

Value for Money and Policy Review of Disability Services in Ireland

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DEPARTMENT OF HEALTH

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Glossary

VFM terms

economy	Securing the appropriate quality of inputs at the best price.
effectiveness	Effectiveness is defined in terms of the extent to which the objectives have been achieved and the planned benefits delivered. In terms of the Programme Logic Model (<i>see below</i>), the study of effectiveness is a study of the relationship between outputs and results. Effectiveness will consider the immediate to short-term effects that the availability of outputs had on the targeted beneficiaries.
efficiency	Optimising the ratios of inputs to outputs. An examination of efficiency looks at whether the same level of output and result could be achieved with fewer inputs (e.g. at a lower cost) or whether a higher quality or quantity of outputs might be delivered from a fixed amount of input.
impacts	Impacts are the wider effects of the programme, from a sectoral or national perspective, in the medium to long term. They include the medium to long-term effects on the targeted beneficiaries.
inputs	Inputs are resources put into a programme and include human inputs (grades of staff), system inputs (procedures), financial inputs (budget made available for programme) and data inputs (e.g. information flows).
outcomes	Outcomes combine the results and impacts of a programme.
outputs	Outputs are what are produced by a programme. They may be goods or services.
performance indicators	Performance indicators are data points used to measure inputs, activities, outputs or outcomes, and are used to monitor the progress of the programme being reviewed.
Programme Logic Model	Maps out the shape and logical linkages of a programme and provides a systematic and visual way to present and share understanding of the cause–effect relationships between inputs, activities, outputs and outcomes.
results	Results are the effects of the outputs on the targeted beneficiaries in the immediate or short term. Results can be positive or negative.

Other terms used

agency staff	All staff who are employed by the HSE or a service provider on a temporary basis and who do not appear as part of the agency's whole-time equivalent (WTE) head count.
capacity-building	Capacity-building is the process of ensuring that an individual or organisation has the skills, competencies, knowledge, structures and resources to realise their goals effectively.
challenging behaviour	<i>'... culturally abnormal behaviour of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy or behaviour that is likely to seriously limit use of, or result in the person being denied access to ordinary community facilities'</i> (Emerson, 1995).

congregated setting	Setting where ten or more people with disabilities are living together (HSE, 2011).
Disability Finance Book	The Disability Finance Book (DFB) was compiled by the HSE for the VFM Review and was drawn primarily from the HSE's Corporate Reporting System (CRS). CRS data had a number of limitations. As a result, it was necessary to bring raw financial data through a number of stages which would greater enhance and develop its usefulness for the purpose of the Review.
Genio	The Genio Trust, a registered charity, was established in 2010 to support innovative projects that positively impact on the lives of people in Ireland who are marginalised in society. It works in the disability, mental health and dementia fields, supported by the Atlantic Philanthropies and in collaboration with the Department of Health, the HSE, and non-governmental advocacy and service-providing organisations.
Grant Aid Agreement	A formal arrangement between the HSE and a provider for the provision of services to service users under specific terms and conditions, where the allocation provided is under €250,000 in a calendar year.
individualised budgeting	Individualised budgeting is an umbrella term that may take many forms, ranging from a method of determining resource allocation to agencies based on assessed client need and actual costs, to a 'money follows the client' model, a brokerage system or a personal budget model administered by the individual service user. With individualised budgeting, the main transfer to the service user is the transfer of choice and control over funding decisions. This might or might not involve the transfer of actual funds to the individual.
intellectual disability	A disability characterised by significant limitations both in intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills. This disability originates before the age of 18 (AAIDD, 2010).
multi-annual investment programme	The multi-annual investment programme (MAIP) 2006-2009 was announced in December 2004 as part of the National Disability Strategy. It made provision for the development of additional residential, respite places and day care places for people with intellectual disability and autism, and additional residential care and home support services for people with physical and sensory disabilities. Approximately €425m has been spent to date (i.e. up to end 2011) on disability services under the MAIP by the HSE.
market-shaping	Market-shaping is the process by which those who fund services examine the market (both supply and demand) for services and take appropriate action to shape and optimise the provision of those services. It includes active intervention to ensure a responsive market, capacity-building at individual, organisational and community level, and the development of collaborative relationships with service providers to achieve positive outcomes and obtain value for money.

National Disability Strategy	<p>The National Disability Strategy (NDS) is the overarching Government policy on people with disabilities and has five main elements:</p> <ul style="list-style-type: none"> • the Disability Act 2005; • Education for Persons with Special Educational Needs (EPSEN) Act 2004; • Sectoral Plans published in 2006 by six Government departments; • Citizen's Information Act 2007; • €900m multi-annual investment programme (allocated across a number of Government departments) to support the development of high-priority disability support services over the period 2006-2009. <p>The objective of the NDS is to put in place the most effective combination of legislation, policies, institutional arrangements and services to support and reinforce equal participation for people with disabilities.</p>
non-statutory disability service provider	A body funded by the Health Service Executive to provide specialist disability services under Section 38 or Section 39 of the Health Act 2004.
Pobal	Pobal is a not-for-profit company with charitable status that manages programmes on behalf of the Government and the EU. Its remit includes the provision of support to communities and local agencies towards achieving social inclusion, reconciliation and equality.
Section 38 agencies	Agencies funded under Section 38 of the Health Act 2004, which states, <i>inter alia</i> , that ' <i>The Executive may, subject to its available resources and any directions issued by the Minister under section 10, enter, on such terms and conditions as it considers appropriate, into an arrangement with a person for the provision of a health or personal social service by that person on behalf of the Executive</i> '.
Section 39 agencies	Agencies funded under Section 39 of the Health Act 2004, which states, <i>inter alia</i> , that ' <i>The Executive may, subject to any directions given by the Minister under section 10 and on such terms and conditions as it sees fit to impose, give assistance to any person or body that provides or proposes to provide a service similar or ancillary to a service that the Executive may provide</i> '.
Service Level Arrangement	A formal arrangement between the HSE and a service provider for the provision of services to service users under specific terms and conditions, where the allocation provided is greater than €250,000 in a calendar year.
skill mix	The various skill levels of health service staff required, either within a particular discipline or for the total staff within an organisation, to provide effective care.
statutory service provider	The Health Service Executive, established under the Health Act 2004.
voluntary agency	An autonomous non-profit and non-statutory organisation providing a social or community service. In the context of the VFM Review, a voluntary agency is a specialist non-profit provider of disability services or supports.

voluntary sector	The voluntary sector is the collective name for organisations with a social, charitable or philanthropic function that are not established by statute (i.e. non-statutory) and that do not generate profits or distribute dividends (non-profit or not-for-profit). Where surplus funding is accrued by a voluntary sector organisation, it is used to further the goal of the organisation.
whole-time equivalent	Whole-time equivalent (WTE) is the equivalent number of combined part-time and full-time staff resources operating on a full-time basis; for example, two staff members both working half-time are equivalent to one whole-time post.

