds invested in disability services

The vision for people with disabilities, whatever their impairment, is that they are supported to live full lives, of their choosing, in the mainstream community.

A central task of the Value for Money and Policy Review is to establish how better outcomes and a better life for people with disabilities could be achieved through refocusing the current orientation, funding and systems for disability services.

The NDA advises that such better outcomes can be achieved through

- aligning services with the policy goals of promoting community integration, independent living, choice and participation
- delivering genuinely person-centred services to support people to live the lives of their choosing
- shifting the focus of the services from funding of organisations to funding of individuals, i.e. money follows the person
- a staff mix and staff skills that are appropriate to new models of service delivery
- provision as far as possible of services to people with disabilities through mainstream channels

Align services with policy goals

The NDA advises that the Value for Money and Policy Review of Disability Services is an opportunity to align Disability Services policy both with existing national policy goals, as articulated by Government and the social partners in Towards 2016, and with international disability policy norms, as set out in the UN Convention on the Rights of Persons with Disabilities.¹ Both of these key documents emphasise inclusion in the mainstream community, independence, choice and participation.

Towards 2016, the ten-year social partnership agreement, states:

¹ Ireland has signed the Convention. Work on the Mental Capacity Bill, to enable Ireland ratify the Convention, is underway

The parties to this agreement share a vision of an Ireland where people with disabilities have, to the greatest extent possible, the opportunity to live a full life with their families and as part of their local community, free from discrimination.

- 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 in society and to maximise their potential.
- Every person with a disability would, in conformity with their needs and abilities, have access to appropriate care, health, education, employment and training and social services²

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 needs³

In addition, under Article 4 of the Convention, State parties agree to the development of universally designed goods, services, equipment and facilities.

The NDA advises that the central task of the Value for Money and Policy Review of Disability Services should be to design a framework which ensures that disability services and the funding mechanisms which support them deliver on these values. In other words, funding for disability services should be explicitly linked to programmes to support people with disabilities to live the lives of their choice; to support people with disabilities to live in the community as independently as possible; to support people to access mainstream services and facilities and to give people choice about how their support is delivered. These values should equally underpin services for people with physical disabilities, sensory

² Department of an Taoiseach, (2006) Towards 2016 Ten-Year Framework Social Partnership Agreement 2006-2015

³ A 2009 United Nations (2006) UN Convention on the Rights of Persons with Disabilities. Geneva: United Nations

or intellectual disabilities. They echo the values underpinning the Government's mental health strategy **Vision for Change**, of putting the individual at the centre, community inclusion, and partnership with service users.⁴

An overarching framework for disability service provision

A number of very significant policy developments are under way or have nearly reached completion - the HSE's Review of Adult Day Services, the HSE Congregated Settings Working Group, the Housing Strategy for People with Disabilities, the Comprehensive Employment Strategy - which will shape areas of disability service provision for the coming years. A Vision for Change sets out the framework for delivering a community-based mental health service focused on the recovery model, and based on a firm partnership with service users. The Value for Money and Policy Review of Disability Services affords the chance to provide an overarching framework to support independent community living and to ensure that the above policy reforms are successfully integrated with each other to deliver a better life to people with disabilities, whatever their impairment.

NDA work on which policy advice paper is based

This policy advice paper draws on different pieces of NDA research, including work specifically undertaken to inform the NDA's advice to the Value for Money and Policy Review process. This work includes:

- 15 focus group consultations with people with disabilities, their families, advocates and frontline service providers held in March 2010
- A review of systems of disability service provision in England, Scotland, Netherlands, Norway, New Zealand, and the state of Victoria (Australia),⁵ regarded as models of innovation and of good practice
- Commissioned research on costings for disability services in these six jurisdictions
- Review of US research on outcomes and costs of disability services⁶
- Ongoing liaison with Human Services Research Institute, which advises many of the US State Developmental Disabilities directorates, on costing and resource allocation models in an number of US states
- Site visits to investigate independent living models in US, England and Wales
- A review of literature on costings methodologies in UK
- A detailed review of employment services for people with disabilities in Norway, US, England

⁴ A Vision for Change, p. 15

⁵ Background material on the 6-country study which informs this advice paper will be available on www.nda.ie in autumn 2010

⁶ See in particular Stancliffe and Lakin (2005) Costs and outcomes of community services for people with intellectual disabilities. Baltimore: Brookes

- NDA analysis of the data from the Survey of Congregated Settings carried out by the HSE Working Group on Congregated settings

Further work in train by the NDA (see 19 below) will assist in offering more detailed advice to complement the broader advice in this paper.

2. Disability in Ireland

Some people experience a lifelong disability, but most people with a disability experience its onset in adulthood or in old age. The incidence of disability rises significantly with age - Census 2006 showed just under 4% of people under 4 had a disability, while that rose to 30% of those aged 65 or over.

Numbers with a disability

The 2006 Census showed just under 400,000 people, or 9.3% of the population, had a disability. Using a broader definition of disability, the National Disability Survey 2006 found there could be up to twice that proportion of the population could consider themselves as having a disability.

The number of people receiving, or on a waiting list, for specialist disability services can be estimated using the disability databases maintained by the Health Research Board. In 2008 there were about 26,000 people on the National Intellectual Disability Database, and about 27,000 on the National Physical and Sensory Disability Database, a total of 53,000. However, coverage of the National Physical and Sensory Disability Database is acknowledged as incomplete.⁷

Majority do not use specialist disability services

However disability is measured, it is clear that only a small minority of people with disabilities are in receipt of specialist disability services, and the health and social care needs of a majority of people with disabilities are addressed via mainstream services (or older persons' services), and/or through family or friends.

According to the National Disability Survey 2006, about half of people with disabilities get help with everyday activities. Family is by far the most frequent source of help, followed by friends or neighbours, then by official sources of help - public health nurses, home help, or carer/personal assistant.⁸

⁷ It is generally acknowledged that the coverage of the NSPDD is incomplete as participation is voluntary and progress towards achieving target coverage for the NPSDD is uneven for several groups and areas. The NPSDD does not generally record people over 65, as these are catered for by the HSE's older persons' services rather than specialist disability services.

⁸ National Disability Survey 2006 vol 2 Table 2.7

The National Disability Survey 2006 produced a lower and a higher bound estimate of the number of people with disabilities in Ireland.⁹ Taking the lower of these estimates, there were 218,000 people with significant degree of disability, those who said they had a lot of difficulty or total difficulty with everyday activities. The disability databases, in contrast, showed 53,000 of people receiving or on a waiting list for specialist disability services in 2008. Even allowing for measurement errors, and gaps in coverage of the disability databases, it is clear from the scale of the difference between these numbers that most people with disabilities are supported through mainstream rather than specialist disability services. This is particularly so for people with physical or sensory disabilities.

Strengthening mainstream services and supports to families

These figures underline the importance of maintaining and strengthening the capacity of mainstream services to support people with disabilities, of filling gaps in service provision that could support people to live at home in independence, and of supporting families and other informal carers who are the mainstay of supporting people with disabilities to live at home.

Mainstream services

Mainstream health services, including GPs, physiotherapists, public health nurses and other members of the primary health team, play an important role in helping people manage chronic and progressive medical conditions. Enhanced mainstream services and greater efficiencies can deliver better care, promoting well-being and independence.¹⁰

Unmet needs

The National Physical and Sensory Disability Database provides estimates of unmet need for personal support services, and for aids and appliances that could support people to live more independently. A striking feature is the large number who are waiting for

⁹ As disability represents a continuum rather than a discrete concept, the estimated number of people with disabilities is sensitive to the definitions used and the method of measurement. The smaller end of the range from the National Disability Survey (325,000) is based those in the sample who recorded a disability in both the Census and the follow-up National Disability Survey (Census Disability Sample). The larger figure from the National Disability Survey (750,000) is based in addition on those in the sample who were recorded as having a disability in the National Disability Survey (using a wider definition of disability than used in the Census), but not in the Census, and is subject to wider sampling error (total population sample).

Level of difficulty	Census Disability Sample	Total population sample
Just a little	7,100	24,900
A moderate level	101,300	327,400
A lot of difficulty	138,800	287,300
Cannot do	78,700	109,500
Total	325,800	749,100

Source: National Disability Survey vol I, Table 1B

¹⁰ One example of service innovation delivering greater efficiency is the Neurolink project in St Vincent's Hospital Dublin, a web-based GP referral service, which in conjunction with a reconfiguration of hospital practice in Neurology has led to substantial improvements in service, earlier intervention, a reduction in waiting times for new patients from 18 months to under 14 weeks from without significant changes in staffing numbers. See Neurological Alliance Newsletter June 2010, www.nai.ie

assessments. About half of those on the database in 2008 were seeking an assessment for therapeutic intervention or rehabilitation; about a quarter were awaiting assessment for personal assistance or personal supports, and about a third for technical aids.

Assistive technology

The National Disability Survey confirms a picture of people, particularly those with significant mobility, dexterity, or hearing disabilities, and those experiencing significant levels of pain, who lack the technical aids they might need. About 60,000 people with significant mobility/dexterity difficulties, about 32,000 people with significant pain disabilities, and about 12,000 people with significant hearing difficulties said they would need one or more technical aids.¹¹

Assistive technology is usually a very cost-effective way to promote and enhance independence. Disability aids, home adaptations, personal alarms or systems to monitor for falls can enhance people's ability to manage alone and reduce the need for support personnel, and often at little cost. Mobility aids, shower aids and grab bars are the most-frequently listed technical aid items under unmet needs on the physical and sensory disability database. Bathroom adaptations are the most commonly-cited home adaptation people with disability have already made (20% of people with disabilities) or state they would require (12%).¹²

Family care

50% of those registered on the National Physical and Sensory Disability Database live with their parents, 30% with a spouse or partner, and 10% live alone. 20% of carers for this group are spouses/partners, and 70% are parents.¹³

About 50,000 under-25s with disabilities live with and are supported by their parents.¹⁴ A quarter of adults aged 30-34 with a disability, 16% of those aged 35-39, and 10% of those aged 40 to 44 live with their parents.¹⁵ The model of service and their support needs from the state change as they and their parents get older.

One in five full-time carers is aged 65 or over, which would include those caring for a spouse, those caring for an elderly parent, and those caring for an adult child with a disability.¹⁶

¹¹ NDA analysis of National Disability Survey 2006 vol 1, tables A8, B8, C8, D8,E8, F8, G8, H8, I8, taking those in the categories "a lot of difficulty" and "cannot do at all". There may be significant overlap between people in the different categories of impairment cited.

¹² National Disability Survey 2006 vol 2. tables 5.6 and 5.7

¹³ NSPDD 2008, Tables 5 and 6

¹⁴ Census 2006 Vol 1 I Table 36

¹⁵ Census 2002, special tabulation for NDA. See NDA (2005) How Far Towards Equality, Table 7.1 p. 77

¹⁶ Census 2006 vol 1 I, table 44A - caring for 43 hours or more

Most people with disabilities live at home, and only a small minority live in residential services. However residential services absorb about half of the specialist disability service budget. So policies to enhance natural community supports, to support family carers, and to enable people live independently at home are cost effective in minimising the reliance on staffed residential care. Services such as home supports and respite play a key role in supporting families as primary carers.

3. Current specialist disability service provision

Key features

A brief description of the system by which specialist disability services in Ireland are organised and funded is contained in Appendix I. This section summarises some key features of the system.

Voluntary service providers

The voluntary sector was the main driver of the development of specialist disability services and today provides about 90% of specialist intellectual disability services and about 60% of specialist physical and sensory disability services. The HSE is also a significant service provider, while private for profit service provision is minimal. Intellectual disability service providers provide a range of services, including education, training, employment, day services, respite, home support and residential services. Physical and sensory disability organisations usually began as support groups for people with a particular condition or difficulty, while some have now become significant providers of services. Voluntary organisations and their staffs are a considerable locus of expertise. While historic models of service provision often originated from a medical model, many voluntary organisations have shown considerable innovation in developing new models of service provision. Individual providers may operate a range of services ranging from traditional institutions to innovative community services and supports.

Voluntary providers receive block funding for services, which is not specifically calibrated either to the levels of need of service users or to achievement of quality standards.

Advocacy and support role

Some voluntary disability organisations primarily offer information, advice and support, including individual advocacy and advice. These are the central roles of most of the support groups for people with specific conditions.¹⁷ This advice and advocacy has an important health promotion role, helping people stay well and out of hospital, as well as guiding individuals with individual problems and helping them in securing the right mix of services and supports they need. This tailored support and expertise in specific conditions goes beyond the generic advocacy available through Citizens Information Centres. Many of

¹⁷ Examples are individual support groups for relatively rare disabling conditions such as Friedrich's Ataxia or Guillan-Barré syndrome

these individual support groups are based in Carmichael House, where there is some sharing of overhead costs.

Only one in six in residential services

Of the 53,000 or so people availing of or waiting for specialist disability services, just under 9,000, or 17% are in disability residential services. That is about one in six service users. 8,000 of these are people with intellectual disabilities, and 700 are people with physical or sensory disabilities.¹⁸

People with intellectual disabilities¹⁹ the majority of service users

92% of people in residential services are people with intellectual disabilities. About 14,000 of the 25,000 users of adult day services are people with intellectual disabilities.

As residential and adult day services between them account for about three quarters of the budget for specialist disability services, and as people with intellectual disabilities currently form by far the largest service user group for specialist disability services, much of the content of this policy advice paper focuses on how services for people with intellectual disabilities, and how residential services in particular, might be reconfigured to promote independence, choice, and community integration. These same principles apply equally to delivery of services to people with physical, sensory or mental health disabilities.

Recent policy focus - service expansion, community services

Since the mid-1990s there has been considerable expansion of disability services funding, including the Multi-Annual Investment Programme 2005-9, under which residential places, service staffing and support hours increased significantly. 3.2m. personal assistant and home support hours were given in 2009 compared to 2.5m hours in 2006. On the intellectual disability side, between 1996 and 2008, respite care expanded by 428%, and the numbers in community group homes grew by more than 60%. Some of the additional resources for disability services over the last decade have been given to fund the award of special pay increases to particular grades rather than contributing to expanded services.²⁰ As acknowledged by the Comptroller and Auditor General in his 2007 Report on the HSE, some development monies earmarked for disability were diverted to other HSE priorities.

The thrust of policy over the last 20 years has been towards support for independent living, expansion of provision of personal assistance, and providing new residential care places within the mainstream community.

¹⁸ While nursing homes cater mainly for elderly people, in addition there are also a number of younger people with disabilities who are living in nursing homes. See Department of Health and Children - Long-stay Activity Report http://www.dohc.ie/publications/long_stay_activity_report_for_2008.html

¹⁹ Intellectual disability is a disability characterised by significant limitations both in intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills. Internationally-recognised definitions of intellectual disability cover such a limitation which originates before age 18.

²⁰ In 2001 the grade of social care worker was awarded a special pay increase of between 20 and 27%.

Residential circumstances

Today, most people with disabilities receiving services live in their own homes (Table 1).

Table 1: Main residential circumstances of people with intellectual, physical or sensory disabilities in Ireland, 2008

	%	N
National Intellectual Disability Database		
Living in the family home	64%	16,708
Living in full-time residential service	32%	8,290
Living in independent settings	4%	950
National Physical & Sensory Disability Database		
Living in the family home	86%	23,500
Living alone	10%	2,591
Living in full-time residential service	3%	697

Sources: National Intellectual Disability Database 2008; National Physical and sensory disability Database 2008

About half of residential service provision is in the community, mainly in community group homes, with the remainder in institutional or congregated settings of ten or more people living together on a residential campus.

Where the money goes in specialist disability services

Residential disability services account for about half the total budget for disability,²¹ with adult day services accounting for a further quarter (Table 2). So approximately three quarters of the budget for disability services goes on services for the 9,000 people in residential services, and the 25,000 people receiving adult day services. For both residential and day services, the majority of service users are people with intellectual disabilities. So about €900m of the total of €1,500m. allocated for 2010 will go on services to people with intellectual disabilities.

About 80% of the specialist disability budget consists of staff costs.

There are two separate legal bases for funding voluntary organisations. S.38 of the Health Act 2004 covers agencies delivering health or personal social services on behalf of the HSE. Most of the big service providers come under this heading. In 2009 there were 40 agencies, accounting for 90% of funding, receiving over €5m; their average funding was €26.4m. per agency. S. 39 grant aids bodies providing services "similar to or ancillary to" HSE services. These are generally the smaller niche organisations who provide advice, support and advocacy for their members, and in some cases, some service provision. The HSE grants supplement what they raise themselves. In 2009 small grants of under €1m. each accounted for 3% of HSE expenditure on disability agencies.

²¹ 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.

Supports to maintain people living independently account for a relatively minor share of the budget -

- personal assistance services account for 6%
- respite accounts for 4%
- rehabilitation accounts for 3%
- aids and appliances account for 3%

Table 2: Disability Service Programme Expenditure by Service Type and agency, 2009

Service area	%	% excluding allowances	HSE share	Voluntary agency share
Residential	43	48	10%	90%
Adult Day Care	23	26	10%	90%
Allowances	10	-	100%	-
Multi-disciplinary teams	5	6	50%	50%
Personal Assistant Services	5	6	-	100%
Respite	4	4	5%	95%
National Rehabilitation Hospital & other specialist services	3	3	20%	80%
Aids and appliances	3	3	80%	20%
Inappropriate placements	3	3	50%	50%
Early Intervention Teams	1	1	30%	70%
Total	100	100	31%	69%

Source: Department of Health and Children

Other features of disability service system in Ireland

- Not for profit disability service providers provide the majority of disability services (90% of intellectual disability and 60% of physical/sensory disability services), with the remainder largely provided directly by the HSE. Private providers play a minimal role
- A statutory assessment of need process is in operation for under-5s. No single system of needs assessment operates for other groups
- People are generally assigned to a specific disability service provider in their locality rather than having a choice of provider or of model of service
- Block funding of providers is based largely on historical allocations, topped up by development monies. The development monies are in principle related to unit prices for services at the time an individual is assigned to the service, but the basis for the core of historical funding is unclear. The result is little consistency in funding of services across agencies, and a poor relationship to levels of need
- In addition to HSE funding of specialist disability services, some additional funding for these services is drawn from other public sources (e.g. FÁS-funded staff), from fundraising, and from contributions by those in residential services from their Disability Allowance

- A high proportion of staffing, particularly in residential centres, consists of nursing and other health or social care professionals, a degree of professionalisation which is out of line with international norms
- While standards for residential services have been agreed by the Health Information and Quality Authority, there is no system of registration, statutory standards or inspection yet in place. No standards have been developed for community or for day services, although HIQA has begun work on day service standards

Other countries have gone the same journey

Up to the 1980s, many disability support systems in developed countries would have shown similar characteristics of significant levels of institutional provision, block-funding of services and limited systems of oversight. Most developed countries (including Ireland) have taken efforts with varying degrees of success to reform their disability support systems over the past few decades. The challenges Ireland now faces to reorient its services are not unique, and we can learn from the experiences of other countries which have undertaken a similar journey, and from innovative service developments here in Ireland. Building on our work to date looking at other jurisdictions, the NDA continues to explore specific policies and practices in other countries that could guide implementation in an Irish context.

It is worth noting that the UK's Valuing People Now strategy for intellectual disability, which sets out a very similar policy direction around choice, control and community integration, was preceded by publication of a draft policy paper and a period of formal consultation on the draft. The NDA has already conducted focused group consultation on emerging policy ideas from the Policy Reference Group for the current review. The NDA sees the merit in issuing the completed draft paper from the Policy Reference Group for consultation, as an important step in securing buy-in to an alternative vision for services.

4. What NDA learned from consultation

In March 2010, the NDA conducted consultation on community and independent living, and on emerging ideas from the Policy Review Group, via a series of 15 focus groups of people with disabilities, of families, of advocates and of frontline service providers.

Key findings

Independence

These groups documented the aspirations of people with disabilities to live more independently, and a level of dissatisfaction with rigid routines, regulations which imposed everyday restrictions on their lives: when they could go out, what they could eat, who could visit, or having privacy in their own room. Some parents also referred to the institutional mindset which prevents people with disabilities from living more independent lives.

As one individual with a disability put it

"People should be allowed to make mistakes, There is too much control. You have to give people choices and be able to make mistakes."

About half the people with intellectual disability would like to live independently. Those already living independently expressed satisfaction with this choice.

Difficulties and obstacles identified

Some of the main obstacles to independent living detailed by consultees include:

- poor co-ordination of disability services, together with low levels of long-term planning
- institutionalised mindsets and practices in services, which sustain ingrained ways of doing things and inhibit more creative initiatives
- deficient transport options; issues with access and use of buildings and facilities
- insufficient and declining resources, which reduce Personal Assistant hours and impact on services generally
- difficult access to information in an appropriate format; inadequate transition support
- a lack of adult services
- low levels of independent advocacy
- low expectations of people with disabilities
- public attitudes and thoughtlessness
- a lack of personal confidence poor practical skills
- lack of support and encouragement from families and staff
- the nature of a person's disability

Section 2 - Implementing the values

5.A person-centred approach to disability services

The NDA advises that the system of disability services in Ireland be modelled on a person-centred approach where the individual with disabilities is at the centre of how services are organised, funded and delivered.

Person-centred services

Nationally and internationally, a person-centred approach has been a key value driving changes in disability service provision. The National Health Strategy (2001) set out

"people-centred services" as a core principle.²² The Renewed Programme for Government²³ states

"We will advance measures to specifically strengthen collaborative working across Departments, Public Bodies and the voluntary disability sector to ensure **person-centred** public service provision"

Internationally, person-centred approaches have been at the heart of change in the jurisdictions which the NDA has examined. A 2009 review of contemporary disability services systems identified the shift to person centred services as the most significant shift in disability services in recent years.²⁴

What is person-centred planning

At the heart of a person-centred approach to planning lies an appreciation of the person as a unique individual, requiring that all planning is based on supporting each individual to lead his or her life as and how he or she wishes. In practical terms, this means that all planning around the design and delivery of all services for people with disabilities should be both based on, and actively involve, the individuals availing of these services, and each of those individuals' unique characteristics, capabilities, needs and wishes (NDA Guidelines on person-centred planning).²⁵

Some experts have described the aims of person-centred planning as follows:

"

- aims to consider aspirations and capacities expressed by the service user or those speaking on their behalf
- attempts to include and mobilise the individual's family and wider social network, as well as to use resources from the system of statutory services
- and aims to provide the support required to achieve goals, rather than limiting goals to what services typically can manage²⁶

This approach to organising services has developed in a number of jurisdictions internationally over the past three decades and is becoming the norm by which disability services are organised. It is central to the Valuing People policy framework by which supports for people with disabilities are being reformed in England and it is written into the primary legislation governing disability service delivery in Victoria. The outcome of the person centred planning process should be a plan of **individualised supports**, which is a

²² Government of Ireland (2001) Quality and Fairness: A Health System for You, p. 11

²³ Department of the Taoiseach. Renewed Programme for government (October 2009). p. 19

²⁴ KPMG (2009) The Contemporary Disability Service System. Department of Human Services, Victoria, Australia

²⁵ NDA (2005) Guidelines on person-centred planning in the provision of services for people with disabilities in Ireland, p.11

²⁶ Mansell, J. and Beadle-Brown, J. (2004) Person-centred planning or person-centred action? Policy and practice in intellectual disability services. Journal of Applied Research in Intellectual Disabilities, 17, 1-9.

combination of specialist, mainstream and informal supports coordinated to deliver the best outcome for a person taking account of their abilities and aspirations.

Person-centred planning needs to be central to how supports to people with disabilities are organised and delivered. It is of central importance to have regulations and standards in place that mandate person-centred planning, and to ensure person-centred services are a fundamental condition of service-level agreements. Reform processes which do not place individuals' preferences and aspirations at the centre of how supports are delivered have repeatedly failed to deliver the outcomes that policy makers intended.

Developing a system which organises supports around the preferences of the individual is as fundamental as physical deinstitutionalisation. New Zealand provides an example the importance of a person-centred approach in addition to deinstitutionalisation. New Zealand began its deinstitutionalisation process in the 1980s and saw itself, and was seen by others, as a champion and innovator in this regard. However, by 2003 New Zealand had come to see its group home model (which replaced its institutions) as "custodial," and as denying people "an ordinary life" because

it is common [for residents] to have no choice about what to eat, no privacy, no key to the door, and little, or no, say about being moved from one house to another²⁷

The NDA, therefore, advises that the first consideration for the Value for Money and Policy Review should be how best and most efficiently to organise disability service around the preferences and ambitions of the individual with a disability.

The model proposed envisages people accessing support based on their assessed need not on the basis of their disability type or their proximity to one provider or another. At present, a significant amount of service provision is organised by type of impairment. Such a model should be better than the present system at supporting people with a wide range of needs, irrespective of their type of impairment.

Creating a system based on person-centred planning would involve a very significant transformation in how disability services are delivered, structured, and funded. Part 2 of the Disability Act, 2005, with individual needs assessment followed by an individual service statement, offers a structure to organise supports around the individual in accordance with person-centred planning. However, to deliver on the potential of Part 2, there would need to be changes in how resource allocation and service funding link in to an assessment of need process.²⁸

²⁷ National Health Committee (2004), To Have an 'Ordinary' Life. Background papers to inform the National Advisory Committee on Health and Disability, Wellington: National Health Committee

²⁸ The Comptroller and Auditor General's 2005 report on disability services has stated "with the evolution to needs-based services, procurement practices will need to adjust so as to align the services being procured or delivered with the assessed needs of clients whether at individual level or on an aggregated basis"

6. Promoting independence

What NDA consultees said

Participants with disabilities, their families and carers who took part in the NDA's focus group consultation articulated clearly the difficulties and obstacles to achieving independence to live the lives they want to lead.

For those with physical and sensory disabilities, independent living was perceived by this group to be primarily about choice and control. It was about knowing what they wanted and having sufficient support and resources to ensure it happens. This group identified flexible personal assistance, and assistive technology, as the main ways of being more independent. An accessible environment, access to transport, and technology were other important ways they could stay independent. They valued self-directed supports, and were interested in direct payments.

The group with intellectual disabilities spoke of wanting to be treated as adults. They saw having a job as a key to independence. They were critical of policies, regulations and regimes that limited their freedom. They valued having a place of their own, where it would be safe, and private; others would have to knock to be admitted.

Choice and self-determination

A central element of independence is the exercise of choice and self-determination about the life people want to live and about the day to day activities and routines of that life.

Assistive technology

Assistive technology can provide a very cost-effective way to promote independence. Adaptations and equipment can yield better outcomes for individuals while producing savings to health and social care budgets; housing adaptations and equipment can sometimes save money on a significant scale when they are alternative to residential care.²⁹ The National Disability Survey 2006 has catalogued the proportion of people with different impairments who use or would need disability aids, and the degree of difficulty in everyday living experienced by those who would require any such aid. About half those with severe or profound mobility difficulties, and of those with severe or profound hearing disability, reported they needed an aid they did not have.³⁰ Lack of money was the most frequently-cited obstacle to having specialised features in one's home, named by over 40% of those requiring such features.³¹ It is striking that most people listed on the physical and sensory database as requiring such disability aids have not been formally assessed. In contrast, in Norway in 2008, the average time for handling applications for adaptive

²⁹ Heywood, F., Turner, L (2007) Better outcomes, lower costs: Implications for health and social care budgets of investment in housing adaptations, improvements and equipment: a review of the evidence <http://www.officefordisability.gov.uk/publications/> (accessed 03 December 2009)

³⁰ National Disability Survey - NDA calculations from Vol 1, tables A8, B8, C8, D8, E8, F8, G8, H8, I8, taking those in the categories "a lot of difficulty" and "cannot do at all"

³¹ National Disability Survey Vol 2, table 5.10

equipment and devices was 1.8 weeks, and 77% of devices were delivered within a 3-week goal.³²

Aids and appliances account for 3% of the total disability budget at present, with spending of about €50m. The NDA advises that consideration 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. In terms of value for money, it may be worth revisiting current HSE policy around reuse and recycling of disability aids, and to explore safe and cost-effective ways of doing so, to increase their availability to the public.

Sharing one's life with care personnel

The degree to which people share every aspect of their lives with support staff or are enabled to live more independently with for example 'just in case' support, accessed through technology, affects people's sense of independence. As leading authority on intellectual disability Professor David Felce has said;

'put simply, people living with only partial staff support appear to conduct their lives more independently than do people living with constant staff support. This is not due to differences in their independent capability but to the inhibiting effect of staff presence'.

Risk and independence

Attitudes to and management of risk by caregivers and service providers are key factors in whether independence is maximised or not. A risk avoidance strategy might minimise outing unaccompanied by a staff member, or use of a mainstream service such as normal public transport. A risk management strategy on the other hand would identify different risks and their likelihood, and adopt strategies to mitigate those risks, e.g. training people with disabilities in how to manage public transport and how to manage around town on their own.

NDA advice

Promoting and maximising independence should be a formal goal for disability services, and an explicit criterion of systems to monitor performance and outcomes.

Policies and practices to support independence include

- an effective system of timely assessment
- provision of personal assistance with everyday care requirements and living tasks to enable people live and remain in their own homes

³² Sund (2005) The Norwegian model on provision of assistive technology, Division of Assistive Technology, The National Insurance Administration, Oslo, Norway (conference presentation in Exeter, England, April 2005)

- technological aids that promote independence. These would include disability aids, communication and other aids for people with sight or hearing losses, home adaptations, smart homes, and remote monitoring and support systems
- increased employment opportunities, as part of the comprehensive employment strategy, to create greater financial independence
- a shift from a service to a support model e.g. supporting individuals where possible to do everyday living tasks for themselves, for example supporting people to choose and cook their own food rather than be handed prepared meals³³
- supporting parents, families and schools to foster and promote attainment of maximum independence
- supporting individuals with disabilities in making the transition into independent accommodation or in moving from the parental home
- greater use of supported independent living arrangements as an alternative to group homes
- limiting the size of group homes to typically no more than four residents,³⁴ and ensure choice and independence is promoted in everyday life
- adopting a risk management rather than a risk avoidance approach
- effective harnessing of natural community supports
- access to transport
- co-ordinated supports from different public bodies - HSE, housing authorities, FÁS, with organisations working together at a strategic level and at the level of the individual service user

7. Inclusion in the mainstream community

The learning from other countries

In one sense community inclusion describes less a service area than an approach to how services should be delivered, such as the focus on Active Support in residential services in the UK and Victoria or the 2008 reorientation of the Home and Community Support Scheme in New Zealand from being a home help and personal care scheme into a scheme which allows for Personal Assistance-type support to access social and cultural events.

³³ Active support where staff are trained to provide facilitative assistance to residents, as opposed to completing tasks on their behalf, is an important predictor of quality of life for residents. See for example Felce D, Jones E and Lowe K (2000) Active support: Planning daily activities and support for people with severe mental retardation. In DS Holburn & P Vietze (eds) Person-centred planning: research, practice and future directions. Baltimore: Paul H Brookes

³⁴ Advice from international experts to the NDA suggests that 4 should be the maximum size for group homes. In the US, 47% of people with ID in residential services lived in places with 3 or fewer residents - Prouty, Alba and Lakin (2008) Residential Services for people with developmental disabilities - status and trends through 2007:v. <http://rtc.umn.edu/risp07>

However, a number of jurisdictions reviewed have developed dedicated programmes of support aimed specifically at supporting people to access services in their community. Local Area Coordination, which is being used in a number of Australian States, in Scotland and is at a planning stage in New Zealand,³⁵ involves co-ordinators playing a brokerage role in assisting people with intellectual disabilities to access both mainstream services (e.g. health and housing services) and community activities such as sports clubs.³⁶ Other jurisdictions have developed similar brokerage services and / or volunteer coordination services. In Ireland, the Disability Equality Specialist Support Agency works on social inclusion initiatives for people with disabilities and their families.

NDA advice

Allow people choose different elements of service from different providers

Disability service provision should be reconfigured, so as to support people with disabilities to access mainstream community activities and appropriate mainstream and specialist services. The NDA suggests that 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.

Separate housing and care support

The segregation of housing provision from disability support services can enable people with disabilities in residential care to make choices about their service provider and service configuration without risking losing their home. This segregation of housing from care support underpins the new housing strategy for people with disabilities now being finalised, and is consistent with the Government's 2003 decision that the health and personal social services should concentrate on their core functions.

Facilitate participation in mainstream work and day activities

A focus on participation in mainstream activities and services could involve a shift in roles from providers of sheltered segregated services such as sheltered work or segregated therapeutic day activities, towards a role of facilitating participation in the mainstream. In the jobs area, it could involve a shift from models of sheltered work towards options like supported employment and community employment. The NDA welcomes the emphasis on support for involvement in mainstream activities emerging from the Adult Day Services Review and the multi-departmental engagement towards the development of a comprehensive employment strategy.

³⁵ (New Zealand) Ministerial Committee on Disability Issues, (2009) Initial Thoughts on Local Area Coordination-type Processes

³⁶ Stalker, K.O., Malloch, M., Barry, M.A., Watson, J.A. (2008) Local area co-ordination: strengthening support for people with learning disabilities in Scotland. British Journal of Learning Disabilities. Blackwell Publishing Ltd.

The NDA is undertaking research in 2010 on natural community supports which could further guide practice in this area.

Making the model work

- caseworkers, service brokers, support groups

A key to making such a model of service work is a system of service brokerage, alongside development and maintenance of natural community supports. Caseworkers or keyworkers can ensure different mainstream services are joined up for individuals. Specialist disability organisations do valuable work in educating mainstream providers around the needs of people with particular conditions, and in acting as a support to individuals to access services. The NDA continues to explore good practice models in ensuring individuals with disabilities effectively access mainstream services and that support through different channels is co-ordinated.³⁷

- a joined-up approach by mainstream services

The new model will require close collaboration between the health services and mainstream providers, including in particular, with the Sectoral Plan departments and with agencies at local level such as local authorities, FÁS, local HSE, in ensuring that the appropriate health and personal supports are identified and provided within the mainstream system, and that systems join up at local level. Protocols are being developed in a number of areas e.g. on housing and health service supports, to deliver integrated actions. When the provision of housing via mainstream housing providers is successfully bedded down, this will enable the health sector to focus on provision of personal supports.