Acronyms

AAIDD	American Association on Intellectual and Developmental Disabilities
AFS	annual financial statement
ALS/PA	Assisted Living Service and Personal Assistance
C&AG	Comptroller and Auditor General
CAS	Capital Assistance Scheme
CB	challenging behaviour
CEEU	Central Expenditure Evaluation Unit, Department of Public Expenditure and Reform
CIS	Clinical Indemnity Scheme
CNM	Clinical Nurse Manager
CRS	Corporate Reporting System
DFB	Disability Finance Book
DA	Disability Allowance
DECLG	Department of the Environment, Community and Local Government
DFB	Disability Finance Book
DML	Dublin Mid Leinster
DNE	Dublin North East
DoH	Department of Health
DPER	Department of Public Expenditure and Reform
ECF	Employment Control Framework
EPSEN	Education for Persons with Special Educational Needs
ERG	Expert Reference Group on Disability Policy
ERHA	Eastern Regional Health Authority
GAA	Grant Aid Agreement
HIQA	Health Information and Quality Authority
HRB	Health Research Board
HSE	Health Service Executive
ICF	International Classification of Functioning
ID	intellectual disability
IDS TILDA	Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing
IQ	intelligence quotient
ISA	Integrated Service Area
LGSS	Local Government Superannuation Scheme
LHO	Local Health Office
MAP	Measure of Activity and Participation
MAIP	Multi-annual Investment Programme
NAD	National Association for the Deaf
NCBI	National Council for the Blind
NDA	National Disability Authority
NDS	National Disability Strategy
NHASS	Nominated Health Agencies Superannuation Scheme

NIDD	National Intellectual Disability Database
NPSDD	National Physical and Sensory Disability Database
NSP	National Service Plan
ODMH	Office for Disability and Mental Health
OECD	Organization for Economic Cooperation and Development
P&S	physical and sensory
POM	personal outcome measure
PRSI	Pay-related Social Insurance
RA	resource allocation
RDO	Regional Director of Operations
RTA	road traffic accident
SIS	Supports Intensity Scale
SLA	Service Level Arrangement
STI	science, technology and innovation
ToR	Term of Reference
VFM	Value for Money
VFMPR	Value for Money and Policy Review
WHO	World Health Organization
WTE	whole-time equivalent

Executive Summary

INTRODUCTION

The Executive Summary outlines the key message from this Value for Money (VFM) and Policy Review of Disability Services in Ireland and sets out the priority recommendations and immediate actions needed to achieve it. The background to the Review is then described, followed by a synopsis of key findings, conclusions and recommendations under the following thematic headings:

1. Programme objectives and policy
2. Economy and efficiency
3. Effectiveness
4. Governance and accountability
5. Information framework
6. Funding framework
7. Re-articulation of objectives and future policy development

KEY MESSAGE AND PRIORITY RECOMMENDATIONS

The Review proposes a fundamental change in approach to the governance, funding and focus of the Disability Services Programme, with the migration from an approach that is predominantly centred on group-based service delivery towards a model of person-centred and individually chosen supports. The recommended model of supports should be underpinned by a more effective method of assessing need, allocating resources and monitoring resource use. A re-articulated vision and goals is proposed, with a recommendation that a set of realistic, meaningful and quantifiable objectives be developed to support their realisation. The achievement of measurable outcomes and quality for service users at the most economically viable cost underpins the recommendations.

A core principle that guided this Review is that agencies which receive funding from the State for the delivery of services and supports to people with disabilities are accountable for that funding, and the necessary systems and protocols should be put in place to ensure full accountability and transparency on a standardised basis.

A set of implementation priorities is outlined below. Some actions are prioritised because they provide the necessary infrastructure to support other key recommendations, others because they have the potential to result in immediate efficiency savings. All recommendations should be considered in the light of the national financial position and the funding available to the health sector during the period of the National Recovery Programme 2012-2014 and also into the longer term. Implementation of the recommendations should be driven at national level by a strong, standard and consistent approach if they are to be effective. While policy development is the responsibility of the Minister for Health and the Department, the transformation of the

health services which is currently being planned will mean that the Department will also have a more active involvement with policy implementation in the future than has been the case in recent years.

IMPLEMENTATION PRIORITIES

Administration and governance

1. The national disability function within the Health Service Executive (HSE) should be strengthened and given a central directional role in funding, shaping and driving the Disability Services Programme. The implementation of the recommendations in this Review should be the responsibility of a Director of Disability Services who would have the qualifications, skills and experience necessary at senior management level to drive the change management process.

Person-centred services and supports

2. The HSE should drive migration towards a person-centred model of services and supports through the Service Level Arrangement (SLA) process. Demonstration projects should be initiated by service providers as proof of concept and run in parallel with current services, and their suitability for wider application subsequently evaluated.

Commissioning and procurement

3. The HSE should, in consultation with the disability sector, work towards the directional re-shaping of certain services and models of service delivery based on a new commissioning and procurement framework.

Resource allocation

4. A national resource allocation model should be developed, based on a standardised and appropriate assessment of need process, a methodology for associating standard costs with assessed needs and transparent protocols for determining the basis for allocating finite resources.

Information infrastructure

5. The strategic information requirements needed for the effective management of the Disability Services Programme should be established, having regard to existing information sources and datasets, and an implementation plan put in place.

IMMEDIATE ACTIONS

Streamline SLA process

1. Make the recommended adjustments to the SLA process to facilitate immediate improvements to basic information gathering and performance monitoring.

Standardise financial reporting

2. Immediate action should be taken to arrive at a system where allocations and expenditure can be tracked, analysed and compared at national, regional and local levels. The basis of this will be the development of a common coding system and work on this should commence as a matter of urgency.

- | | | |
|----------------------------------------------------------------|----|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Prepare groundwork for individualised service provision | 3. | A unique identifier should be put in place for those seeking or receiving services, consistent with plans for a wider health sector identifier, to facilitate individual needs assessment, person-centred planning and individualised budgeting. |
| Examine VFM findings | 4. | Each agency should undertake an immediate and robust examination of the findings and key recommendations of the VFM Review, and draw up an implementation plan to give effect to the recommendations. The following recommendations should be advanced as a priority: |
| <i>Audit of rosters</i> | a. | Agencies should immediately audit and critically review their rosters, and make necessary adjustments to rationalise staff deployment patterns across service units, consistent with client need and cost-effectiveness. |
| <i>Skill mix</i> | b. | The appropriate mix of professional and non-professional staff needed to deliver services and supports should be determined through an examination of skills, functions and grades. Agreed national guidelines should be determined. |
| <i>Unit cost base</i> | c. | The HSE and disability service providers should critically examine their existing cost base in the light of the findings and recommendations in Chapter 5 of the VFM Review. The HSE should also engage with disability agencies to establish the reasons for costs that remain higher than the average costs detailed in the Review. |
| <i>Average costs</i> | d. | Pending the implementation of a resource allocation model, the HSE should work with agencies from 2012 onwards through the mechanism of the SLA process to reduce current direct pay costs to the levels set out in Table 5.18 (based on data given by agencies in respect of staff/client ratios on their 2009 SLA Schedule 3 returns). |
| Policy appraisal | 5. | The new policy approach endorsed in Chapter 7 of this Review should be appraised. The appraisal should be conducted according to Government guidelines on policy appraisal, i.e. the VFM Code. |
| Implementation plan | 6. | Develop an implementation plan, taking into account the outcome of the policy appraisal, the scale of the organisational change required and the capacity constraints already referred to. |