- an appropriate skill mix

The NDA advises that, to re-orientate services from a model of wrap-around service provision, to supporting people with disabilities to access appropriate mainstream and specialist services and community activities, it will be necessary to consider whether our service providers currently have the appropriate skills mix to deliver such support and if not, how such a skills mix could be achieved - e.g. through training, retraining, redeployment in the short term and changing industry entry and qualification routes in the medium term.

Successful inclusion in mainstream life may require preparation and support for mainstream bodies and providers to enable them to really include people with disabilities,

³⁷ In her paper commissioned for the Health Core Functions report, Dr. Virpi Timonen identified the following as critical for joined-up services:

- Coterminous boundaries
- Strong role of local government
- Provision of financial and other incentives to facilitate the smooth and fast transfer of clients
- Professionals or groups which serve to bridge social services
- Programmes and service centres that help overcome organisational and service delivery fragmentation

for example enhancing the capacity and competence of state agencies, of individual healthcare providers such as GPs and dentists, and of community, cultural and sporting organisations to serve individuals with disabilities, including complex disabilities.

Keep personal social services under health ambit for the present

While many other countries deliver personal social services via the local government system, the Government agreed, following the recommendations of the report of the Working Group on Core Functions of the Health Services (2006), that overall responsibility for health and personal social services should remain with the Department of Health. In considering the merits of a move of these services elsewhere, the Group identified as key factors the availability of an alternative infrastructure to deliver the service and the possible disruption to service which would arise in the context of any transfer of responsibility. As the care needs of people with disabilities are rarely strictly social or strictly medical, there is a logic to keeping health and personal social services together. The NDA advises that the priority for the near future should be to deliver a changed focus for disability services, and relocating such personal supports to another Department at this stage would distract from that task.

Policies and practices to support inclusion in the mainstream of the community include:

- a commitment that people with disabilities live in mainstream housing, and a transition towards the closure of all congregated settings and their replacement with housing in the community
- providing residential services in individually-located homes rather than in clusters³⁸
- supporting people with disabilities to engage with the everyday life of the community rather than provision of segregated activities
- a move from sheltered work towards supported employment and other options in a mainstream work environment
- enhancing the capacity of community actors to engage with people with disabilities
- joined-up actions across housing, employment, health care, community services, and disability supports to create an accessible environment and a seamless network of support for individuals
- a suite of inter-agency protocols and their effective operation at local level to deliver joined-up working
- case-worker or advocacy support to individuals to co-ordinate access to linked supports from different providers
- provision of personal assistance and other supports which enable people to continue living in their own home and neighbourhood

³⁸ Mansell J and Beadle Brown J (2009) Dispersed or clustered housing - a systematic review

8. From specialist to mainstream services

Many of the jurisdictions reviewed by the NDA developed an overarching policy framework to dictate how support should be provided in the community (some of these plans were in effect deinstitutionalisation implementation plans). These plans had significant impacts on what is funded as specialist disability services and what is to be sourced from (and funded by) mainstream authorities. For example, England has decided, under the Valuing People Now policy, that housing provision should come from mainstream housing authorities, and this is to be fully achieved by 2010. Under this policy, nursing and allied health should come via mainstream primary care networks.

Housing

It is Government policy, in the context of mainstreaming and a focus by the department of Health on its core health and social service functions, that responsibility for housing people with disabilities should move to housing authorities. The Housing Strategy for People with Disabilities, being prepared by the Department of Environment Heritage and Local Government, is now being finalised. This sits into a housing policy framework whereby local authorities act as a gateway to different housing options, including provision by voluntary housing bodies, private rented housing, different purchase options, or direct provision of housing by local councils. Housing associations are seen as playing a key role, and people with disabilities are one of the main target groups identified for the recently-advertised round of Capital Assistance funding to such bodies.³⁹

The benefit of separating housing from support services, is that individual would retain their home if they wished to change their care arrangements. The challenge is to ensure that budgets for housing and for care support are aligned, so that people with disabilities who are allocated housing can have the care package available to them simultaneously. The NDA's focus groups expressed some concerns about the practical impacts of such mainstreaming, and about joining what were perceived as lengthier mainstream queues. In Victoria, the separation of housing from care supports has led to significant delays in securing housing for people with disabilities as they join mainstream queues for available housing.

Therapy services

The NDA also advises that multi-disciplinary early intervention teams be put in place in those Local Health Office areas that have not yet established them.

Incorporate therapy services in local primary care teams

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 therapists, physiotherapists, psychologists, psychiatrists).

³⁹ [See Department of Environment Heritage and Local Government, Circular SHIP 2010/13: Capital Assistance Scheme: Proposals for the provision of accommodation by Approved Housing Bodies for people with specific categories of housing need](#)

Individuals who are attached to the specific service can avail of the services of these therapists, whereas as already shown, a majority of people with significant disabilities are not attached to a disability service. The international practice is that such therapy services are generally provided within the mainstream health service. Providing these therapy services within the mainstream primary care system would promote more efficient resource allocation and equitable access. A relocation of therapy services to the primary care team could also play a role in upskilling other members of the team on disability. Such a move could also help focus specialist disability services more clearly on a role of supporting and facilitating inclusion, not on a treatment model.

The NDA advises that publicly-funded therapy services should be available to everyone in the catchment area, not just those attached to an individual service, and that therapy services should be integrated into local primary care teams. In a given Local Health Office area, there would be, in addition to generic therapists, specialist therapy teams with disability expertise serving a larger catchment. A realignment of services on these lines would also involve a reassignment of the relevant budget to the primary care service.

Challenges posed by mainstream system

In the context of mainstreaming, there is a need for the Value for Money and Policy Review to consider which aspects of disability services may be best delivered by the mainstream, and what resources (assets, ongoing finance and personnel) such a decision would free up to support people accessing mainstream services and community activities.

Service fragmentation

A characteristic of Irish specialist disability service provision today is that for many who are in receipt of a service they receive a comprehensive wrap-around service, meaning that all their services probably come from the one provider. This would have been true for most of the countries reviewed up until a decade or two ago. The disadvantage of such a model, as discussed above, is that people with disabilities don't access mainstream services and mainstream community activities and move through each stage of life in specialist settings which have been shown to have poor quality of life outcomes.

However, the wrap-around service model has one very significant advantage: diminishing the need for different providers to coordinate service provision across different sectors. A stark example of this challenge is the experience of Victoria where the decision by disability service funders to stop funding new group home places meant that mainstream housing and disability support delivery needed to be very neatly dovetailed. In fact this coordination has proved to very difficult and problematic in Victoria.

Therefore, if the Value for Money and Policy Review recommends that areas of specialist disability service provision would be better provided by the mainstream agencies alone or by mainstream and specialist providers in partnership, it is crucial that this mainstreaming of services does not result in a system that is unworkably fragmented from the point of view of the person with a disability. Arguably, both the existence of the whole-of-government disability strategy (encapsulated in the National Disability Strategy) and the

potential for Part 2 of the Disability Act to create a single service coordination point means that Ireland has some important building blocks in place to avoid the fragmentation that can emerge from mainstreaming. Nonetheless, to ensure that fragmentation is avoided, the NDA advises that the recommendations of the Value for Money and Policy Review will need to be endorsed and driven by a whole-of-government implementation plan rather than by health sector implementation only.

9. From institutions to community living

Internationally, a key driver of reform has been the decision that it is no longer acceptable to deliver services for people with disabilities in institutions, or by institutional means.

The Report of the EU's Ad Hoc Expert Group on the Transition from Institutional to Community-based Care (2009) argued that institutionalisation is not just about buildings, it is about relationships:

....institutional care segregates users and tends to be characterised by **depersonalisation** (removal of personal possessions, signs and symbols of individuality and humanity), **rigidity of routine** (fixed timetables for waking, eating and activity irrespective of personal preferences or needs), **block treatment** (processing people in groups without privacy or individuality) and **social distance** (symbolising the different status of staff and residents)

Ending institutionalisation also means replacing institutionalised care practices, where people are treated as a group, with a system of organising supports centred on the abilities, preferences and ambitions of individuals.

Research shows better outcomes in the community

There is an extensive international research literature which has examined the quality of life for people with disabilities comparing institutional and community options. The conclusion of this literature is overwhelmingly that the quality of life for people living in community settings is better than for people living in institutional settings. Furthermore, NDA research shows that the quality of life for people with intellectual disabilities living in dispersed community settings is better than when living in clustered housing in the community.⁴⁰

This literature is reviewed in more depth in the Report of the HSE Working Group on Congregated Settings (HSE 2010, forthcoming). The literature takes account of two factors that affect judgements about the impact of living arrangements and life outcomes for persons with intellectual disabilities. Firstly difference in outcomes is strongly associated with the personal characteristics of the individual with intellectual disabilities,

⁴⁰ Mansell J and Beadle-Brown, J (2009a) Dispersed or clustered housing for disabled adults: a systematic review. NDA

and in particular with their level of intellectual disability or adaptive behaviour.⁴¹ Secondly, people with more severe intellectual disabilities tend to live in larger or more institutional style settings.⁴² From one study to another, there has been variation in the composition of the study population, the kind of community provision, and the degree to which those services follow a person-centred model, which are factors which can affect the results of individual studies. Notwithstanding this point, there is a consistency in findings spanning over thirty years of such research that points predominantly towards a better quality of life for people in community settings compared to living in institutional care.

Mansell and Beadle-Brown's paper to the NDA conference in 2009 surveyed a series of successive reviews of this extensive literature:⁴³

"The large number of relevant studies (*i.e. comparing outcomes in institutions and in community living*) have been summarised in a series of reviews which illustrate typical findings. Kim, Larson and Lakin (2001) reviewed 29 comparative and longitudinal American studies between 1980 and 1999. In terms of adaptive behaviour, 19 studies showed significant improvements and two studies showed significant decline. In terms of challenging behaviour, five studies found significant improvements while two studies found a significant worsening in behaviour. Of the remaining studies where change was not significant, eight reported a trend towards improvement while six reported a trend towards decline.

Emerson and Hatton (1994) reviewed 71 papers published between 1980 and 1993 which examined the effect of moving from institutional to community services in the UK and Ireland. In five of six areas (competence and personal growth, observed challenging behaviour, community participation, engagement in meaningful activity and contact from staff), the majority of studies reported positive effects; only in one area (reported challenging behaviour) did the majority of studies report no change. Young *et al* (1998), reviewing 13 Australian studies of deinstitutionalisation published between 1985 and 1995, showed a similar pattern. In six of the nine areas studied (adaptive behaviour, client satisfaction, community participation, contact with family/friends, interactions with staff and parent satisfaction), the majority of studies report positive

⁴¹ Walsh, P.N., Emerson, E., Lobb, C., Bradley, V., and Mosely, C., (2007) Supported Accommodation Services for people with Intellectual Disabilities: a review of models and instruments used to measure quality of life in different settings. NDA

⁴² Stancliffe, R., Emerson, E., and Lakin, C., (2004) Residential Supports in E. Emerson *et al.*, **The International Handbook of Applied Research in Intellectual Disabilities**. New York & Chichester: Wiley

⁴³ Mansell J. and Beadle-Brown, J. (2009b). Cost Effectiveness of Community Living for People with Intellectual Disabilities: an international perspective (conference paper). www.nda.ie

effects and in the remaining three (problem behaviour, community acceptance and health/mortality) the majority report no change.⁴⁴

Kozma, Mansell and Beadle-Brown (2009) reviewed 67 papers published between 1997 and 2007. In seven out of ten areas (community presence and participation, social networks and friendships, family contact, self-determination and choice, quality of life, adaptive behaviour, user and family views and satisfaction) the majority of studies showed that community living was superior to institutional care. In three areas (challenging behaviour, psychotropic medication and health, risks and mortality) research reported mixed or worse results.

Thus the general finding is that community-based service models achieve better results for the people they serve than institutions."

International experience

One of the key drivers of change in how disability services are configured has been the decision to end care in residential institutions and replace this by alternative community living arrangements.

In the US, since 1977 the number of residents in institutions had fallen from approximately 150,000, to 36,000 in 2006. An extensive closure programme has seen the number of large state facilities for people with intellectual disabilities fall dramatically. In 1977, 84% of people with intellectual disabilities receiving residential services were in centres of 16 or more people, By 2008, that had fallen to 13%. There are now eleven US states⁴⁵ which have no residential institutions for people with intellectual disabilities.

Sweden had closed its residential institutions by 2000, and provision of residential institutions is now illegal there.

⁴⁴ Kim, S., Larson, S. A. and Lakin, K. C. (2001) Behavioural outcomes of deinstitutionalisation for people with intellectual disability: a review of US studies conducted between 1980 and 1999. **Journal of Intellectual & Developmental Disability**, 26(1), 35-50;

Emerson, E. and Hatton, C. (1994) **Moving Out: Relocation from Hospital to Community**. London: Her Majesty's Stationery Office;

Young, L., Sigafos, J., Suttie, J., Ashman, A. and Grevell, P. (1998) Deinstitutionalisation of persons with intellectual disabilities: A review of Australian studies. **Journal of Intellectual & Developmental Disability**, 23(2), 155-170;

Kozma, A., Mansell, J. and Beadle-Brown, J. (2009) Outcomes in different residential settings for people with intellectual disability: a systematic review. **American Journal on Intellectual and Developmental Disabilities**, 114(3), 193-222

⁴⁵ Alaska, District of Columbia, Hawaii, Maine, New Hampshire, New Mexico, Rhode Island, Vermont, West Virginia, Michigan and Oregon. See Lakin, Larson, Sami and Scott (2009) Residential services for people with developmental disabilities - status and trends through 2008. University of Minnesota. Available <http://rtc.umn.edu/risp08>, p. iii

Across the 6 jurisdictions in the NDA comparative study, there is a consensus that providing disability services based in large institutions is no longer acceptable. All the jurisdictions covered have fully or partially replaced their congregated settings for people with disabilities with smaller, more independent community based settings. Some jurisdictions closed all institutions in a very short timeframe, for others it has taken or will take a few decades.

What kind of community accommodation?

There are ongoing policy considerations in the 6 jurisdictions reviewed which relate to the most appropriate form of community based setting but the inappropriateness of congregated settings is agreed by all parties in the jurisdictions reviewed.⁴⁶

There are three important issues which relate to deinstitutionalisation itself which need to be mentioned.

Firstly, moving out of institutions to settings in the community is necessary, but it is not sufficient on its own to deliver quality of life and community inclusion.⁴⁷ The re-emergence of institutionalised ways of delivering services in community groups homes in New Zealand or in small community settings in Norway have been noted for example.⁴⁸ Variation in the ability of community-based settings to deliver good quality of life outcomes reflects the degree of needs of services users, service design and differences in staff performance, particularly the extent to which they provide facilitative assistance or 'active support'.⁴⁹

Secondly, in a number of jurisdictions the "community" housing model which drove deinstitutionalisation (campuses in England and group homes in New Zealand and Victoria) have subsequently been considered not be appropriate.⁵⁰ It seems not unlikely that the 4 - 6 person group homes will turn out to be a stage which will be replaced with supported living here too.

There may, therefore, be better "value for money" over the medium term for our remaining deinstitutionalisation work (for those currently in congregated settings) to attempt to 'skip' the group home phase.

⁴⁶ Eidelman, S (2005) Foreword in Stancliffe, RJ., Lakin KC. Eds (2005) Costs and outcomes of community services for people with intellectual disabilities. Baltimore: Paul H. Brookes Publishing Co.

⁴⁷ Mansell and Beadle-Brown (2009) "Cost effectiveness of community living for people with intellectual disabilities - an international perspective" Paper to NDA conference 6 October 2009

⁴⁸ National Health Committee (2004), To Have an 'Ordinary' Life. Background papers to inform the National Advisory Committee on Health and Disability, Wellington: National Health Committee. Tøssebro (2009) ANED country report on the implementation of policies supporting independent living for disabled people: Norway

⁴⁹ Mansell, J (2006) Deinstitutionalisation and community living: progress, problems and priorities. Journal of Intellectual and Developmental Disability, 31 (2), 65-76

⁵⁰ In all these three jurisdictions, the policy direction is now towards housing and other supports delivered separately, though progress on delivering on this vision differs across the three jurisdictions

Thirdly, in a number of countries it was the process of deinstitutionalisation which drove many of the system level changes in how disability supports are structured and funded. The impetus to develop a money-follows-the-person system in the USA and to tender service contracts in England and Wales related to larger deinstitutionalisation initiatives. Therefore, moving the remaining residents out of our congregated settings offers not only a chance to develop new community residential options but a chance to leverage this process to drive system level changes.

In addition, the NDA advises that the Value for Money and Policy Review should recommend the implementation of a transition towards the closure of residential institutions. An initial part of this process should involve an unambiguous commitment to not admitting new service users to these settings. In Sweden, that policy is backed by legislation which makes it illegal.