BACKGROUND TO THE REVIEW

This Value for Money and Policy Review is an evaluation of the efficiency and effectiveness of disability services in Ireland wholly or partly funded from Vote 40 (HSE), including the statutory and non-statutory sectors. The Review was conducted under the auspices of the Government's programme of Value for Money Reviews for 2009-2011. The Steering Group established to oversee the Review was chaired by an independent chairperson, Mr. Laurence Crowley, and had two other independent members, as well as members drawn from the disability sector, Department of Health, Department of Public Expenditure and Reform, and the Health Service Executive (HSE). The purpose of the Review was to assess how well current services for people with disabilities meet their objectives and support the future planning and development of services, and to make recommendations that will ensure that the very substantial funding provided to the sector is used to maximum benefit for persons with disability, having regard to overall resource constraints which affect all sectors at this time.

The Review used a number of data sources and methods, undertook a public consultation, issued detailed questionnaires to disability service providers and carried out extensive data analysis. Some of the data required was not available from the HSE or from non-statutory service providers in a form needed for the purposes of the evaluation and this finding is addressed by a number of recommendations in Chapters 4, 5 and 8. Much of the analysis on both inputs and outputs presented in the report is the first time that such data have been collated and examined in this way.

As part of the overall VFM Review, an Expert Reference Group on Disability Policy was established to look specifically at existing disability policy and assess whether it needs to be changed to better meet the expectations and objectives of people with disabilities. A public consultation process on existing disability services was undertaken, which confirmed that people with disabilities and their families are looking, more than anything else, for more choice in the services they receive and more control over how they access them. The public consultation was conducted via an online questionnaire on the objectives, efficiency, effectiveness and funding of the disability services, and the results provided an input into the work of the Expert Reference Group.

While the Review was confined to an examination of specialist disability services provided from the Health Vote, it is acknowledged that people with disabilities who receive specialist services under the Disability Services Programme are part of a wider cohort of people with disabilities, including those who acquire disabilities through life-events or advancing years, who use all aspects of the public health services, including cross-cutting services such as preventative services and health promotion. The Review acknowledges that the delivery of efficient and effective health services and supports which are fit for purpose and which are relevant to the needs of people with disabilities is vitally important in ensuring that people with disabilities are facilitated in living their lives as fully included citizens of the State.

KEY FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

PROGRAMME OBJECTIVES AND POLICY

Key Findings and Conclusions

Rationale: The VFM review has been conducted in the context of the current economic climate and the prospect of continuing resource constraints into the foreseeable future. The rationale for the provision of publicly funded services and supports for people with disabilities – that it serves the needs of those who could not otherwise afford to provide basic social and personal supports for themselves – remains valid. On the one hand, information on demographics shows that there will be increasing demand for disability services in the future. On the other hand, the current model of service delivery is not providing a sufficient quality and quantity of services at an affordable price. The thrust of the recommendations in this Review are aimed at resolving this dichotomy and pointing the way to a more affordable service that is fit for purpose and better meets the needs of those who avail of it.

Relevance: In the context of the current social, cultural and economic climate, many of the services being provided to people with disabilities are not considered as relevant to people's lives as they would once have been. The findings from the public consultation conducted as part of the VFM Review clearly show that people are now looking for more choice in disability services and control over how they access them. They are looking for flexible services that meet their individual needs and systems that vest more control with the service user and, where appropriate, their families. These features are not generally available in the existing system, particularly to people with intellectual disabilities. It is worth noting, however, that some agencies, particularly those serving people with physical disabilities, have developed from a community base with the aim of promoting and protecting client choice, control and independence. Some of these agencies already operate a client-focused model of service and they provide examples of good practice, which can be used to inform decision-making in the wider disability sector.

Key Recommendations

A re-articulation of the vision and goals of the Disability Services Programme has been proposed by this Review. This vision and goals should be underpinned by a comprehensive set of realistic, meaningful and quantifiable objectives which are specific to individual services and supports. A more sustainable approach should be adopted to the realisation of the vision, goals and objectives. Greater transparency and accountability should become an integral part of the delivery and funding of services and supports.

Migration toward a more effective policy approach should take place within the constraint of reducing expenditure ceilings for the health sector and within the context of the prevailing national economic climate.

For the full list of key recommendations on programme objectives and current policies, see Chapter 7.

ECONOMY AND EFFICIENCY

Key Findings and Conclusions

An objective determination of value for money and efficiency is dependent on extensive supporting quality and outcomes data and empirically derived costs for a range of standardised service types. The Review found that despite substantial investment and centrally driven policy change, the required information was not available from the HSE or voluntary disability providers in a form which would enable conclusive findings to be made in many areas. Significant efforts were made by the Project Team and the HSE to remedy this by undertaking original data collection, collation and analysis for the purpose of the Review. Some outputs were complex and not easily defined, or were not maintained in comparable formats at agency level and did not facilitate interagency comparison and analysis. Since these complex outputs comprised 27% of total pay expenditure, the Review concentrated on the analysis of data on outputs that represented the bulk of the funding (and in particular, on the analysis of funding on residential service provision).

The results of the data analysis conducted as part of this Review reflect the complexities of disability service provision, which is not a single, homogeneous and easily measured programme but rather a multiplicity of service types and agency types serving a varied client population with widely differing needs.

An examination of the available data shows that in general some agencies or agency types are more efficient at one particular type of service and less efficient at another. Some models of service are extremely cost-efficient, but would score poorly on any 'quality of life' scale. Other types of service are cost-efficient and support the move to social inclusion and mainstreaming. The remaining services should become more cost-efficient during the period of transition from less supportive to more supportive services.

An analysis of outputs in Chapter 5 found that there is a requirement to put a framework in place to assess need, identify outputs and outcomes, and plan and monitor resource usage. The Review found that there is no national standard methodology for assessing client need or for linking those needs with target outcomes. Similarly, there is no nationally agreed means of predicting the amount of resources which an individual is likely to require, nor is there any common method of calculating the amount of resources which an individual actually consumes and the cost of those resources.

Calculating the amount of resources used and their cost at individual service user level was identified as being the key building block to a more cost-efficient service, regardless of the model of service. Key contributors to unit costs were identified as being pay and conditions, staff/client ratio, rostering practices and skill mix. Of these, rostering is a primary determinant of cost-efficiency since it is the means by which the needs of the individual are matched on a 24-hour, 365-day basis with the appropriate staff numbers, skills and grades. At client level, contributors to unit costs were found to be level of functional ability, challenging behaviour and co-morbidity (particularly mental health conditions and autism).

The Review concluded that ensuring the efficiency of the current system will prepare the groundwork for the migration to a more person-centred model of service delivery. Not to do so would result in carrying forward inefficiencies into any new approach.

Key Recommendations

An overarching recommendation on the achievement of efficiency is that there should be a focus in every organisation in receipt of public funding on driving efficiency on an ongoing basis, contingent on client need within a value for money framework. This should be coupled with a more sophisticated risk assessment and management process.

The Review addressed its findings on efficiency by way of appropriate recommendations on the development of a service delivery framework of standardised client assessment, resource allocation and resource usage tools. A national resource allocation methodology is recommended as being fundamental to the equitable distribution of resources and is a key recommendation of this Review. Since it will not be feasible for all assessed needs to be met in full by the HSE in the context of competing resources, the protocols for prioritising need, and deciding which needs are met and which are not, should be transparent, fair and equitable.

Because of the substantial contribution of direct pay costs to unit costs, the Review recommends the establishment of national best practice guidelines on staff utilisation and deployment practices with the aim of ensuring best fit between staff resources, service levels and, most importantly, service user needs, while supporting service quality and effectiveness. At a local level, a critical examination of rosters, staff skills, grades and attendance patterns should be undertaken by every service provider, including the services directly provided by the HSE. A number of recommendations in the Review address other areas that contribute to costs, including non-pay and allowances, administration costs, tendering arrangements and transport services.

While work on tools to support the service delivery framework should start immediately, they will take time to complete and will require pilot implementation before being rolled out nationally. Other recommendations, for example, the audit of rosters and examination of skill mix mentioned above, can be put into practice at agency level without delay and do not need to await a national response. As an immediate step, therefore, it is recommended that an immediate and robust examination should take place within each agency of the Review's findings and recommendations, and agency-level plans should be drawn up to put relevant recommendations into effect.

Another recommendation which should take immediate effect, pending the implementation of a resource allocation model, is that the HSE should work with agencies from 2012 onwards through the mechanism of the SLA process to reduce costs to the standard cost per band identified by the VFM Review.

For the full list of key recommendations on economy and efficiency, see Chapters 4 and 5.

EFFECTIVENESS

Key Findings and Conclusions

There are no national indicators defined to objectively measure the effectiveness of the Disability Services Programme in promoting personal progression, community inclusion and the application of choice, control and independence. Many people's lives have been enhanced by the services provided to them by disability service providers, even where these services may not now fully accord with our current understanding of best practice.

The public consultation, conducted by the Project Team for this Review, found that once the initial hurdle of accessing services had been overcome, the services received were considered by respondents to have a beneficial effect. However, almost all respondents to the consultation agreed that the objectives of the Disability Services Programme had not been fully met, and that services did not support choice, control and independence.

Another important finding of the Review is that the health services provided for persons with disabilities, whether under the auspices of the Disability Services Programme or through the generic health services, have been effective at protecting health and prolonging the lives of people with disabilities.

Key Recommendations

The Review recommends that guidelines for a national quality framework should be established to address standards, inspection or audit, quality assurance, person-centred planning and outcome measurement. Agencies should be encouraged to engage in continuous quality assessment and improvement, preferably by means of an internationally accepted methodology.

The future delivery of services and supports to people with disabilities should acknowledge the views of stakeholders – that choice, control, independence and community inclusion are the keys to an effective, person-centred service. Recommendations on setting, monitoring and measuring outcomes are regarded by the Review as of vital importance in the future provision of an effective service. A focus on outcomes is considered by the Review to be an essential part of the recommended service delivery framework and it is recommended that funding is linked to the achievement of specified outcomes at individual, programme and organisational levels in order to forge the link between cost-efficiency and effectiveness. Performance indicators should be developed to measure and monitor outcomes at a national level.

The Review makes reference to the implementation of recommendations in the HSE's 2011 review of Congregated Settings and recommends that priority should be given to putting a new model of community-based supports in place for persons moving from congregated settings, discontinuing admissions to existing settings and ending the commissioning of new settings.

For the full list of key recommendations on effectiveness, see Chapter 6.

GOVERNANCE AND ACCOUNTABILITY

Key Findings and Conclusions

The Review found that national governance and accountability structures for the Disability Services Programme are in a state of transition. The practical application of statutory oversight in respect of certain services will be realised from 2013 onwards when the HIQA's *National Quality Standards: Residential Settings* are put on a statutory footing.

The Review found that while the National Disability Unit of the HSE has lead responsibility for the planning, monitoring and evaluation of the Disability Services Programme nationally, it has no authority over resource

allocation or operational service delivery, which lies with the Regional Directors of Operations and the Integrated Service Area Managers. On a positive note, partnership structures that are representative of the major stakeholders do operate within a collaborative framework at a regional and local level.

Key Recommendations

The Review is strongly of the view that all agencies that receive funding from the State for the delivery of disability services should be accountable for that funding and the necessary systems should be put in place to ensure full accountability and transparency. It is recommended that a reconfigured governance framework is put in place which will encompass the standardised assessment of individual need; allocation of resources; procurement and commissioning; quality assurance; risk management; performance management, review and accountability; information systems; and management structures.

The implementation of the recommendations in this Review should be the responsibility of a Director of Disability Services in the HSE who would have the qualifications, skills and experience necessary at senior management level to drive the change management process. He or she should have sufficient decision-making authority to ensure that these changes are implemented and should also have full accountability for all resources allocated to the Disability Services Programme. The national disability function in the HSE should be strengthened in a number of areas, including resource allocation and monitoring, operational policy setting, identification and dissemination of best practice, procurement and commissioning of services. Clear lines of responsibility for decision-making should be established at local, regional and national levels, which are consistent with levels of responsibility for the budget of the Disability Services Programme.

Geographic-based administrative structures within the Disability Services Programme should be examined to maximise service user choice, minimise duplication of administrative effort by service providers and facilitate regional and local planning and management.

For the full list of key recommendations on governance and accountability, see Chapter 3.

INFORMATION FRAMEWORK

Key Findings and Conclusions

The Review's Terms of Reference required the identification of issues regarding the availability of information on current outputs and outcomes, and the specification of performance indicators that might be used to better monitor service provision in the future. Information on output delivery, one of the main requirements of the Terms of Reference, was not available in a comprehensive and easily comparable form, and despite efforts at data collection from the HSE and non-statutory service providers by the Project Team, it was deemed that the degree of data validation and checking would be too resource-intensive to be feasible within the confines of the Review. As a result, the VFM Review could not directly link the substantial expenditure increase in recent years to changes in output levels – a critical data gap that prevented the Review from assessing trends in output delivery over the period 2005-2009.