Development of parallel systems

Some jurisdictions which have deinstitutionalised over a prolonged period of time have in effect ended up funding two systems at the same time. Large institutions in some jurisdictions have been left open to cater for older people or people with complex needs. Operating institutions under capacity is expensive in itself but coupled with the costs of supporting former residents in the community results in very poor value for money. As Lakin put it;

the common practice of downsizing - i.e. size reduction but not closure - at a leisurely pace not only deprives those in institutions of better quality of life. but subjects taxpayers to prolonged periods of paying inordinately high prices for inferior outcomes"⁵¹

I0. Residential supports

Supporting families

Families are a key provider of residential support. Living in the family home is the most common residential situation whatever the type of someone's disability. Parents, spouses, siblings or adult children are the first line of support. The need for residential supports may change over time, with a progressive condition or as individuals, and their family members who support them, get older.

In most countries examined, public policy and the system to support families in respect of adults with disabilities tend to be less developed than out-of-home residential supports. In the jurisdictions examined there are efforts being made to address this issue. In New Zealand, the focus of funding increases has been on carer and respite supports.⁵² Victoria,

⁵¹ Stancliffe and Lakin (2005) Costs and outcomes of community services for people with intellectual disabilities. Baltimore: Brookes

⁵² Ministry of Health. The Health and Independence Report 2004: Director-General of Health's annual report on the state of public health. Wellington: Ministry of Health.

which stopped increasing group home places over a decade ago, has put funding into individualised support packages.⁵³

However, in the case of intellectual disability, Ireland would seem to have a higher reliance on out of home residential care than other jurisdictions:

- In the US, 82% of people with intellectual disabilities live in their own or a family home, and 18% of persons with ID receive out-of-home residential placements⁵⁴
- 74% of adults with ID in England were living with a family member or partner⁵⁵
- Virtually all Irish children and 50% of Irish adults with ID live in a home setting⁵⁶

Because the cost of out-of-home services is so significant, there is less money available in many jurisdictions to fund supports to people living with their families or independently. However, it is the case that across the jurisdictions examined, the financial commitments involved in out-of-home residential supports for people with disabilities limits the resources available to support those living at home independently or with their families. Ireland's use of out-of-home services for people with intellectual disabilities seems somewhat higher than international norms, and, as elsewhere, the cost of such care tends to crowd out the choice or capacity to fund supports to other living arrangements.

Residential services account for 17% of those on the disability databases but about half of the Disability Service Programme budget. Residential services receive the biggest share of the budget in other jurisdictions too. Some people will always require a residential service, and these services tend to be expensive, particularly in those cases where support is required on a continual basis. However, from a value for money as well as a community inclusion perspective it makes sense to target resources at services that will keep people out of full-time residential care - i.e. carers' supports, respite, Personal Assistant Services, technical aids other and supports to assist people to access mainstream services and community activities.

Supported Living

A common policy aspiration in the jurisdictions reviewed by the NDA is to move from group homes to supported living. This in effect involves splitting accommodation from personal supports. New Zealand and Victoria have a form of this model and are committed to expanding it. However, England and Wales are to the forefront in developing this approach. Supported living was identified as the preferred residential

⁵³ These generally consist of a mix of PA hours, carer support hours, respite hours and case-management hours.

⁵⁴ 26% of adults with ID are in their own homes, and 56% in the family home, a total of 82%. Prouty, Alba and Lakin (2008) Residential Services for persons with developmental disabilities: status and trends through 2007, tables 2.8, 2.9

⁵⁵ National survey of people with intellectual disabilities, 2003-4

⁵⁶ Kelly, F., Kelly, C., Maguire, G. and Craig, S., (2008) Annual Report of the National Intellectual Disability Database Committee 2008

option by service providers in Wales for all persons with disabilities, irrespective of level of need. Supported living is becoming more and more common in England where it is endorsed by Government policy as part of the commitment to mainstreaming.⁵⁷

Supported living properties are typically owned by housing associations (social housing charities) who provide both the property and housing management services (such as furniture, gardening, heating, lighting, etc) under an assured tenancy. Through contractual agreements with funding bodies, such as grants accessed to build the property and local authority grants to provide services, the property is specifically identified as a residential property for supported living. The premises can therefore only be used to support tenants as per the specification of tenants within the contractual agreements for the property.⁵⁸ Depending on the level of need of tenants, supports from domiciliary care agency staff may range from 24 hour on-site support to drop-in floating support.

Supported living can be provided in singular or shared dwellings. Where dwellings are shared, the maximum number of tenants is usually four. Tenants may also be offered supported living in community-based self-contained flat developments. These developments contain between four and seven self-contained flats, each with its own front door. A communal area is available for tenants and usually comprises a living or dining space.

The tenancy status of supported living residents ensures their security of tenure. Tenants cannot be moved to other premises unless they are in breach of generic tenancy agreements such as failure to pay rent or causing nuisance to neighbours. Tenants have exclusive occupation of the premises which means that the tenant can refuse access to the property and has control of visitors. The provision of short-term or respite beds within supported living residences would be considered atypical and contrary to the ethos of supported living. Supported living tenants may however wish to avail of respite services, most typically where challenging behaviour issues are being addressed.

While there is an acknowledgement that supported living is a new model and has yet to be comprehensively evaluated, the limited studies that are available suggest that supported living provides greater opportunities for choice and community participation^{59,60} and is

⁵⁷ Department of Health (2009) Valuing people now: a new three year strategy for people with learning disabilities. London HM Government

⁵⁸ Domiciliary Care Agencies provide similar supports to those outlined above to tenants and home owners who are living in residences that are not designated as 'supported living properties'. Older persons living in their own homes and people with intellectual disabilities living in the family home, for example, may benefit from these services. These supports are not defined as 'supported living' arrangements but rather as 'sessional' or 'domiciliary care' supports.

⁵⁹ 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.

⁶⁰ 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

more economical given the lower staffing costs.⁶¹ People in supported living arrangements were found to have more friends outside the home, were more likely to be known by their neighbours, and to receive visitors^{62,63}. In comparison with their peers in clustered settings, people in supported living were found to be six times more likely to use community resources.⁶⁴

Size of residential settings to be developed

Most of the current debate in the international literature and in the jurisdictions reviewed is no longer concerned with questions relating to the merits of institutional provision but with the organisation of community residential provision. One of the questions addressed is around the costs and outcomes of larger and smaller community residential units. Research commissioned by the NDA has shown that where the evidence is available, it generally indicates that outcomes are better in smaller settings. A review of supported living and group homes in the UK showed that better outcomes are observed for those residing in smaller group homes (1-3 co-residents) than those in larger dwellings (4-6 co-residents). Residents in smaller group homes report less 'depersonalisation', larger social networks, and were considered at less risk of abuse from co-residents than their counterparts in larger group homes.⁶⁵

A number of jurisdictions have made progress in reducing the size of residential setting. Smaller settings are endorsed in the UK's Valuing People Strategy. In the US the average number living in each "non-family" residential service setting for persons with ID/DD is of 2.6 persons.⁶⁶ In Norway individuals receiving residential supports are housed in their own self-contained apartments.⁶⁷ The apartments are on average grouped together in units of 3 to 5 in residential areas. As mentioned previously, both New Zealand and Victoria have made the decision to move away from the 4 - 6 person group home model in favour of forms of supported living.

⁶¹ 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.

⁶² Emerson, E., & McVilly, K., (2004). Friendship activities of adults with intellectual disabilities in supported accommodation in Northern England. *Journal of Applied Research in Intellectual Disabilities*, 17, 3, 191-197

⁶³ Forrester-Jones, R., Carpenter, J., Coolen-Schrijner, P, Cambridge, P, Tate, A., Beecham, J., et al., (2006). The social networks of people with intellectual disability living in the community 12 years after resettlement from long-stay hospitals. *Journal of Applied Research in Intellectual Disabilities*, 19, 4, 285-295

⁶⁴ McConkey, R., Abbott, S., Walsh, P.N., Linehan, C., & Emerson, E., (2007). Variations in the social inclusion of people with intellectual disabilities in supported living schemes and residential settings. *Journal of Intellectual Disability Research*, 51, 3, 207-217.

⁶⁵ Emerson, E., Robertson, J., Gregory, N, Hatton, C., Kessissoglou, S., Hallam, A., Jarbrink, K, Knapp, M., Netten, A., & Walsh, P.N., (2001). Quality and costs of supported living residences and group homes in the United Kingdom. *American Journal on Mental Retardation*, 106, 5, 401-415

⁶⁶ Prouty, Alba and Lakin (2008) Residential Services for persons with developmental disabilities: status and trends through 2007, Table 2.3

⁶⁷ Tøssebro (2009) ANED country report on the implementation of policies supporting independent living for disabled people: Norway

Clustered or dispersed housing

In 2009 the NDA published research comparing of quality of life outcomes for people with disabilities living in clustered and dispersed residential settings. The reviewed reports on 10 identified studies found a "broadly consistent picture" indicating that dispersed housing leads to better quality of life outcomes.⁶⁸ Clustered housing tends to be less expensive but this is largely a result of staffing levels. "There is no evidence that clustered housing can deliver the same quality of life as dispersed housing at a lower cost".⁶⁹

The range of residential options in Ireland

There is a relatively narrow range of supported residential options for people with intellectual disabilities who are not living with their family. Almost one in three service users live in group homes, with only a small percentage (3.7%) living in independent settings, as Table 2 above demonstrates. The NDA considers that a broader range of independent living options would make it easier to have options tailored to people's circumstances and preferences. Some of these options would also tap into natural community supports and as such may be more cost-effective than options which rely almost exclusively on paid support staff. A mix of natural supports, technology supports, monitoring and case management could support a range of different housing options such as

- living in one's own home (e.g. a family home, one rented from a local authority or voluntary housing organisation) with the provision of supports from the health services
- someone with a disability sharing their accommodation with a non-disabled housemate
- shared living, based on the fostering model, where someone shared their home with someone with a disability

Such non-traditional options are growing in several states across the U.S.

II Day supports

Day Services

Focus on inclusion in mainstream community based activities

The Review of Adult Day Services emphasises supports for inclusion in mainstream community activities rather than segregated day activities. This is in line with the NDA's findings in the jurisdictions it examined. One of the trends observable in these jurisdictions is a move away from "day services" being something which happens in a segregated facility to a system which supports people with disabilities to actively

⁶⁸ Mansell, J., and Beadle-Brown, J., (2009) Dispersed or Clustered Housing for Disabled Adults: A Systematic Review

⁶⁹ Mansell, J., and Beadle-Brown, J., (2009) *ibid*

participate in a range of community activities. Community-based non-work services in the US vary in definition but are defined by the Institute for Community Inclusion as non-job-related supports focusing on community involvement such as access to public resources (recreational/educational) or volunteer activities; they are typically identified as Community Integration or Community Participation Services. Similarly in New Zealand, a central aspect of the Pathways to Inclusion process was to establish clear goals for non-work day services programmes. The result of the process was that these organisations now have clear service specifications which focus on participation in community activities.

The NDA concurs with the focus on supporting people to access mainstream activities (including, education, training, social and cultural activities) rather than segregated, centre-based programmes.

Self-directed day services

In Victoria, as part of the overall aim of making services individualised and self-directed in, day services funding has recently become "individually attached and portable". This means that those currently in day services can leave and take their budget with them to another provider or they could reduce their time with their current provider and fund one-to-one support to enable them to take part in a mainstream activity. Once again this underlines that once a system is developed to allocate resource to individuals based on need, it is a short step from there to allowing people to significantly individualise their support.

12. Employment

Having a job is an important aspect of inclusion in mainstream society, and in promoting financial independence. In 2006, the employment rate of people with disabilities was 35%, compared to 74% for non-disabled people.⁷⁰

A review of international practice by the OECD on disability and employment highlighted not only the high levels of underemployment of people with disabilities but also the poorly designed policies aimed at supporting employment.⁷¹ As in Ireland, employment rates of people with disabilities in the jurisdictions reviewed by the NDA are low. There are however a number of innovations across the jurisdictions aimed at improving employment outcomes and increasing community inclusion of people with disabilities.

Employment Services

Sheltered Work

Though some level of provision of sheltered work programmes continues in a number of the jurisdictions reviewed by the NDA, some states are seeking to move away from segregated employment. England has set a target of 2025 for the end of its support for

⁷⁰ People aged 20-64, principal economic status. From Census 2006 vol 11 Table 9

⁷¹ OECD (2003) Transforming Disability into Ability: Policies to promote work and income security for disabled people. OECD, Paris

sheltered work. New Zealand has abolished segregated work places as part of its Pathways to Inclusion process.⁷² Some states in the USA have prohibited sheltered work settings. Other jurisdictions have high numbers of people in sheltered employment and do not appear to be planning to change policy direction.⁷³ However, for most of the jurisdictions reviewed there is a recognition that people with disabilities, including people with intellectual disabilities, overwhelmingly aspire to have paid employment in a mainstream work place.⁷⁴

The OECD review, cited above, noted that despite the continuing existence of sheltered employment there is a prevailing recognition that it is inappropriate for 'large numbers of people with disabilities'. From a value for money perspective it notes that sheltered employment has a poor record of helping people transition to mainstream employment and it is also expensive to operate.

This segregating approach is not good enough for disabled people, even if it may provide income security for many of them. This approach is also very expensive and therefore, ultimately, not good enough for the taxpayers as well.

Across the jurisdictions studied, while there are different ranges of employment support options, there is a recognition that the core focus of employment support programmes should be supporting people with disabilities to access mainstream employment.

Supported Employment

One of the noticeable trends is the move towards a mainstream approach whereby people with disabilities are supported by generic employment services. In the UK and the US the trend is very much towards supported employment being delivered by mainstream employment providers.

In New Zealand, and increasingly in the UK and the US, the commissioning of open employment supports is based on 'outcome based' payments whereby service providers front-load the cost of job-seeking and are reimbursed by the public purse when employment is secured. While such approaches are seen as being successful in supporting people with disabilities to access employment, overall such policies can incentivise providers away from engaging with people with greater levels of need who experience specific challenges in securing employment.

The NDA advises that while such programmes are appropriately focused on placing as many people in work as possible, they need to recognise the diversity of the population they need to support. It is important therefore that commissioners of such services can

⁷² New Zealand Government, Department of Labour (2001) Pathways to Inclusion. Wellington.

⁷³ For example the Netherlands has 30,000 adults in sheltered employment.

⁷⁴ For example, 65% of adults with ID in England indicated that they want to be in paid employment. (United Kingdom) Department of Health (2009), Valuing Employment Now: real jobs for people with learning disabilities

incentivise service providers to support service users with a range of abilities. As in other service areas, developing the ability to allocate resources based on needs would be of significant advantage in improving outcomes and efficient use of resources.

13. Children with a disability

Organising Specialist Disability Services for Children with Disabilities

Part 2 of the Disability Act, and the Education for Persons with Special Education Needs Act form an interlinked framework for the assessment of the health and education needs occasioned by a child's disability, for development of an Individual Education Plan and the allocation of services and supports. Part 2 is in operation for under-5s since June 2007.

Different professionals and different teams may use different assessment tools, for example depending on where they were trained or the practice in the former Health Board concerned. The outcome can be that individuals in similar circumstances may receive a different assessment of need and consequently different services, depending on what assessment tools were in use in their area. The NDA is examining a number of standard assessment tools being used in other jurisdictions, as part of the resource allocation process, e.g. the Supports Intensity Scale used in many states in the US. A child version of this scale is currently being tested, and without prejudice to the adoption of any particular assessment tool, it might be useful to include Ireland as one of the pilot sites.

Early intervention is vital if children with disabilities are to get the best start in life. Not all LHOs have an Early Intervention Team in place. The NDA advises that the process of establishing appropriately-staffed Early Intervention teams in every LHO in the country be completed, building on the HSE's framework document on early intervention services.

The Early Childhood Care and Education scheme recognises the importance of early childhood education for all children. Children with disabilities are entitled to a second year's place on this programme. The inclusion of children with disabilities in mainstream pre-school education can advance their development and inclusion with their peer age group. In Norway, for example, children with disabilities are a priority group for available pre-school places.

As the ability to communicate is vital, the NDA advises that addressing the shortfall in speech and language therapy services for young children should be a priority. Bacon reviewed the availability of these therapists and recommended an increase in training places which has been implemented. Efficient systems which maximise the contact and therapy hours and minimise back office tasks for speech and language therapists and other therapy professionals can get best value from such professionals who are in short supply.

It should be noted that children tend to be under-represented on the physical and sensory database, sometimes because they are not in contact with specialist disability services, and it can be an inadequate planning tool for this age group.

Planning for transition to adulthood

There is interesting learning from the UK's "Getting a Life" project which was set up to look at ways of enhancing the life chances and employment of young people with intellectual disabilities. The project found generally low aspirations about what young people with learning disability can achieve in their lives – from the whole system, including schools and professionals who work with young people. As a result, many young people and families become conditioned to accept those low aspirations as fact. A key finding was that it was important from age 13/14 onward to support young people in thinking about employment and about a plan for their future life.⁷⁵

Safeguarding and protecting children with disabilities from abuse and neglect

It is generally acknowledged that children and young people with disabilities are vulnerable to abuse and neglect. While there is only limited data available, at present, on the prevalence of abuse against people with disabilities in Ireland, the international evidence shows that people with disabilities are at greater risk of abuse than the population at large. A recent American study found that caregivers abused children with disabilities almost twice as much as children without disabilities and research from Canada suggests that the risk estimate of abuse of people with disabilities may be as high as five times greater than the risk for the general population.⁷⁶

The NDA is also concerned that at present not all children using 'out-of-home' services enjoy, equally, the fullest possible legal protection of the state in respect of these services. At present, approximately 5000 children and young people receive out of home care in Ireland. Approximately 6% of these (300) are children with disabilities. While these children are generally understood to be in the voluntary care of the HSE, it is the case that they may not be afforded the full range of protections that those without disabilities enjoy. Consistent with the philosophy that children's needs are best met within the family setting, the U.S. government has implemented measures to reduce the number of young people (aged 21 years and younger) with disabilities in group settings to zero by 2010.⁷⁷ To achieve this it is recognised that adequate and accessible community services, including access to appropriate medical, therapeutic and respite supports, to promote and maintain the well-being of all family members are necessary. NDA considers that it is important that providing the full range of services to families to meet the needs of their children with disabilities within the family home is a priority and that those who are in out-of-home placements enjoy the full range of protection as by virtue of their disabilities such children may be additionally vulnerable.