Key Recommendations

The most basic requirement for national management of the disability function was identified as being accurate and timely information at national, regional and local level on funding allocated and expended, at a reasonable level of detail.

An immediate action required at national level is the adoption of a common financial coding scheme (or a reliable means for matching disparate coding schemes) and maintenance of central records on allocations and expenditure, to include the HSE's own services and the For Profit sector as well as Section 38 and Section 39 agencies.

Another key recommendation is the implementation of a unique identifier for those seeking or receiving services, consistent with plans for a wider health sector identifier, to facilitate individual needs assessment, person-centred planning and individualised budgeting.

These actions should be supported by a revised SLA Schedule 3 dataset, consolidated at regional and national level, which will collect information on key cost drivers identified by the VFM process and will build on the dataset collected by the HSE for the purpose of this VFM Review. Access to this information will allow the national disability function to monitor unit costs and to identify, understand and address cost disparities. Information availability will also be the key to supporting the HSE in developing commissioning, market-shaping and capacity-building expertise, which it can use as tools for ensuring efficient and effective service delivery in the future.

Data on outcomes and performance indicators should be collected and aggregated at regional and national levels to allow effective monitoring of performance. Data quality, enforced through data standards and verified by audit, will be essential.

For the full list of key recommendations on an information framework to support the management and delivery of the Disability Services Programme, see Chapters 4, 5 and 8.

FUNDING FRAMEWORK

Key Findings and Conclusions

The block-grant approach to funding had a pragmatic historical basis, but is not sufficient to address the degree of accountability and transparency expected of the modern Disability Services Programme. The implementation of the Service Level Arrangement process is a welcome development in that regard, but requires review, evaluation and refinement so that it will make a more positive contribution to monitoring performance, controlling expenditure and shaping service development.

Key Recommendations

The Review recommends that a resource allocation framework be developed, which would consist of a standardised assessment of service user needs, a means of costing those needs prospectively, a framework for identifying how much of those needs will be met and the facility to identify the quantum and cost of the services actually received.

A resource allocation model should take into account service user needs, on the one hand, and the amount of resources available at national level, on the other. The model should be predicated on finite resources and should provide a framework for the distribution of available resources to meet assessed need in as fair and transparent a way as possible. It should also include protocols for determining eligibility and prioritisation.

Resource allocation should be on a programme budget basis, where the objectives, outputs and outcomes of each element of the budget are specified, rather than incremental budgeting based on the calculation of changes to the previous year's baseline. The position of funding places rather than people should reverse over time.

For the full list of key recommendations on a funding framework, see Chapters 3, 4, 5 and 8.

RE-ARTICULATION OF OBJECTIVES AND FUTURE POLICY DEVELOPMENT

Key Findings and Conclusions

The Review found that current objectives are still valid, but the policy approach used to deliver these objectives has not been effective. The continued sustainability of the current policy approach is questioned, particularly given the demographic pressures and changing societal and family expectations, all of which will place increasing demands on services. It was recognised that the delivery of services and supports has been evolving towards a more person-centred approach, but that the pace of change has been slow and uneven.

The Review came to the conclusion that instead of a slow and tentative drift towards individualised services, the policy approach should be recalibrated to focus more closely on the proposed vision and goals, and that all future developments would be planned and evaluated in terms of their progress towards the vision and goals. This progress should be advanced in parallel with the recommendations around reframing existing services, so that the development of new resource allocation models and units of cost can provide a basis upon which the transition from traditional programme type to more individual costing approaches can take place.

Key Recommendations

The Review considers that the person-centred model described in this report would form the basis of the future direction of disability policy. The policy will be grounded in the vision:

To contribute to the realisation of a society where people with disabilities are supported, as far as possible, to participate to their full potential in economic and social life and have access to a range of quality personal social supports and services to enhance their quality of life and well-being.

This vision will be supported by the twin goals of:

1. full inclusion and self-determination through access to the individualised personal social supports and services needed to live a fully included life in the community; and
2. the creation of a cost-effective, responsive and accountable system, which will support the full inclusion and self-determination of people with disabilities.

The Review recommends migration towards the new policy approach through the mechanism of the SLA process from 2013 onwards by requiring agencies to identify relevant demonstration or pilot projects and prepare plans for their implementation. Inputs should be clearly ring-fenced and fundable into the medium term within ongoing funding limits. Adequate monitoring structures should be put in place in the HSE and costs and benefits evaluated. Agencies should be required to report to the HSE at predetermined intervals on progress in implementing these initiatives as an integral part of the SLA monitoring process. The HSE should identify an evaluation framework for these projects.

For the full list of key recommendations on the re-articulation of objectives and future policy development, see Chapter 7.

Chapter 1: Introduction

1.1 INTRODUCTION

This Value for Money and Policy Review (VFMPR) is an evaluation of the efficiency and effectiveness of services for people with intellectual, physical or sensory disabilities wholly or partly funded from Vote 40 (HSE), including the statutory and non-statutory sectors.

1.1.1 VFM REVIEW INITIATIVE

The VFMPR was conducted under the aegis of the Government's Value for Money and Policy Review Initiative 2009-2011, which was part of a framework introduced to secure improved value for money from public expenditure. The objectives of the initiative were to analyse Exchequer spending in a systematic manner and to provide a basis on which more informed decisions could be made on priorities within and between programmes. It was one of a range of modernisation initiatives aimed at moving public sector management away from the traditional focus on inputs to concentrate on the achievement of results.

Value for Money reviews are undertaken under the aegis of steering committees representative of the Departments/Offices managing the programmes or areas being reviewed. A Central Steering Committee monitors the review process in Departments/Offices, with particular reference to the selection of topics for review and progress with the conduct of reviews.

1.1.2 STEERING GROUP AND EXPERT REFERENCE GROUP

The Steering Group established to oversee the present VFMPR of Disability Services was chaired by an independent chair, Mr. Laurence Crowley, and had two other external members, as well as members drawn from the disability sector, Department of Health, Department of Public Expenditure and Reform (formerly Department of Finance) and the Health Service Executive (HSE). The Steering Group, which met 16 times between July 2009 and June 2012, was supported by a Project Team comprised of officials from the Department of Health, Department of Public Expenditure and Reform, and the HSE.

In order to inform the work of the VFM Review, an Expert Reference Group, chaired by the Policy Advisor to the Office for Disability and Mental Health, Department of Health (DoH), was established to review current policy in relation to disability services. Membership of the Expert Reference Group, which met 18 times from August 2009 to November 2010, included officials from the DoH and HSE, disability agencies and representative groups.

Membership of both groups, and the Project Team, is given in Appendix 1.

1.2 BACKGROUND

1.2.1 RATIONALE FOR REVIEW OF DISABILITY SERVICES PROGRAMME

The disability services were selected for review in consideration of the significant annual expenditure on the programme, the size of the population directly affected by the services and the scope and nature of services provided. Disability services' infrastructure has developed in an ad hoc way over many years and systems of allocation of resources and accountability have evolved differently in the former Health Board regions. Different organisation types have also followed different development paths. Concerns were expressed by the stakeholders regarding the number of agencies providing disability services, the likelihood that inefficiencies had crept into the system, the potential for geographical or sectoral inequities in resource allocation and service provision, and the potential for duplication of costs. Other issues of concern included the level of administrative costs, management structures, and non-pay expenditure on research, advertising, profile-building and infrastructure.

Another key reason for carrying out this Review was the significant increase in funding in recent years, in particular through allocations under the Multi-Annual Investment Programme (MAIP). Allied to this, there was little data regarding the additional outputs achieved through increased allocations and extensive gaps in performance information for many of the disability services.

The Review offered an opportunity to take stock of the entire system and, if warranted, to make recommendations for policy changes or reform, with the aim of ensuring that the system would meet the needs of the service users in the future in the most efficient and effective way possible.

1.2.2 CONTEXT

The current model of service provision should be considered in the context of the economic climate, changing demographics and changing expectations. Expenditure on disability services increased by 30% in the period from 2005 to 2009 (see Table 1.1). This rate of increase became clearly unsustainable in the emerging financial environment, and yet information on demographics showed that there will be increasing demand for disability services in the future (Doyle *et al*, 2009).

The Comptroller and Auditor General (C&AG) in his 2005 Report 52 on the *Provision of Disability Services by Non-Profit Organisations* found that *'The State's relationship with non-profit organisations has 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 procurement ... The current approach to the funding of non-profit organisations is based on incremental increases and the cost of new placements. The risk with this approach is that the core funding allocation will over time become weakly linked to levels of identified need and as a result that funding may not always be targeted to areas of greatest need.'*

The Competition Authority stated its views on the need for structural reform in a 2005 submission to the Department of Health and Children. The Authority took the view that the manner in which service providers were selected and funded did not necessarily foster cost-efficiency and effectiveness in the delivery of services, did not provide incentives to respond to changing needs, to innovate, and could restrict service users' choice and ability to switch service providers.

In parallel with the changing economic climate and demographics, the expectations that people with disabilities and their families have of disability services have also altered. The findings from the public consultation conducted as part of this Review clearly show that people are now looking for more choice in disability services and control over how they access them. They are looking for flexible services that meet their individual needs and systems that vest more control with the service user and, where appropriate, their families. These features are not generally available in the existing system, particularly to people with intellectual disabilities. It should, however, be noted that some agencies (particularly those serving people with physical disabilities) have developed from a community base, with the aim of promoting and protecting client choice, control and independence. These agencies already operate a client-focused model of service and provide examples of good practice, which can be used to inform decision-making in the wider disability sector.

In the short to medium term, the changed economic climate dictates that there will be little additional investment for disability services. It is timely now to consider if the increased investment in services in recent years is meeting the needs of people with disabilities and, if not, how the system should be reconfigured to meet these needs. This has to be considered in the context of a conclusion in the C&AG's (2005) Report 52, stating that:

'Any restructuring of the service should be based on clearly articulated agreements setting out the respective roles of the health service, as funder, and the service providers. The capacity of non-profit organisations to meet the additional requirements relating to the implementation of the standardisation of services, good governance and greater accountability will need to be addressed.'

Scale of Disability Services Programme

Residential services are provided by almost 60 agencies to around 8,500 people with disabilities at over 1,200 locations, ranging from large congregated settings to community group homes to supported independent living.

Day services are provided to around 18,500 service users with intellectual, physical or sensory disabilities and autism at 850 different locations by 80 organisations (the health sector also provides day services to over 7,000 people with mental health disabilities, which were outside the remit of the Review). Day services are a key component of the support services that enable clients to live within the community. Services include day activation, special high-support and special intensive day services for adults and developmental day care for children. Work-like programmes provide a range of opportunities, which include work activation, supported work in the community, and personal and social development. Specialist services are also provided for persons with Autistic Spectrum Disorder and those with Acquired Brain Injuries.

A variety of other services are also provided under the Disability Services Programme, including respite, home support, personal assistance and assisted living service, early childhood/family support, community-based medical, nursing and therapy services, rehabilitative training, aids and appliances.

Expenditure on disability services increased from €1.28 billion net in 2005 to €1.68 billion net in 2009 – the year studied in this Review. A significant percentage (76%) of that funding was provided to non-statutory service providers. Expenditure decreased to €1.48 billion net in 2010 and again to €1.45 billion net in 2011, in line with the global reduction in public expenditure. (Chapter 4 gives greater detail on HSE annual expenditure.)

Table 1.1: Annual HSE-funded expenditure on disability services, 2005-2009 (net and gross)

	2005	2006	2007	2008	2009	2010	2011
Net	€1,284.6m	€1,412.6m	€1,589.2m	€1,694.1m	€1,679.1m	€1,488m	€1,450m
Gross	€1,338m	€1,475.3m	€1,662.5m	€1,781.4m	€1,789.4m	€1,684m	€1,708m

Notes:

- Gross expenditure represents the total amount expended.
- Net expenditure is calculated by deducting income from gross expenditure. Income arises primarily from employee superannuation deductions and client long-stay charges, with smaller amounts coming from a wide variety of other sources, including other payroll deductions; RTA payments; maintenance charges; canteen receipts; recoupment of disability pay and maternity benefit pay; PRSI refunds; as well as sundry other minor receipts.
- The HSE did extensive validation and re-apportionment from multiple sources of financial data in order to produce the most accurate possible gross expenditure figures for 2005 to 2009. Gross expenditure figures for 2010 and 2011 are estimated. Since the years 2010 and 2011 are outside the period under review, the high-level net figures in the National Service Plan have been used.

Source: HSE, Disability Finance Book (years 2005 to 2009) and National Service Plan 2010-2011

The Review analysed data from 217 specialist disability service providers, categorised as follows (see Table 1.2 and also Chapter 3 for further details):

- the HSE, which is a body established by statute (Health Act 2004);
- non-statutory agencies funded under Section 38 of the Health Act 2004;
- non-statutory agencies funded under Section 39 of the Health Act 2004.

These providers had two types of contractual agreement with the HSE in 2009 (see Chapter 3 for further details):

- Service Level Arrangements (SLAs), signed by service providers who received allocations from the HSE of more than €250,000 in that year.
- Grant Aid Agreements (GAAs), signed by service providers who received allocations from the HSE of less than €250,000 in that year.

There are 17 specialist disability service providers funded under Section 38 of the Act and these are listed in Appendix 13. (Note: The Brothers of Charity Services have formed 6 separate legal companies for administrative reasons, but are counted as one organisation for the purpose of this analysis.) All Section 38 agencies signed SLAs in 2009 and five also signed GAAs. The number of agencies funded under Section 39 can vary from year to year since funding may be on a once-off or recurrent basis. For the purpose of this Review, data were analysed from 92 Section 39 agencies with SLAs (19 of which also had GAAs) and a further 107 Section 39 agencies with GAAs only. A full list is given in Appendix 14.