⁷⁵ Jordan and Gittsham (2009) Progress report on **Getting a Life** for the Learning Disability Programme Board

⁷⁶ Public Health Agency of Canada, 2009

⁷⁷ US Department of Health and Human Services. Healthy People 2010. 2nd ed. With Understanding and Improving Health and Objectives for Improving Health. Washington, DC : US Government Printing Office; 2000.

14. Ageing with a disability

The issues facing the cohort of people who acquire a disability later in life are relatively well understood. The *Towards 2016* partnership agreement sets out the agreed policy to provide the supports, where necessary, to enable older people to maintain their health and well-being, as well as to live active and full lives, in an independent way in their own homes and communities for as long as possible, and details a series of high-level goals and policy commitments to this end.⁷⁸ There is however a less well developed policy framework for people with lifelong disabilities as they age. Some disabling conditions are progressive, resulting in significant changes in support needs over time. Regular assessment of needs is important if changing needs are to be captured to inform service provision.

The Council of Europe has noted that while people who acquire disabilities in old age tended to live among friends and families and were supported by the same services provision mechanisms as other older people, people with a long-term disability often face more disjointed service provision.

The NDA in 2009 presented a policy advice paper for the National Positive Ageing Strategy, drawing among other sources on a review of the research literature on ageing with a disability. To summarise the NDA's advice:

- Ensure new facilities are universally designed, so they can be readily accessed and used by people regardless of age or disability. New housing should be to Lifetime Home standards
- Include a framework for housing, health and support services to people with disabilities as they age. This should include systematic planning for planned transition of adults with disabilities from the parental home to appropriate community housing, and collaboration between housing and health services in this regard. It should include supports to the individual with a disability to make the transition and over the transition period. It should include training for frontline community care and medical staff to care for people with disabilities as they age, including those with a dual diagnosis of disability and dementia
- Ensure an effective system for access, take-up and use of assistive technologies, and deployment of emerging technologies to promote independent living. The NDA's Centre for Excellence in Universal Design can advise on best practice frameworks

As a first option, 'ageing in place', that is supporting an older person to remain in the residential accommodation of his/her choice for as long as is possible, is deemed good practice in service provision for older people with disabilities.⁷⁹ This model, however,

⁷⁸ Department of an Taoiseach, (2006). *Towards 2016 Social Partnership Agreement*

⁷⁹ Bigby, C., (2004). *Ageing with a lifelong disability. A guide to practice, program and policy issues for human services professionals*. London: Jessica Kingsley Publishers. Cited in B. Maes, & P. Van Puyenbroeck,

requires that resources are made available to meet need. Home modifications, such as level walkways, sturdy railings and appropriate lighting, for example, can enable older persons with disabilities to remain in their residence of choice at a relatively low cost.⁸⁰ For ageing in place to become a reality, housing providers are encouraged to incorporate best practice in the design of their dwellings. Initiatives such as the UK's Supporting People⁸¹ programme provide housing-related grants for non-personal home care. The supports vary by individual need but may include supports such as maintaining a tenancy, home improvements, access to community alarm services or home visits for short periods each week. These grants provide the kind of flexible funding required by individuals to maintain their independence as they age.

Without appropriate forward planning, persons with lifelong disabilities may find that their residential support needs are considered within the context of 'crisis'.⁸² These situations may arise where a sole caregiver, typically a parent, dies or is no longer able to cope with the demands of caregiving. In the absence of any preparation for a substantial change in lifestyle, the individual is likely to experience considerable emotional and social loss.⁸³ In addition, the individual may be inappropriately placed in a service where a current vacancy exists. Unfortunately, the 'fit' between the individual and co-residents is typically poor due to a lack of common interests thereby socially isolating the individual.⁸⁴ This is the antithesis of the person-centred approach. The NDA's consultation with parents showed a pervasive sense of worry about what service will be there for their child when the parent dies.

15. Standards and Outcomes

From our research in this area, it is the NDA's understanding that Ireland is unique among economically advanced countries in having no system of inspection for its residential homes for people with disabilities. Provider registration and inspection against agreed national standards are internationally accepted as a valuable mechanisms of quality assurance and monitoring across a variety of both older and newly emerging models of service provision.

A registration and standards regime was present in all jurisdictions reviewed by the NDA. Even in the Netherlands, where provision has now become substantively insurer-led,

(2008). Adaptation of Flemish services to accommodate and support the aging of people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 5, 4, 245-252.

⁸⁰ Hutchings, B.L & Olsen, R.O., (2008). Home modifications to support ageing in place with an intellectual disability (ID). *Journal of Intellectual Disability Research*, 48, 425-443.

⁸¹ <http://www.spkweb.org.uk/>

⁸² Forbat, L., (2006). Valuing People: hopes and dreams for the future. *British Journal of Learning Disabilities*, 34, 20-27.

⁸³ Ibid

⁸⁴ Bigby, C., Webber, R., Bowers, B., & McKenzie-Green, B., (2008). A survey of people with intellectual disabilities living in residential aged care facilities in Victoria. *Journal of Intellectual Disability Research*, 52, 5, 404-414.

insurers continue to maintain approved provider registers and the national inspectorate (IGZ) continues to implement an ongoing programme of inspection. Northern Ireland's Regulations II (7) and (8) on registered providers are a good example of a set of robust standards with minimum licensing criteria.

In general, the NDA found that external procurement of services in other jurisdictions is conditional on registration of providers and achievement of service standards. The Health Act 2007, which established the Health Information and Quality Authority, provides a framework for registering and accrediting service providers, which has not yet been implemented.

As the national standards for designated residential services have not been implemented at this stage, there is no national, independent evidence available with regard to the quality of disability services in Ireland. The NDA urges that the standards be implemented statutorily at the earliest opportunity.⁸⁵

The latest (2007) figures show over 8,000 people with intellectual disabilities live in some form of residential care. The work of the HSE's Congregated Settings Working Group has identified approximately 4,000 people with disabilities living in residential centres of ten or more people, who constitute roughly half of those in residential care. Initial findings show a majority have communication difficulties, and a third are not in regular contact with their families, so there is nobody to speak for them. The absence of standards makes this group in particular very vulnerable. Admissions to these institutional settings continue to this day.

It is noteworthy that a June 2007 survey of 300 people with disabilities in specialist disability services found that only 57% per cent of those surveyed indicated that they felt 'safe' and that only eighteen per cent felt that they 'exercised [their] rights'. 70% of those surveyed indicated that they were free from abuse.⁸⁶

It is worth recalling that the Ryan report has documented significant abuse which took place against children with disabilities living in residential institutions, and that most of these have continued in care as adults.⁸⁷ Chapter 5 of the report, which details abuse against children with intellectual disabilities in one particular centre, draws attention to

“an enclosed and inward-looking institution...where children with a near-total dependence on others to care made them very vulnerable”⁸⁸

⁸⁵ In the meantime, the NDA is collaborating with HIQA on the development of a self-assessment tool for use with the standards on a voluntary basis.

⁸⁶ McCormack, B and M. Farrell (2007) The Quality of Life of People with Disabilities in Ireland: Results of National Survey. Outcomes Network of Ireland and Delivering Outcomes to People Project.

⁸⁷ Chapter 15 documents 59 reports of abuse, in 14 different schools or services. It noted that 25 of 28 witnesses continued in the same care services as adults.

⁸⁸ Ryan report s.5.223 vol 2

The report drew attention to the lack of external supervision, where service providers alone assessed the quality of care.⁸⁹ Among the report's recommendations are that the lessons of the past need to be learned, that objective standards be introduced and that independent inspection is essential.⁹⁰ This learning can inform how standards and quality are addressed in services for people with disabilities.

The Human Rights Commission recently published a report detailing its concerns at, among others, overcrowding, poor accommodation and a lack of day activities in a particular disability service.⁹¹

The NDA notes the Government's commitment to enable statutory registration and inspection of residential service for children with disabilities to begin by the end of 2010. The NDA advises there is also a compelling need to implement statutory standards for adult services and to ensure a system to inspect residential services for people with disabilities against such standards, in order to protect the wellbeing of this very vulnerable population.

Disability service provision standards in the jurisdictions reviewed

Inadequate inspection and regulation is regarded by the Council of Europe as a structural issue which contributes to the risk of abuse of people with disabilities, a point further elaborated in the research literature.

Outcome-oriented Standards

Amongst the jurisdictions reviewed, the trend to move away from setting out minimum levels of performance to be achieved towards setting out outcomes can best be observed in the stated intent of England's new Care Quality Commission to replace National Minimum Standards with Compliance Guideline Criteria. The essential difference between minimum performance standards and outcome oriented standards is as follows:

- 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

Scotland's National Care Standards for care in the home are also notable for the manner in which they:

- capture outcome and performance dimensions of each standards statement as needed and

⁸⁹ Ryan report, s.5.44 vol 2

⁹⁰ Ryan report s. 7.12 vol 4

⁹¹ 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 a Severe to Profound Intellectual Disability. www.ihrc.ie

- present these statements in an exceptionally service user focused and service user friendly way

Victoria established an outcomes standards regime in 2008 and a parliamentary inquiry in New Zealand in 2008 recommended that New Zealand develop outcomes standards too.

The HIQA standards for residential services were designed with an outcomes focus. The preparation of Regulations and introduction of a system for inspection are required before these standards are operational.

Similarly, standards are required for other elements of disability service, which in addition to setting minimum criteria, have a focus on outcomes. Overall, a system which focuses on outcomes, and whose performance is measured against outcome criteria, is likely to deliver better outcomes and better value for money.

Quality assurance in community settings

In Ireland one of current challenges is to have a standards and inspection regime for designated centres for disability supports. However, for most of the jurisdictions reviewed the current concern with regards to standards and inspection is how to guarantee quality while facilitating innovation in community-based and self-directed supports.

It is important to strike an appropriate balance which manages the risks of independence rather than an over-protective system where safety becomes a reason to restrict independence and choice.

Areas of service delivery outside registration and standards regime

In a number of jurisdictions, the development of consumer-directed support programmes has resulted in some areas of support being delivered by people (often individuals as opposed to agency staff members) who are not subject to standards or inspection. Certain support staff recruited by those with an individual support package in Victoria or some personal assistants recruited in England can provide support outside the existing standards framework. As the site of this support is often the service user's own home there is a balance to be reached between inspection and privacy. The NDA advises that when the Value for Money and Policy Review considers recommendations, it keeps standards and inspection in mind when it considers home and community based supports and vice versa to ensure that its recommendations in these two areas are aligned.

Outcomes

The NDA advises that to ensure that specialist disability service providers have clarity about what they are supposed to be delivering, a set of service area-specific outcome indicators should be written into service specifications, attached to Service Level Agreements.

Section 3 - Resource allocation and value for money

16. Resource Allocation

In Ireland funded disability organisations, as noted in section 1, fall into two categories - those delivering specified care or support services to individuals on behalf of the HSE, and those which are grant-aided, generally the smaller bodies whose main focus is on information, advice and advocacy for their members. In both cases, they receive block funding. The discussion of block funding that follows refers to the block funding of providers in relation to their delivery of care services and supports to individuals.

The degree of state, voluntary and private provision varies across the jurisdictions studied by the NDA. Where services for individuals are delivered by external agencies, a number of different funding and pricing arrangements apply. These include:

- **Block funding:** where providers receive central funding in line with agreed regulations and standards, to provide a particular service
- **Block funding linked to standard unit prices:** Some US states fund services based on standard prices for different elements of service e.g. fixed prices for elements such as an hour of speech therapy or for overnight residential support (HSRI 2009). Funding in New Zealand and Victoria is also based on standardised unit prices.
- **Commissioning:** where public money is awarded to service providers from commissioners following a contractual agreement to provide a given service. Commissioning can become complex when joint commissioning is required, for example across housing, social and health services. This approach is used in England and in Wales and for new funding in Victoria.
- **Individualised funding** whereby an individual budget is arrived at following a standardised assessment and rates. This is the most recently developed of the service options. Payments may be disbursed to service users, to brokers or to service providers to commission an individually-based service. This approach is used in the USA, England, Scotland, South Australia and Victoria.

Some of the jurisdictions reviewed contain an element of all methods of funding listed above. The funding arrangements for disability services may reflect the historical service arrangements, service model ideal and policy-makers' preferences. Therefore, what is necessary to consider in posing the question of what funding system Ireland needs, is what type of disability service system do we currently have and what system do we wish to create?

Current Irish funding approach

Reflecting on the Irish funding model, in the context of the jurisdictions reviewed, there are some basic observations that can be made on the current funding approach:

- Block funding has serious deficiencies in terms of both efficiency and equity. In terms of efficiency, it is a poor means of targeting resources as some individuals may get more services than they need while others may get less. Efficiency gains can come

from understanding exactly what it costs to provide a service at a given level of quality for a particular type of person. However, under block funding arrangements, agencies may know little about actual per person costs.⁹²

- An equitable system would match resources to needs, and ensure that people with similar needs would get similar levels of service. Where resource allocations are not linked to assessments of current need, over time a mismatch can emerge between where resources go and where the needs are. In particular, cognisance needs to be taken of changing needs as people get older - baseline budgets of earlier years may bear little relationship to today's needs. Where funding is based on incremental increases on a baseline budget that bears little relationship to today's needs, the outcome is a variation in funding relative to need across different service providers, so that service users in one part of the country served by a particular service provider may be resourced very differently from service users in other areas served by other providers. The data from the Congregated Settings Survey (Table 5 below) showing very substantial variations in expenditures per head, which do not appear to have any systematic relationship to need, illustrate this point very clearly.
- The Irish model of block funding lacks transparency about where resources go and on what basis.
- Governments or those contracting services on their behalf, across the jurisdictions reviewed have a far greater role than in Ireland in setting the costs of disability specialist services either by dictating the unit prices (USA, Victoria, New Zealand) at which they would contract services or allowing the market to dictate prices through commissioning for services (England and Wales).
- Most importantly, investment in Irish specialist services has for the most part been about incrementally increasing funding for existing support models (e.g. more beds in group homes, more day services places). Ireland, unlike many of the jurisdictions reviewed, to date has not reappraised its specialist disability service funding in light of its mainstreaming commitments and disability policy objectives. Recent reductions in service funding under the heading of value for money have largely been apportioned pro rata across agencies.

Block funding of service providers does not match resources to individuals' needs. Even where an initial allocation of funding is based on an individual's initially-presenting level of need, that allocation tends to be built into the ongoing funding arrangement and never subsequently reviewed, even though the individual's needs may change over time. In practice, in many other countries as well as Ireland, funding allocations to a service may be a poor match to need levels. As Lakin and Stancliffe put it:

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 thought to need, and are assumed to receive, more staff support and so require greater per-

⁹² Jon Fortune, Human Services Research Institute, presentation to NDA, December 2009

person expenditure to provide appropriate services. Studies have reported widely varying relationships between expenditures on services and characteristics of service recipients.⁹³

There is limited service-level data on expenditure readily available in Ireland.

A paper by the Federation of Voluntary Bodies in 2004 estimated the cost of different services as shown in Table 3 below

Table 3: Indicative cost of different services, 2004

Service Type	Cost
Community group home - 5 day	€58,428
Community group home - 7 day, 52 week	€71,283
Psychiatric Hospital	€71,283
Intensive placement (challenging behaviour, profound disability)	€162,292

More recently, an action research study for the Brothers of Charity estimated the costs of existing services received by 45 service users participating in the project, both actual costs, and estimated costs adjusted for levels of independence (Table 4).⁹⁴

Table 4: Estimated costs of different types of service, Jan 2009

	Actual cost €	Adjusted for independence level €
Group home	52,200	43,700
Large residential centre	60,500	49,600
Family home	10,300	27,600
Supported living	15,000	43,000

The Report of the HSE's Working Group on Congregated Settings (2010, forthcoming) conducted a survey of the 72 residential centres which provide care to people with intellectual, physical or sensory disabilities in centres or campuses of ten or more people. The results show significant variation in costs per head across different centres.

⁹³ Stancliffe, RJ. and Lakin, CK. (2005) Context and Issues in Research on Expenditures and Outcomes of community Supports in Stancliffe, RJ., Lakin KC. Eds (2005) Costs and outcomes of community services for people with intellectual disabilities. Baltimore: Paul H. Brookes Publishing Co.

⁹⁴ McClean, Brian (2010) The cost of person-centredness. Paper to conference Transitions to Socially-inclusive Living, Tullamore, 28 May 2010.

Table 5: Spending per head 2006 in ten most expensive and ten least expensive congregated centres

Ten most expensive centres		Ten least expensive centres	
Ranked by Gross cost	Ranked by HSE cost	Ranked by Gross cost	Ranked by HSE cost
€ per capita	€ per capita	€ per capita	€ per capita
385,550	385,550	69,137	67,747
250,648	205,905	68,668	66,553
197,166	192,748	67,747	65,861
192,748	190,261	66,553	60,721
190,261	183,285	60,721	55,227
183,285	168,146	55,227	50,457
168,146	163,318	53,576	49,972
163,318	161,171	50,457	46,084
161,171	160,797	49,972	45,525
157,697	157,697	46,084	41,273

Source: HSE survey of congregated settings. Data covers 70 centres with 3,943 or 98% of total residents. Gross costs include non-HSE funding which averaged 3.7% across all centres; however many centres received HSE funding only. Per capita cost has been calculated by dividing 2006 expenditure figures by 2008 resident numbers

The survey also collected data on expenditure by these centres in 2006, as well as on staff assessments, using the Dependency Rating Scale,⁹⁵ of the degree of dependency of residents. Statistical analysis by the NDA on the relationship between expenditure per head in a centre and the four levels of dependency calculated from the Dependency Rating Scale showed little correlation between costs per head and the dependency composition within centres, and no systematic link between high-cost centres and those with high-dependency residents.

Funding must link to standards

As noted in the previous section, the development of a standards framework in Ireland, covering both residential and non-residential supports, will be required regardless of how services are funded in the future. Even if there were no change to the current funding system, the introduction of mandatory standards, and inspection against those standards, is of vital importance.

It should be noted that, across the jurisdictions reviewed by the NDA, funding for disability service providers is contingent on providers being registered and providing supports in accordance with agreed standards.

This paper considers different resource allocation and budgeting mechanisms, including commissioning of services, tendering out of services, and individual budgets. To safeguard individuals, it is important that the system of registration of service providers envisaged in

⁹⁵ The Dependency Rating Scale used for this exercise combined assessments of physical dependency, safety and security, social skills and behaviour, with residents ranked into one of four categories depending on the number of areas where they had high independence or high dependency scores

the Health Act 2007 is introduced. It is essential that the criteria for selection of preferred providers of services are based on achievement of quality standards, judged in terms of the key values of person-centredness, choice, independence, and community participation, and not on price alone. **The NDA advises that the introduction of any alternative models of funding is explicitly linked to the achievement of standards.**

Washington DC offers one example of a quality management strategy for the disability services that it procures. It introduced a rigorous, hands-on approval process for new providers requiring in-person interviews and site visits. It introduced new annual certification procedures for day, vocational, supportive living, in-home support and host home providers. There are bi-annual performance reviews by commissioning staff and senior management to track continuous quality improvement plans. Increased training and competence testing requirements for all employees of provider agencies were introduced. There is competency and values-based training for staff.

Fairness, accountability, transparency

The Service-level Agreements now being implemented across the disability services should address many of the issues around the accountability and transparency of non-profit disability services raised by the Comptroller and Auditor General in his 2006 report.⁹⁶ However, transparency is not enough, if the system of allocation of resources is in itself inequitable relative to needs.

Individualised budgets

The 2009 Australian KPMG review identified three elements to a person-centred approach:

- person centred planning
- individualised support, based on the person-centred plan
- individualised funding

There are a range of possible individualised funding models. Whatever form they take, individualised funding models would normally be linked to an independent and robust system of assessment of need.

At their simplest, resources follow on from an assessment of need, and are linked to individuals' needs. These can be systems where on the basis of someone's needs, the person is assigned to a low, medium or high band of funding, and the service provider is funded accordingly.

Another variant is the "money follows the person" approach, where the funding transfers with an individual if they move from one service to another. Resources to be allocated may be broken down as between different elements of service, which could be sourced

⁹⁶ Comptroller and Auditor General, 2005, Provision of Disability Services by Nonprofit Organisations

separately from different providers, for example one provider offering a day service, and therapy supports sourced separately.

At the far end of the spectrum are direct payments, where individuals or their families are given funding, again usually based on assessment within a given band, and can source the services themselves.

KPMG (2009) defined individualised funding as:

resources that are allocated based on needs which are identified through the planning process, to support the design and identification of supports that are flexible and responsive to individual needs⁹⁷

Individualised resource allocation

Across the jurisdictions reviewed by the NDA, approaches to needs assessment differ. Some jurisdictions employ a standardised, quantifiable needs assessment tool.⁹⁸ For examples, assessment tools used in the US (including the Supports Intensity Scale, and Wyoming's Doors model) assess individual needs according to a standardised framework, and individuals are then assigned to one of a range of bands reflecting low, average or high levels of support needs. Other jurisdictions attempt to achieve consistency through standards and common training routes for assessment officers.⁹⁹ However, across the jurisdictions reviewed by the NDA, assessments produce an indication of the level of support needed which is then translated into a real or indicative or monetary allocation in accordance with some form of standardised resource allocation model.

US resource allocation models typically assign individuals, using a standardised assessment tool, into one of a number of bands by degrees of support need. Resources are linked to the funding band, in line with variations in assessed needs. For example, there are six separate funding bands used in the state of Virginia. In the US typically, about 5% of service users have exceptional needs which would lie outside the funding bands and would fall to be assessed individually; these individuals would typically account for about 13 to 15% of total budget.¹⁰⁰

⁹⁷ KPMG (On behalf of Victorian Department of Human Services), (2009) op cit

⁹⁸ 14 US States, 2 Canadian and 14 other countries, for example, use the Supports Intensity Scale as a tool to standardise assessment and resource allocation. Fortune, J. (2009) Key Issues to Consider When Implementing Individual or Level-Based Budget Allocation. Presentation to the NDA, 8th December 2009. For an evaluation of different assessment instruments, see Smith and Fortune (2006) Assessment Instruments and Community Services Rate Determination: review and analysis. Colorado Department of Human Services, Division for Developmental Disabilities

⁹⁹ New Zealand for example achieves consistency in assessments by means of a standards framework and common training framework for assessors but nonetheless puts assessment results through a Support Package Allocation tool to arrive at an indicative individual support budget.

¹⁰⁰ Fortune, Agosta and Smith, Human Services Research Institute. Information brief Dec 11 2009. to NASDDS conference - in states with no or fewer than 100 people in residential institutions, the percentage of ID budget for alternative community services going to 5% of most expensive individuals ranged from 13% (4 states) 14% (2 states) 15% (1 state), 18% (1 state), 20% (1 state)

As an alternative to block funding, the linking of resources to individual needs can match resources more effectively to individuals' needs. Such a system can ensure that to the greatest extent possible those with the highest needs receive most support, and conversely that those with lower support needs are supported in care models that maximise their independence.

Indications from Irish action research conducted by the Brothers of Charity services (2010) suggests that individualised support packages, which give a better quality of life for the individuals concerned, can result in lower support costs for those with lower support needs, but higher costs for a small number of individuals with high support needs related to severe challenging behaviour.¹⁰¹ However, this service's experience is that for a small proportion of those with challenging behaviour, an individualised service will come at a lower cost. That reality would generally balance out the extra costs of an individualised service across the group.¹⁰²

Sharing a support resource can spread the cost over the individuals concerned, but may also mean that some individuals are given supports that they do not actually require. Individualised supports can better tailor services to what individuals actually need. In the Brothers of Charity project, some of the cost savings for individuals arose from providing staff support only at hours where it was needed.

Match resources to assessed needs

The NDA advises that a system of individualised budgets, that match resources to assessed needs, using a standardised framework of assessment, offers the right strategic direction. This can ensure a rational and efficient resource allocation model, as well as a fairer matching of resources to individual needs. It is important the system would build-in regular reviews that capture the changing needs of individuals, such as for people with progressive conditions, or changing needs across the lifecycle.

The NDA suggests that this approach could be piloted initially in a small number of local health offices, using the assessment/service statement framework set out in Part 2 of the Disability Act 2005. The Disability Act framework also builds in reviews as individuals' needs change over time.

Although the NDA strongly recommends the need to move to a system where funding is based on a national standardised resource allocation framework, we would caution that such a transition will be challenging for service providers. The wider implications of the

¹⁰¹ Brian McClean (2010) The cost of person-centredness. Paper to conference Transitions to Socially-inclusive Living, Tullamore, 28 May 2010. This paper estimated that, for 46 individuals, giving them the service of their choice would cost an additional €4,654 per person, an 8.6% increase in frontline staff costs; however if four individuals needing individualised, high support accommodation due to challenging behaviour were excluded, there would have been a saving of €1,158 per person, or 3% in frontline staff costs for the remainder

¹⁰² Brian McClean (2010) op cit, oral presentation.

industry transformation will be discussed below but the practical implications in relation to funding are that any new approach will require a set of skills that some service providers who operate in the present funding environment may not have.¹⁰³The NDA advises, in order to minimise potential disruption in introducing a new system, that service provider management, should be offered upskilling and support as part of the introduction of a new funding model. Equally, introduction of the new model will require an upskilling of HSE staff involved in commissioning and funding services, as well as changes to established procedures.

However, there will be no rational basis for considering alternatives to the current system of block grants to service providers for their person-to-person services until we have a mechanism to link assessed needs to resource allocation.

Evidence-based pricing

In other jurisdictions studied, outsourced services are either procured through a competitive tendering process (England, Netherlands) or standard rates of payment are set (many US states, Victoria, Styria (Austria)). In remote or sparsely-populated areas, procuring services through competitive tendering may be less effective, and standard pricing may be the best way to ensure value from solo providers. In the US an iterative approach has been used to develop the schedules of standard payment rates for different elements of service, starting with a baseline set of prices (often based on an initial group of service users) and then fine-tuning the system. To develop a suite of standard prices for Ireland, technical advice from people who have developed such systems in other jurisdictions may be beneficial.

Either mechanism - developing a schedule of standard prices linked to costs, or establishing the appropriate price through a tendering mechanism - could introduce an improved evidence-based pricing model. There may be merit in piloting these two different pricing systems in different geographical areas, or for different elements of service. It is critical, as already stated, that any model of tendering is not based on the lowest possible price, but on value for money - the best price which satisfies core quality criteria.

An assessment and planning process producing a monetary allocation (whether real or indicative) is a prerequisite to producing a personalised support system and to building a system which uses resources efficiently and fairly.

The NDA is preparing a research paper examining different resource allocation and needs assessment systems, due for completion at the end of 2010.

¹⁰³ Some providers already compete for different elements of their business (e.g. contract work) or for service contracts in other jurisdictions

Self-directed services

Across the jurisdictions reviewed by the NDA, there is significant variation in the numbers of people with disabilities who access, and have the possibility to access, individualised funding in the shape of direct payments from which individuals or their families can source service provision. These numbers range from a few hundred to over a hundred thousand in the Netherlands. Nevertheless, some element of individualised funding exists in all the jurisdictions reviewed. What is common to all these programmes is that the assessment and planning process produces a real or indicative amount of support funding. This allocation may translate into choice between providers or choice of supports from a costed menu provided by a provider as is the case in some US states or an actual allocation of cash as is the case in a number of jurisdictions including the UK. A number of jurisdictions which had operated money-follows-the-person type systems, indicative allocations (such as New Zealand and Victoria) have more recently committed to providing more allocations via actual direct payments of budgets to individuals.

Choice of service provider was at the heart of the reform which introduced the medical card in 1970 - it was referred to as the choice of doctor scheme. Direct payments to individuals to source a package of service of their choosing, on the basis of experience in other countries, may have a modest take-up in the intellectual disability services, but giving individuals the potential to choose their service provider would add an important element of accountability to the service user to the system.

The NDA's focus group research suggests that a suitable model of direct payments is of considerable interest to people with physical or sensory disabilities who use personal assistance service, and they see this as important in offering them choice and control over their lives. The NDA is currently undertaking an examination of direct payments, and expects to finalise a policy analysis paper on this during 2010.

17. Value for money

Key components of a value for money approach are **effectiveness** - delivering outputs that make a difference to people's lives, and **efficiency** - delivering those outputs at an economic cost.

Effectiveness

This paper has shown that the present mechanism of block funding for service providers is not consistently linked to assessed needs nor to achievement of outcomes. A resource allocation model of individualised funding linked to bands of assessed need has the capacity to deliver more person-centred services at the same time as matching resources more efficiently to needs. In this way, such a resource allocation model could be more cost effective.

The research demonstrates that institutional services deliver poor outcomes for service users. In Ireland, the estimated average HSE-funded unit cost of institutional services, according to the Congregated Settings Survey, was €115,000 (dividing 2006 expenditure

by 2008 resident numbers). There was considerable variation around this average, with a quarter of services costing less than €82,000 a head, while a quarter of services cost over €130,000 a head. So this is a poor quality model of service at considerable cost.

Outcome measures

Ultimately, the only way to judge the value for money of funding provided is to set clear outputs *and* outcomes and a system to assess the extent to which service providers (statutory or non-statutory) deliver on what they are funded for. We have or will have a comprehensive system and unit level picture of the outputs in the system¹⁰⁴ but still have very little idea about outputs either at a system or unit level. For example, three quarters of Disability Services Programme budget¹⁰⁵ is spent on the two largest service output areas - beds and day services places - which are by and large delivered in settings apart from the mainstream. We have, however, no systematic way of knowing whether these outputs deliver on the overall policy goals of accessing mainstream services and inclusion in community activities.

The NDA advises that a set of clear outcomes measures (derived from overall policy objectives) for each service area should be written into the service specification attached to Service Level Agreements with providers. Robust monitoring mechanisms, including sanctions where appropriate, will be required to ensure that outcomes are being achieved.

In **England**, each local authority (which are responsible for many of the services required to enable people with disabilities to live independently) is required to report annually on social care performance against nine outcome measures, in **Scotland** single outcome agreements, based on national quality indicators, are made between local authorities and Health Boards, and the Scottish Government. Independent monitoring of agency performance against the Standards for Disability Services in **Victoria** was trialled in 2008-9, and independent monitoring is anticipated to be implemented from 2009-2012. In the **US**, 30 states now participate in the Core Indicators Project developed by the National Association of State Directors of Disability Services to enable them measure service delivery system performance.

Efficiency

The NDA has been able to gather some limited information on a like-for-like basis on costs in Ireland relative to other jurisdictions. All the indications suggest that Ireland has, comparable to others, a high-cost model of disability service provision.

Taking expenditure on specialist disability services per head of total population, the following comparison gives a broad sense of how Ireland's expenditure is significantly higher than in other jurisdictions. Ireland's figure was over twice as high as the next

¹⁰⁴ At present the HSE nationally reports on Disability Service Programme outputs and the new SLA framework will provide clear information on agency level outputs, but present there is no framework to ensure that the significant investment in disability services delivers on our policy goals

¹⁰⁵ See table 2 above for details.

highest-spending country. While differences between countries in what is covered under specialist disability services and what is covered in mainstream services may affect the figures, another likely driver is inter-country differences in pay costs, as in most jurisdictions, pay accounts for of the order of 80% of service costs.

Table 7: Specialist disability 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: unpublished study on costings, 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
USA - 2008	€38,369
England - 2009	€63,570
Australia	€63,000

Sources: Federation of Voluntary Bodies; Congregated Settings Survey; Lakin et al 2009; Price Waterhouse Coopers 2009¹⁰⁶

The main driver of costs is pay. In the Congregated Settings Survey, pay represented 84% of the costs of these services in 2006. Pay costs in turn reflect the model of service, the skill mix employed, the underlying pay scales, and the system of rostering and premium payments in place.

Staff mix and level

The number and mix of staff is highly correlated with the model of care provision. In international terms, Ireland's disability care services are significantly professionalised, with a high complement of nursing staff as a legacy of the "hospital" model of care. Overall, one in four staff members in specialist disability services is a qualified nurse. This is particularly the case in institutional settings, where residents may have historically been seen as 'patients'. In congregated settings nurses constitute 36% of staff. The corresponding figure for group homes is 19%, based on a comparator survey of 27 group homes conducted as

¹⁰⁶ Lakin, Larson, Salmi and Scott (2009) Residential Services for Persons with Developmental Disabilities: Trends through 2008. University of Minnesota; Price Waterhouse Coopers (on behalf of Victoria Government Department of Human Services) , 2009, Price Review Out of Home Disability Services Final Report. The report actually shows that the state sector can deliver a group home place at €67,000 and the non-state sector delivers a group home place at €58,000. €63,000 is a weighted average based on the relative sizes of the state and non-state group home provision.

part of the Congregated Settings Survey. Site visits to 30 of the larger congregated settings by the Project Manager to the Working Group ascertained that in many centres, skilled staff were engaged in delivering basic care.¹⁰⁷

Overall, Ireland's large residential centres have over twice as many nurses per head as equivalent centres in the US, in spite of a lower level of staffing overall. US data for large state residential facilities shows a ratio of 2.87 total staff members per resident, a ratio of 1.56 direct support staff, and of 0.24 nurses per resident.¹⁰⁸ This compares with a ratio in Irish congregated settings of 1.63 total staff per resident, 1.32 direct support staff and 0.64 nurses per resident. Thus while Irish congregated settings have a lower staff ratio per resident compared to US centres, the ratio of nurses to residents is over twice as high.

New skill sets

An issue, closely linked to some of the points made above, is that if the Value for Money and Policy Review recommends a system of supports quite different to the one we currently operate, it should reflect as to whether the current skills mix of the workforce is appropriate to the proposed new system.

Table 6 sets out the current WTE posts in the disability services programme as of the end of 2008.

Table 6: Disability Services Staff Personnel, December 2008

Profession	Personnel (WTEs)
Medical/ Dental	171
Nursing	4,265
Health and Social Care Professionals	3,134
Management/ Admin	1,387
General Support Staff	1,434
Other Patient and Client Care	5,943
Total	16,333

Source: Department of Health and Children (2009), Annual Output Statement 2009 For Health Group of Votes

For example, in some other jurisdictions deinstitutionalisation resulted in primary and specialist healthcare for people with disabilities being delivered via the mainstream health services with the remaining specialist disability funded services focusing on personal support. Increasingly, delivering such personal support is seen as requiring its own

¹⁰⁷ In the congregated settings survey, an unusually large proportion of those who could dress themselves were reported as unable to wash - just 48% of those who could dress themselves, compared to a corresponding figure of 87% from the National Disability Survey. This could reflect an orientation by staff towards providing this type of assistance rather than the actual restriction in capacity for self-care. Half of the residents were neither reported as medically fragile nor as having a concurrent physical or sensory disability.

¹⁰⁸ Lakin, Larson, Salmi and Scott (2009) Residential Services for Persons with Developmental Disabilities: Trends through 2008. University of Minnesota. p V

specialist skills, whether delivering active support in residential settings, personal assistance to access work and social activities or service brokerage and volunteer coordination to build people's links in the community.

The NDA advises that alternative models of care, with a different skill mix, would seem not only more appropriate but could be somewhat cheaper. As part of the process of developing more appropriate kinds of care, it would be important to fully explore the potential to retrain and redeploy a proportion of the qualified ID nursing staff elsewhere in the health service where their skills could be utilised to best effect.¹⁰⁹ In this regard it is notable that a significant number of nurses employed in specialist disability services have general nursing qualifications, mental health qualifications, or some form of dual qualification.

Pay scales and premium payments

Irish pay scales across the health sector are typically higher than in other jurisdictions, e.g. social care worker at €50,000; staff nurse: €47,000, Group Home manager €63,000 per annum. In the US in 2008, starting wages in 2008 for direct support professionals in large residential facilities were \$11.43 an hour (\$23,608 a year), and average wages were €14.13 an hour (€29,390 a year),¹¹⁰ and pay rates in community-based services are lower than those in large centres.¹¹¹ Pay and earnings in disability residential services appear to be over twice those in private nursing homes. The figure of €58,000 for average earnings in congregated settings (across all grades of staff) appears to be well over twice the cost per head of staff in the largest private nursing home provider in Ireland.¹¹²

In Ireland there is a considerable gap between the standard pay scales for a Personal Assistant compared to a social care worker, partly reflecting a special pay award to the social care worker grade. However, some of the tasks carried out by social care workers may not be very different from those of a Personal Assistant.

However, reducing pay rates to a minimum level would have its own dangers. Experts in the US have shown that states with lower pay rates experience higher staff turnover. They have warned that excessively low pay rates may jeopardise the quality of care, and have urged individual states to set pay at rates that can attract and retain suitable staff.

¹⁰⁹ One element in changing the skill mix is to reduce the intake of nurses to the ID nursing grade. In this regard, it is noted that the recent FÁS skill forecasts for the health services assumed that the proportion of ID nurses required to serve this population would remain unchanged

¹¹⁰ Lakin, Larson, Salmi and Scott (2009) Residential Services for Persons with Developmental Disabilities: Trends through 2008. University of Minnesota. p. 55

¹¹¹ In the US in 2000, pay rates in community services were 24.6% lower than in state residential services. Stancliffe and Lakin (2005) op cit p. 295

¹¹² A newspaper report (Cork Examiner 3 Dec 2009) showed the largest provider of nursing home care in Ireland, Mowlam, had a pay bill of €13.4m and a staff of 608 in 2008, which works out at an average pay cost of just over €22,000, compared to almost €58,000 in the congregated setting sample.

The current system of premium payments, shift allowances and rostering adds to the costs of the Irish model. Per capita earnings in congregated settings in 2006 (2006 pay costs divided by 2008 resident numbers) averaged €58,000. The cost of overnight and weekend cover, on current shift premia, is a significant cost driver. In the Brothers of Charity study cited,¹¹³ a significant element of cost reduction in moving to models of more independent living was a reduction in staffed overnights. This project also demonstrated the use of a mainstream security firm and a purposely-designed security system, to support independence. Another example of technology, highlighted at NDA's 2009 Annual Conference, is the Safety Connections system used in Vermont to sustain people living independently.¹¹⁴

Reimbursement models

Internationally, reimbursement systems for provision of disability services tend to come into two categories. For example, one is where there are standard rates set and registered providers offer services at those rates. This system is common across many US states. The standard rates model can suit rural areas where it may not be feasible to have potentially competing providers, as well as being suitable for situations where there are a large number of providers of individual care (e.g. home-sharing).

Another system is where services procured through a competitive tendering process, and providers bid for service contracts. An effective tendering process requires a number of providers (non-profit or private) who are prepared to enter bids. The closure of the UK's residential campuses for people with disabilities is being achieved through tendering for alternative services. Where services are procured through a competitive tendering process, it is open to private providers as well as existing non-profit bodies to tender for services.

Ireland operates neither a competitive tendering model nor an agreed suite of rates for different elements of service. Disability service providers are grant-aided, however grants are related to a significant degree to historic arrangements rather than benchmarked for individual providers against an agreed set of costs for different degrees of support needs.

Tendering

EU public procurement rules generally require that public services provided by third parties are sourced through open, transparent tendering processes. However, while procurement processes for social services must be open and fair, they are not subject to all the detailed rules of the Public Procurement Directive.¹¹⁵ Commissioners of social

¹¹³ McClean(2010) op cit)

¹¹⁴

[http://www.nda.ie/Website/NDA/CntMgmtNew.nsf/DCC524B4546ADB3080256C700071B049/C60FC2E1F2A530068025768E003F108E/\\$File/marie_zura_christine_lamphere_proceedings.htm](http://www.nda.ie/Website/NDA/CntMgmtNew.nsf/DCC524B4546ADB3080256C700071B049/C60FC2E1F2A530068025768E003F108E/$File/marie_zura_christine_lamphere_proceedings.htm)

¹¹⁵ Article 21 of the Directive states that only certain specific rules of the Directive are applicable to such social services. In particular, technical specifications have to be drawn up at the beginning of the procurement process and the outcome of the procurement procedure has to be published. Furthermore,

services therefore have greater flexibility in choosing an appropriate means to procure services. The Scottish Executive, for example, has outlined a number of procurement processes for social services which are compatible with EU procurement framework:

- Open tendering
- Restricted tendering
- Negotiated procedure with a call to competition
- Competitive dialogue
- Framework agreements¹¹⁶

At present, most people with disabilities receive all their services from a sole provider, one to which they had been assigned rather than were able to choose. The NDA has previously advised that the procurement of services 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 delivering better value for money.¹¹⁷ In a September 2005 submission to the Department of Health, the Competition Authority signalled its concerns at the absence of a system of tendering, the absence of a mechanism to enable new service providers emerge, and the absence of choice for service users that the current funding system entails.¹¹⁸

There are two separate reasons why tendering could be valuable

- establishing the appropriate price for services, subject to specified quality criteria
- enhancing innovation, service quality and value for money through competition between alternative service providers, and rewarding quality

Competition for services can take different forms. There may be one successful tenderer chosen to deliver services in a particular geographic area. Or there could be a competition from which a number of different providers are qualified. It is essential that any introduction of competition is accompanied by a rigorous attention to standards and does not become a race to the bottom in terms of quality.

There are currently 40 service providers delivering services to the value of €5m. or more; the average funding they receive is €26m. While these may be located in different areas of the country, or may only deal with certain elements of service, the numbers suggest that there are sufficient service providers to create a meaningful degree of competition for services, leaving aside possible new entrants. The HSE itself as a significant service

the basic principles of Community law, such as the obligation to treat economic operators equally and non-discriminately and to act in a transparent way have to be respected for the award of contracts for social services with cross border interest.

¹¹⁶ Scottish Executive, 2010, Guidance on procurement of social care for consultation; <http://www.scotland.gov.uk/Publications/2010/01/13125045/0>

¹¹⁷ NDA submission (2002) to consultation on Towards Better Regulation

¹¹⁸ Comptroller and Auditor General (2005) Provision of Disability Services by Non-Profit Organisations, par 3.20

provider could also enter a competition for services, but it would be important that a procurer/provider separation be preserved in any award of services through an arms-length process.

In some areas, the funding system may have to create incentives to encourage new entrants into the market. As in other countries, there may be few alternative providers offering to provide niche services, or services in remote areas.

One way to transition towards the procurement of services by a competitive tendering process is to tender any new services.

An appropriate commissioning framework.

The commissioning framework needs to be suitably designed to deliver on the core values of person-centredness, choice and inclusion. Awards of service contracts should be conditional on capacity to achieve these outcomes, evaluation criteria and scoring should reflect their importance. A system for training service provider staff and management in these approaches, and systems for monitoring and verifying what has been achieved are other important aspects of the framework.

Experience in other jurisdictions

Market-orientated reforms in public services in England, Scotland, New Zealand, the Netherlands and Victoria, Australia have included competitive tendering. In Norway while the government promotes competition in the business and public sector, it remains committed to "community solutions and public control instead of compulsory competitive tendering in important welfare fields like education and health care services".¹¹⁹ In Scotland high profile social care procurement exercises since 2006 attracted negative press coverage and has led to ongoing intensive parliamentary scrutiny. This has resulted in the Scottish Government (2010) publishing draft guidance on social care procurement in Jan 2010 for consultation between January and April 2010. This sets out a framework for procurement of social services based on a process involving preparation, analysis, planning, securing of services and review. Important for the present purposes are the analysis and planning phases, which involve developing service specifications which are informed by an analysis of:

- **Need** - an analysis of aggregate need
- **Outcomes**- what positive outcomes are planned for service users and carers;
- **Personalisation** - what choice and control will the service provide,
- **Involvement** - how will service users and carers be included in service design and delivery
- **Care Standards** - relevant care standards
- **Codes of Practice** - relevant codes of practice

¹¹⁹ <http://www.regjeringen.no>

- **Best Value** - what funding is available for the service to be procured, and what issues may there be in relation to balancing quality and cost;
- **Benefit and Risk** - what benefit and risk analysis is needed to assess the potential impact of the procurement exercise on service users, carers, quality, cost and partnership working;
- **Procurement Rules** - what are the implications of procurement legislation
- **Workforce** - what skills and competencies are required to deliver the service
- **Leadership** - what senior management involvement is needed for the exercise;
- **Contract size** - what should the contract encompass, taking into account the needs and outcomes required for service users¹²⁰

The Scottish Executive sees partner engagement - action to engage with service users, carers and providers, as an essential first step in developing a strategy to commission services.

The European Association of Service Providers in Disability have set out recommendations for how tendering for social services might be improved.¹²¹ They recommend:

- good standards involving service users and service providers
- indicators and a set of delivery standards based on quality principles
- a system that facilitates innovation and modernisation of services
- promoting the know-how of contracting authorities on service users' needs
- develop the tendering expertise of contracting authorities
- the underlying objective should be the development of long-term safe services - long-term contracts to ensure stable relationships between service users and those who support them
- contracts should support innovation through contracts that adapt according to needs and technological advancements
- include important aspects of this sector in the tendering exercise - long-term commitment; partnership between authorities, providers and consumers; social added value; social cohesion
- flexibility in services that respond to the evolving needs of their users should be valued

It outlines a clear set of principles to guide procurement activity. This guidance acknowledges that social care services are significantly different to other goods, works and

¹²⁰ Scottish Executive, 2010, Guidance on procurement of social care for consultation; <http://www.scotland.gov.uk/Publications/2010/01/13125045/0>

¹²¹ EASPD newsletter summer 2009. www.easpd.eu

services to be procured by public bodies. A distinct approach must be taken in relation to them. Procurement activity must take place within the context of a wider commissioning strategy. Priority should be given to quality in relation to selection and award criteria.¹²² (Scottish Government, 2010). Alternative methods to competitive tendering for procuring services by local authorities approved by the EU include framework agreement, partnering arrangement, restricted tender, competitive dialogue and direct non-competitive negotiation (<http://www.ldascotland.org>).

Benefits and risks

The Scottish service provider federation, Community Care Providers, has outlined some of the benefits and risks of a competitive tendering model. Benefits of competitive tendering include the stimulation of choice and diversity of provision for people with disabilities; creation of opportunities for service providers to bring their particular approach to service provision; the stimulation of a labour market where support and social care staff can seek a reward for their skills and experience; a tool for purchasers to diversify the local market and promote improvements in both cost and quality.

They argue that risks to competitive tendering are heightened when tendering is driven chiefly by cost considerations. Re-tendering can introduce significant uncertainty about the future of services for people with disabilities and it can cause disruption to the continuity of service. It can curtail rather than promote user choice. It can be a major disincentive for providers to invest in and develop the workforce and the service itself if contracts are systematically re-tendered upon contract expiry and there is a likelihood that business will be lost or retained mainly on cost-grounds. For purchasers it can trigger a price war among providers. Although delivering short-term cost savings, this may have a significant impact on providers' ability to recruit skilled staff, potentially affecting the quality of service.

Transfer of Undertakings - Protection of Employees

If as a result of a competition for services, funding for services moves from one provider to another, the provisions of the EU's Transfer of Undertakings - Protection of Employees Directive applies whereby staff may transfer from one provider to another with their existing terms and conditions. In closing its intellectual disability campuses, and commissioning the provision of services, there is a lot of experience in England about the practical operation of these provisions in disability services from which we might learn.

Conclusion

The commissioning of services for people with disabilities through a competitive tendering model has significant potential to deliver greater innovation, transparency, and value for money, but is not without its risks. An absolute prerequisite is putting in place a system of registration of providers and of outcomes-based standards as a basis for commissioning

¹²² Scottish Government (2010) [Social Care Procurement Scotland: Guidance - Consultation draft](http://www.scotland.gov.uk/Publications/2010/01/13125045/1) Accessed at <http://www.scotland.gov.uk/Publications/2010/01/13125045/1>

services against those standards. Ensuring that the evaluation criteria focus on quality, and in particular on the principles of person-centredness, inclusion, community integration, and choice, and not on price alone, is key. It is also important to ensure that service contracts are not awarded on the basis of skill in writing funding applications, but that there is a robust process to establish service quality, commitment, and capacity to innovate.

Striking the right balance between long-term contractual relationships with providers that guarantee stability and security in someone's life, while leaving the system open to innovation and new entrants is important. There is useful learning from Washington DC about the importance of values-based training, face to face interviews and site inspections in ensuring quality in commissioned services. Further work on transitioning to a model of commissioning of services can draw in more detail on experiences and models in other countries. The NDA advises that work towards an alternative model should be done in partnership with service users, their families and service providers.

Section 4 - Implementation

18. Implementation

A commitment to the vision

Key to developing contemporary disability services is the commitment of management to the vision. Where jurisdictions are resistant to change they tend to add-on new initiatives while maintaining traditional programmes and funding.¹²³ This creates competition for scarce resources between continuing to fund residential/ institutional care while also making funding available for new forms of community support. Similarly segregated day programmes can remain firmly entrenched with resistance to moving towards individualised supported employment programmes. In the USA, New Zealand and Victoria, Australia, for example, efforts to reconfigure residential services and develop liveable communities for people with disabilities have been slowed by the retention of older systems alongside new ones.

The coming years may see specialist disability service providers being asked to embrace new funding structures, new standards and inspection requirements and possibly new outcomes reporting requirements. In addition to this these providers are likely to be asked to deliver their services in a person-centred and possibly self-directed way. The degree of change that service providers may be required to embrace should not be underestimated. A number of jurisdictions reviewed had developed an 'industry plan' in recognition of the fact that their planned reorientation of disability service provision

¹²³ Wehman, P., Revell, WG (2005) An excerpt from expanding the human potential and employment capacity of individuals with mental retardation and developmental disabilities: Implementing system change Accessed at <http://www.start-labor.org/filedir/Implementing%20Systems%20Change%20Wehman%20Revell%20excerpt.doc>

involved very significant organisational adjustments on behalf of those services.¹²⁴ The NDA advises that an industry plan and supports to achieve it are likely to be required to ensure that disability services can successfully become transparently-funded, person-centred, quality-focused services.

Key challenges in implementation

The National Economic and Social Forum has conducted a number of specific studies in policy implementation through which it has identified specific challenges in policy implementation. For example, in its 2009 report on Home Care Packages, the NESF identified the following issues as important to an outcomes-focused approach to policy implementation:

- Strategy plans with agreed outcomes
- Measurement of inputs, outputs and outcomes
- monitoring and evaluation using this measurement
- Linking budgets to performance
- Accountability and incentive structures
- Focus on delivery to the client
 - equity in provision
 - plans for delivery, including national-local links
 - standards for delivery, and review of these
 - client involvement in shaping of services
 - innovative means of delivery (e.g. facilitating access to information, use of private and other service providers, and use of IT)
 - the role of organisational culture

A whole-of-Government approach will be required to successfully implement the new model set out in this paper, linking in to mainstream services and supports. The National Disability Strategy provides the framework for developing and overseeing that approach, and the specific implementation tasks that will fall to other Government Departments.

Implementation will pose specific challenges for the HSE, and for current service providers. The HSE will need to develop skills and competencies in areas such as contracting for quality outcomes and for personalised services, which will require a programme of skills development to develop their technical capacity.

⁹⁷ See for example, Victorian Government Department of Human Services (2006). Partnering for the future: The Victorian Industry Development Plan for the provision of support for people with a disability. Melbourne, Victoria

Leadership, culture change and flexibility

Delivering the new model will require good leadership to drive implementation, from the Department, the HSE, and from service provider organisations.

The proposed model will work and be efficient if people get the service they need, when they need it and no more. This will be a challenge to existing organisational culture but unless the whole of the organisation involved in delivering supports (and not just frontline staff) is geared to delivering person-centred support, the culture, practices and structure of service deliver agencies will inhibit their ability to deliver supports in the way proposed.

Organisations from top to bottom will have to be configured to deliver just enough support to maintain independence. This will require a far greater level of flexibility than some organisations displayed to date.

The new model proposed will also require a changed attitude to risk, from a stance of avoiding risks to one of managing and being prepared for risks. Some families may find a changed approach to risk quite difficult.

Person-centred planning

Person-centred planning is a way of discovering how a person wants to live their life and what is required to make that possible. This requires an ability to envision different futures. What passes for person-centred planning can fall significantly short of this ideal. It will be a significant challenge to roll out and embed this kind of person-centred planning in the system.

Needs assessment

Changing to a model centred around individuals where resources are allocated on the basis of individual need rather than through block funding requires a robust system of needs assessment.

The independent needs assessment system set out in Part 2 of the Disability Act is confined to those aged under 5 in June 2007 and it has been slow to implement within the statutory timeframes. The waiting list for assessment of people with physical or sensory disabilities for disability aids, therapies and personal supports is well documented on the disability database. The adoption of standard international assessment tools could be helpful in implementing a more streamlined system of assessment, and in identifying the numbers of people in different bands of need to aid aggregate planning and strategic commissioning of services.

Moving from block funding

The process of moving from block funding of services to a different funding model will require significant adjustment by service providers. The establishment of both individual service rates and the accounting mechanisms necessary to track individual budgets and manage service billings is difficult for many systems.

In a situation where prices are transparently set and are uniform across individual items of service or across bands (low, medium, high) of service requirements, higher-cost providers will disproportionately face change.

Service providers who are unwilling or unable to compete in a world where the model of service has changed, and with it the funding model, may be faced with closure or with moving into different fields of activity.

If an individual chooses to leave a service, and their money travels with them, service providers need to have strategies to deal with the consequences in terms of higher overhead costs for those who remain. These could include opening up services (e.g. employment supports) to people from a different care group, such as mental health.

Challenges for staff

A new model of service provision, funding and delivery will pose significant challenges for staff, to adapt the way they work, to adapt to changing roles and different workplaces and working patterns. Many service providers and their staffs have already embarked on a road of change and have shown considerable innovation, flexibility and adaptability to different ways of working. It will be important to learn from successful models of change implementation.¹²⁵ For some staff, the different skill mix required in the new model may require them to retrain or to move to other arms of the health services.

From wrap around to separate and co-ordinated services

Moving from wrap-around services to separate services sourced from different providers, such as the separation of housing from residential supports, poses significant challenges to deliver services that are co-ordinated at a macro-level, and are co-ordinated at the level of the individual.

Implementing change in straitened budgetary times

Difficult budgetary times can bring greater realisation and acceptance of the need for systems to change, however, they also make it more difficult to generate any transition funding which can ease the process of moving from one system to another. Graduated change is easier to manage, both for service users and for providers - the one person at a time approach - however, this can mean that both old and new models of service are running in parallel for a period.

Monitoring quality

The new system suggested here is predicated on a different approach to what constitutes quality, and to the commissioning of services based on quality. This will require introduction of robust systems to support the delivery of quality services and to measure

¹²⁵ For example, from organisations which have closed institutions or developed new models. In another example, the Brothers of Charity Clare services undertook staff exchanges with US innovative providers, where US staff trained and supported their Irish colleagues around new models, and where Irish colleagues learned new skills and approaches on the job in the US

its implementation. The withdrawal of funding from service providers who do not meet quality criteria would constitute a major change in practice, one that is currently being implemented in the nursing home area.

Challenges to implementation in other jurisdictions

The NDA's research has highlighted the following challenges to implementation of changes experienced in other jurisdictions:

- Area disparity in service provision
- A lack of comprehensive data-collection
- An increase in the inflexibility in services with the use of national service specifications
- A risk averse culture reducing the impact of service innovation and development
- Under-financing of assessment systems
- New systems that are difficult for service users to navigate
- Lack of understanding and policy development on mainstreaming
- Insufficient staff training provided to achieve buy-in and to maintain the vision for new service models
- Insufficient resources allocated to flexible accommodation and community-based models of support and system navigation supports such as key workers and advocates
- Segregated day programmes remain entrenched with less funding available for individualised programmes.
- High levels of unmet need in some jurisdictions with crises becoming the main driver in resource allocation
- The continuation of inappropriate placements due to a lack of developing suitable services and supports

Conclusion

There are significant challenges to implementation of a new strategy. The NDA would be happy to advise in more detail on how these challenges could be met, drawing on experience in other jurisdictions on how transition processes and challenges to implementation have been managed.

19 Relevant NDA work in progress

A number of pieces of NDA work which are underway and scheduled for completion in 2010 or early 2011 can inform the detail of a changed focus of services. These are:

Study of disability service configurations in 6 jurisdictions

- Synthesis paper
- Individual country reports

Research examining different resource allocation and needs assessment systems, including standard assessment tools used in other jurisdictions

Policy analysis paper on direct payments

Research on natural community supports

Advice paper on transitions from sheltered work

Section 5 - Conclusions

20 Summary Conclusions

The NDA advises that

- the principles of person-centredness, inclusion, community integration, participation, independence, and choice should underpin disability services
- the framework for funding disability supports should explicitly link funding for programmes with outcome targets derived from the aforementioned principles
- outcome as well as output targets should be written into contracting documentation
- individuals with disabilities should be supported to live the lives of their choice in the mainstream of the community
- a new system of resource allocation should be introduced, providing individualised funding, based on assessed need - a "money follows the person" approach - in place of block funding of disability service providers for person-to-person services
- services should be procured through a system of competitive tendering
- direct payments for those using personal assistance services should be piloted
- there should be a change from the current model of health service provision that 'wraps around the service user' in a segregated service to a model of provision of health and person social supports - day and residential - that support the service user in mainstream environments
- people with disabilities should be supported to participate in mainstream community activities rather than segregated activities
- the value, and in particular the economic value, of family-based support needs to be recognised and supports to ensure that people remain outside expensive residential settings should be prioritised

- there should be greater emphasis on, and a clearer system for access to, technological supports which can sustain or enhance independence for people with disabilities
- residential care services should be provided in ordinary housing, dispersed throughout the community. A transition towards the closure of residential institutions should be implemented
- supported living should at least be available as an option for all those requiring residential supports and consideration should be given to endorsing supported living as the standard model of providing residential supports
- therapy supports should be provided via the primary care teams
- the full range of family services be provided, as a priority, to meet the needs of children with disabilities in the family home
- appropriate legislative action be taken to ensure that those children in 'out-of-home' services enjoy the full range of protections as other children in the care of the State
- the process of establishing appropriately-staffed early intervention teams should be completed
- a system to ensure that mainstream pre-schools can access appropriate supports to accommodate children with disabilities should be developed
- a process to ensure that people with disabilities and their families and carers are supported to plan for their future support as they age is required
- that people with disabilities, and in particular people with intellectual disabilities, are living longer needs to be recognised and reflected in greater cooperation between aged care services and disability services
- new housing funded for disability support provision should be to Lifetime Home standards
- to deliver on mainstreaming requires effective cross-sectoral co-ordination based on agreed protocols
- in order to avoid service fragmentation for service users the Value for Money and Policy Review recommendations will need to be endorsed and driven by a whole-of-government implementation plan
- a system of service brokerage centred on a key worker is essential to join up the different elements of service for individuals
- provider registration and inspection against agreed standards is required to develop a quality assurance framework
- a different skills mix will be required to deliver services which are focused on independent living
- an "industry plan" to support the reorientation of disability services may assist the implementation of the required changes

Appendix I

Disability services in Ireland

Composition of disability services

Specialist disability services, funded and delivered by the health services, can be categorised as falling into a number of service areas, as set out in Table 9.

Table 9: Main areas of disability service provision¹²⁶

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	8,450	920
Respite	4,760	3,150
Aids and appliances	-	17,730

* 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.

In keeping with the mainstreaming approach of Irish disability policy, there are a number of policy initiatives at various stages of completion - such as the Comprehensive Employment Strategy and the housing policy for people with disabilities - which will result in more services being delivered through the mainstream public service. These developments pose not insignificant challenges to the relevant mainstream public service providers, but if resources are to be used efficiently they will also require a reduction or refocusing in some areas in which specialist disability service providers provide supports. As will be discussed below, across a number of jurisdictions reviewed by the NDA the move towards more community based service provision for people with disabilities was seen as requiring considerable reorientation in the role played by specialist disability service providers.

Expansion of community ID provision

There has been significant expansion in the number of community-based residential services, and in respite care, since the mid-1990s (Table 10). While total numbers of people with intellectual disability have remained broadly static, the number living in

¹²⁶ Figures from NIDD 2008 and NPSDD 2008. Kelly, F., Kelly, C., Maguire, G. and Craig, S., (2008) Annual Report of the National Intellectual Disability Database Committee 2008; Doyle, A., O'Donovan, M. and Craig, S., (2008) National Physical and Sensory Disability Database Committee Annual Report 2008.

community group homes has grown by two thirds over the 12 year period, and the numbers living independently by 80%. On the other side, the numbers living in psychiatric hospitals has fallen by two thirds, and the numbers in residential centres by 20% over the period. In addition, almost 5,000 benefited in 2008 from respite care.

Table 10: Intellectual disability - main residential circumstances 1996, 2008

	1996	2008	2008 as % of 1996	Change 1996 to 2008
Home setting	16,267	16,722	103%	+3%
Both parents	11,849	11,332	96%	-4%
One parent	2,874	3,945	137%	+37%
Sibling	864	890	103%	+3%
Other relative	409	205	50%	-50%
Non-relative	45	28	62%	-38%
Adoption	36	30	83%	-17%
Foster care, boarding out	190	278	146%	+46%
Independent setting	526	950	181%	+81%
Living independently	105	324	309%	+209%
Living semi-independently	421	626	149%	+49%
Community group home	2,393	3,894	163%	+63%
5-day	638	471	74%	-26%
7-day	846	586	69%	-31%
7-day, 52 week	909	2,837	312%	+212%
Residential centre	3,824	3,015	79%	-21%
5 day	276	85	31%	-69%
7-day	993	402	40%	-60%
7-day, 52 week	2,555	2,528	99%	-1%
Other full-time	1,355	1,381	102%	+2%
Special intensive placement	347	745	215%	+115%
Mental health community residence	-	59	-	n.a.
Nursing home	38	153	403%	+303%
Psychiatric services	970	308	32%	-68%
No fixed abode	6	14	233%	+133%
Insufficient information	2,323	61	3%	
Total	26,694	26,023	97%	-3%

Funding framework for disability service provision in Ireland

Responsibility for delivering specialist health and personal social services for people with disabilities is the responsibility of Primary, Community and Continuing Care, now within the Integrated Care directorate, of the HSE. Specialist disability services are delivered directly by the HSE or by non-government "voluntary agencies" part-funded by the HSE. The documentation for a basic national framework for contracting between the HSE and disability service delivery agencies - Service Level Agreements, letters of understanding - was agreed in early 2010. This is a significant step in the process of developing more

clarity around what services are being contracted between the HSE and voluntary agencies and should mean that information on disability service funding should be more transparent than has been the case to date. However, the funding framework of disability services at present is largely unchanged from the one which the C&AG described as having:

evolved into one where services to persons with disabilities result from a historical pattern of provision and are largely negotiated rather than the result of contested procurement¹²⁷

Therefore, the same basic framework that the HSE inherited on its establishment still holds. That can be broadly characterised by a system whereby the HSE disability budget (€1.476 billion in 2010) is disbursed to HSE Local Health Offices (LHO), or disbursed to large disability organisations at a regional level by the HSE. Analysis of the 2006 figures show 55% of the €1.5 billion was disbursed to LHOs and 45% was disbursed to HSE regions.

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 (now called Section 38) of the State and with the assistance of the State (now called Section 39) was maintained.

Data is available for 2004 and 2009 on funding to non-profit organisations

	2004			2009	
	No of bodies	Share of funding		No of bodies	Share of funding
Over €10m	25	69%	Over €5m	40	90%
€1m to €10m	75	24%	€1m to €5m	34	7%
Under €1m	683	7%	Under €1m	168	3%
Total	783	100%		242	100%
Total spent	€877m			€1,166m	

Sources: C and AG Report 2005; HSE PCC Directorate

In 2004, the 25 largest bodies received on average €24.2m. In 2009 the 40 largest bodies received on average €26.4m. It is notable that while 100 bodies received over €1m in 2004, this had dropped to 74 in 2009, and the number of organisations receiving small grants (under €1m.) fell dramatically from 683 to 168.

There are, therefore, 74 non-statutory service providers operating on a significant scale. These are a mixture of national, regional and local organisations. The extent to which this

¹²⁷ Comptroller and Auditor General, (2005) Provision of Disability Services by Nonprofit Organisations

translates into choice for the person with disability is addressed in the main body of the policy advice paper.

Disability service providers receive "block funding" to provide services. 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 process. 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 ID service needs for the region in line with priorities laid down in the HSE Service Plan and any other conditions placed on the funding . Similarly, 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. However, Section 39 agencies receive a lower share of their funding from the HSE and tend therefore to be more reliant on fundraising and other sources of income. There are a small number of large physical and sensory disability service providers who receive some Section 38 and Section 39 funding but by and large physical and sensory disability service providers tend to receive the majority of their funding under section 39.

Developing systems which best link support need to support allocations is no doubt difficult in many areas of social provision, however, a recent review of contemporary disability service systems noted, "[i]nvestment patterns in disability service provision have historically been driven by the location of services and the ongoing investment in those services"¹²⁸. That is to say, the funding of disability services in most developed countries, including Ireland, has traditionally been based on funding disability services to deliver centre-based supports as opposed to funding the individual support needs of people with disabilities.

¹²⁸ KPMG (On behalf of Victorian Department of Human Services), (2009) The Contemporary Disability Service System

Appendix 2

Models of procurement and funding in different jurisdictions

Jurisdiction	Procurement		Funding		
	Internal or outsourced	Direct commissioning or competitive tendering	Sources of public funding	Degree of self-funding	Role of direct payments
Ireland	HSE 20%, voluntary providers 80% approx	No tendering	Central government grant	Personal contributions in residential care at maximum €153 a week	None
England	Managed by local authorities. Must source 85% from voluntary/private sectors; remaining 15% provided internally	Central government target of 85% of services put out to public tender	Central government. Local taxation (council tax)	Means-tested contributions from service users accounts for about 14% of cost of social care provision. Level of charge determined by local authorities	About 4% of total gross care expenditure. High on policy agenda
Scotland	Managed by local authorities. No requirements of mix to be provided internally or sourced externally	No set targets for tendering. Significant variation between different councils. Edinburgh has put all services to pwd up for tender. In Glasgow, council delivers vast majority of care.	Central government. Local taxation (council tax)	Means-tested contributions from service users. Level of charge determined by local authorities	As in England
New Zealand	District Health Boards responsible.	Contracts only issued to limited number of providers. Initial steps underway to set up quasi market structure	Central government - 73%. local taxation.	Means-tested contributions from service users accounts for about 19% of gross cost of social care provision.	Uptake low and patchy

Jurisdiction	Procurement		Funding		
	Internal or outsourced	Direct commissioning or competitive tendering	Sources of public funding	Degree of self-funding	Role of direct payments
Victoria (Australia)	State government 43%. External providers 57%	All contracts with external providers directly awarded. moves to set up mixed economy of care	Federal government 66%, State government 34%	Means-tested contributions from service users	Uptake currently low but growth expected. New disability strategy lays considerable emphasis on this
Norway	Provided by municipalities	Services mainly provided by municipalities. Some NGO involvement but directly allocated rather than tendered	Central Government financed through social welfare and insurance	Social care and specialist service through general welfare scheme	Although a priority, uptake low
Netherlands	Provided by state, private sector and NGOs	Current drive to increase role of competitive tendering. Insurers can negotiate prices with service providers	Funded via health insurance; social support' special medical expenses	Majority of services covered by mandatory state insurance programme	Small but growing area