Table 1.2: Number of SLAs and GAAs analysed for the Review

Agency type	Service Level Arrangements		Grand Aid Agreements		Total No. of agencies	
	No. of agencies	No. of SLAs	No. of agencies	No. of GAAs	No. of agencies	Comments
HSE	1	32*	–	–	1	
Section 38	17	31	5	8	17	→ 5 Section 38 agencies have both SLAs and GAAs
Section 39	92	203	126	196	199	→ 19 Section 39 agencies have both SLAs and GAAs
Total	110	266	131	204	217	

Notes:

- The HSE's directly provided services filled out SLA forms for the purpose of the analysis.
- The Brothers of Charity Services have formed 6 separate legal companies for administrative reasons, but are counted as one organisation for the purpose of this Review.

Agencies signed separate SLAs or GAAs with each Local Health Office (LHO) area in which they provided services, so the total number of SLAs and GAAs exceeds the total number of service providers.

In addition to agencies with SLAs and GAAs, a further 105 private for-profit providers had a total of 115 contracts with the HSE in 2009. These are considered briefly in Section 5.1.3 and Table 5.3, but are not included in any of the data analysis in Chapter 5.

1.2.3 TERMS OF REFERENCE

The Terms of Reference (ToRs) for this VFM and Policy Review of Disability Services were:

1. To identify the objectives, which have pertained to date, for the Disability Services Programme in the health sector.
2. To examine the current validity of those objectives and their compatibility with the overall strategy of the Department of Health, the *National Disability Strategy* and *Towards 2016*.
3. To define the outputs associated with the programme activity and identify the level and trend of those outputs.
4. To identify any issues with the availability of information regarding current outputs and outcomes.
5. To examine the extent to which the programme's objectives have been achieved and comment on the effectiveness with which they have been achieved.
6. To identify the level and trend of costs and staffing resources associated with the disability services and thus comment on the efficiency with which has achieved its objectives. Compare overall costs, including wage costs and non-pay costs, across the sector (both voluntary and non-voluntary).
7. Having regard to the range of providers of disability services, to examine whether there is scope to minimise overheads, including administrative costs, management structures, research, advertising, profile-building and infrastructure costs.
8. To evaluate the degree to which the objectives warrant the allocation of public funding on a current and ongoing basis and examine the scope for alternative policy or organisational approaches to achieving these objectives on a more efficient and/or effective basis.

9. To specify potential future performance indicators that might be used to better monitor the performance of the Disability Services Programme.
10. To produce a final robust report containing findings and recommendations in relation to ToRs 1-9 above.

1.3 METHODOLOGY

The work of this Review was carried out by a Project Team and Expert Reference Group, working in parallel to respectively:

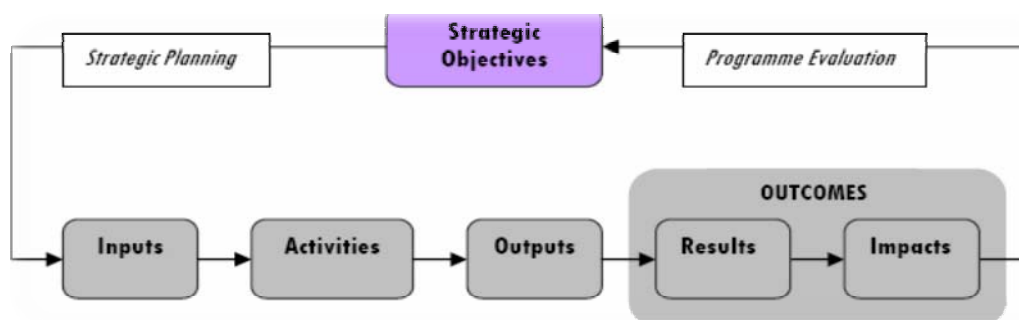
- review the efficiency and effectiveness of the disability services;
- review policy in the context of the objectives of the disability services.

Preliminary work on the Review began in 2009, which was used as the baseline year for detailed data analysis (see Chapter 5). 2009 was also the first year in which national data were collected on the basis of Service Level Arrangements (SLAs) between the HSE and the non-statutory disability providers. The years 2005 to 2009 were designated as the period under review for the purpose of trend analysis (see Chapter 4). Significant additional work was undertaken by the HSE to validate and augment the 2009 SLA minimum dataset so as to provide the Review with sufficient data to support high-level unit cost analysis. This process was not fully complete until mid-2011 and applied specifically to the 2009 dataset. It was not feasible to apply the same process to the SLA data for 2010 or 2011 to bring the analysis up to the current year. However, some work was carried out to estimate high-level expenditure and unit cost figures for 2010 and 2011 (see Table 4.2 and Figure 4.1 in Chapter 4).

1.3.1 PROGRAMME LOGIC MODEL

Sometimes referred to as the input–output model, the Programme Logic Model divides a programme into a logical sequence of linked elements, i.e. inputs, activities, outputs and outcomes (results and impacts), which can be analysed separately and in relationship to one another in terms of meeting the overall programme objectives (see Figure 1.1). Through the development and measurement of programme and contextual indicators, the model can assist in the identification of a sequence of cause and effect concerning the intended (or unintended) benefits that can be attributed to the programme.

Figure 1.1: Programme Logic Model



Source: Department of Finance, 2007

The identification of outputs and outcomes does not imply that these outputs and outcomes are currently measured. Given that the Disability Services Programme encompasses a disparate set of services, the model is necessarily specified at a high level. An application of the Programme Logic Model to the Disability Services Programme is provided in Appendix 10.

1.3.2 METHODOLOGY – PROJECT TEAM

A range of approaches were employed by the Project Team:

- The dataset required to meet the Terms of Reference was identified and data sources considered. The scope of services provided as part of the Disability Services Programme meant that data requirements were extensive and complex, and the data, where available, had multiple sources. An examination of the dataset found that some outputs were complex and could not be easily defined, or were not maintained in comparable formats at agency level and did not facilitate interagency comparison and analysis (*see also Chapter 5 and Appendix 6*). Since these complex outputs comprised 27% of total pay expenditure, the Review concentrated on the analysis of outputs that represented the bulk of the funding (and in particular, on the analysis of funding on residential service provision).
- The HSE generated current and trend information specifically for the VFM Review in the form of the Disability Finance Book (DFB). The data encompassed the directly provided and non-statutory disability services and was based on a combination of actual and derived financial data. The DFB is drawn primarily from the HSE Corporate Reporting System (CRS). CRS data had a number of limitations and as a result, it was necessary to bring that raw financial data through a number of stages to enhance and develop its usefulness at a more practical level. Further details on these stages, and on the derivation exercise, are given in Appendix 2.
- Trend data requirements were identified in respect of the following: background and service profile; funding; service provision; efficiency analysis (outputs, staffing numbers, pay costs, other costs); and quality analysis. Three sources of trend data were identified: the Health Research Board (HRB), the HSE and non-statutory service providers. A pilot exercise was conducted to investigate the feasibility of obtaining trend data directly from non-statutory agencies. While some valuable information was obtained through the pilot, it was not of sufficient quality or quantity to justify a full-scale trend data collection exercise. Following evaluation of the results of the pilot trend questionnaire exercise, the Project Team decided to recommend to the Steering Group that the full trend questionnaire should not be issued to any further agencies. Instead, certain data tables in the trend pilot questionnaire were incorporated into a current non-pay data questionnaire.
- Two sources of current (2009) data were identified: HSE and non-statutory disability agencies. Documentation collected by the HSE as part of the Service Level Arrangement (SLA) process was the primary source of data on current activity, staffing and pay. Current non-pay data requirements were sourced from the HSE and directly by questionnaire from non-statutory disability agencies.
- A unit costing methodology was developed to arrive at a total cost per service user and to act as a resource usage comparator (*see Chapter 5 and Appendix 5*). Data on service user outcomes were also obtained in respect of residential services in order to assess the effectiveness of these services.

- Service user numbers, staff numbers and expenditure in 2009 were examined. The trend in each was examined from 2005 to 2009. Detailed information was received from 111 agencies, ranging from small single issue agencies providing a service to a small number of service users to large agencies providing a range of services to over 1,000 service users, including residential, day services, respite, multidisciplinary supports, early education supports and pre-school support. Agencies working with people with all disability types were included in the Review. The 111 agencies analysed expended €1.225 billion on pay in 2009, employing 23,840 whole-time equivalent (WTE) staff.
- A public consultation process was undertaken to obtain the views of interested parties on the objectives, efficiency, effectiveness and funding of the Disability Services Programme.
- Research was commissioned from the National Disability Authority (NDA) on specialist disability services in six jurisdictions regarded as models of innovation and good practice – England, Scotland, the Netherlands, Norway, New Zealand and the State of Victoria (Australia).
 - This research informed the Advice Paper provided by the NDA to the Steering Group in July 2010 (NDA, 2010a).
 - A synthesis paper presenting the material gathered during the NDA’s exploration of disability service provision, with specific focus on the selected international jurisdictions, was published (NDA, 2010b), as well as in-depth reports on five of the six individual jurisdictions (England, Scotland, the Netherlands, New Zealand and the State of Victoria, Australia). Other recent reports were considered, particularly the *Report of the National Working Group for the Review of HSE-funded Adult Day Services* (HSE, 2012a) and the *Report of the Working Group on Congregated Settings* (HSE, 2011).

The Expert Reference Group and the Project Team were also informed in their work by the United Nations Convention on the Rights of Persons with Disabilities (UN, 2006), the 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* and the C&AG’s Report 52 on the *Provision of Disability Services by Non-Profit Organisations* (C&AG, 2005).

1.3.3 METHODOLOGY – EXPERT REFERENCE GROUP

An extensive policy review was conducted by the Expert Reference Group, including an assessment of the extent to which the objectives of the Disability Services Programme have been achieved. The achievement of objectives was also addressed in the public consultation conducted by the Project Team (*see above*), the results of which informed the Expert Reference Group’s deliberations. The Group was supported by Dr. Fiona Keogh, Independent Research Consultant, who attended meetings, facilitated discussion on key themes, researched national and international documentation on best practice, took account of the parallel consultations by the Project Team and the NDA (*see Chapter 6 for further details*), reviewed national policy documents and drafted interim position papers and the final policy proposals report (Expert Reference Group on Disability Policy, 2011). The Group’s preliminary findings were published on the Department of Health’s website on 3 December 2010. A fuller account of the 2011 report by the Expert Reference Group is given in Chapter 7.

1.3.4 PUBLIC CONSULTATION – OBJECTIVES OF THE DISABILITY SERVICES

A public consultation was conducted by the Project Team on the objectives, efficiency, effectiveness and funding of the disability services. The consultation was initiated by an invitation for submissions on 13 November 2009 and a consultation document and questionnaire were produced to assist people with formulating their responses. The consultation was primarily conducted through an online questionnaire, although submissions in other formats were also accepted.

Replies were received from almost 200 respondents, including service users and their families, statutory and non-statutory service providers, staff members, advocacy organisations and representative bodies. An interim report was provided to the Steering Group on 2 February 2010, with a statistical analysis of the responses. The final report on the qualitative analysis of responses was submitted to the Steering Group in November 2010 and published on the Department of Health's website on 3 December 2010 (*see* www.dohc.ie/consultations/closed/disability_policy_review/vfm_consultation_report2010.pdf).

1.4 STRUCTURE OF REPORT

This report is divided into 9 chapters, covering the following topics:

Chapter 2 describes current national disability policy and its evolution, the historical background to service provision, the legislative background and recent national and international developments. The objectives for the Specialist Disability Services Programme are also examined. The rationale for the Disability Services Programme is outlined, together with the economic case for intervention. The prevalence and extent of need are documented, as are the trends in level of demand, future trends and unmet need. [[Terms of Reference \(ToRs\) 1, 2 and 8](#)]

Chapter 3 describes the organisation and administration of the Disability Services Programme, governance structures and accountability mechanisms. [[ToRs 1, 7 and 8](#)]

Chapter 4 examines the inputs, in terms of financial and staffing resources, used to provide the Disability Services Programme. [[ToRs 6 and 7](#)]

Chapter 5 examines outputs and assesses efficiency. Outputs are defined and efficiency is assessed. Unit costs are analysed, resource allocation issues discussed and staff utilisation and deployment issues considered. [[ToRs 3, 4, 6 and 8](#)]

Chapter 6 describes outcome evaluation, the results of the public consultation and national and international experience. [[ToRs 4, 5 and 8](#)]

Chapter 7 reflects on the objectives of the disability services, their achievement, validity and sustainability. The high-level vision is re-articulated and the alternative policy proposals developed by the Expert Reference Group are examined. The issues posed by the requirement to align efficiency and effectiveness measures are also considered, together with migration from the current to the future model. [[ToRs 5 and 8](#)]

Chapter 8 considers the measurement of demand, assessment of current systems for performance measurement and current and future performance indicators. [[ToR 9](#)]

Chapter 9 documents the conclusions reached on rationale, relevance, efficiency and effectiveness, and gives targeted, time-bound and actionable recommendations. [[all ToRs](#)]

At the end of each main section in a chapter, a **summary of key findings and/or recommendations** for that topic is provided.

The **References** section is followed by a number of **Appendices**, detailing various aspects of the Review.

Chapter 2: How did disability services develop?

2.1 DEVELOPMENT OF DISABILITY SERVICES

This chapter describes the evolution of disability policy within the context of the development of disability services. The historical and current objectives that pertain to the services are identified, together with the policies adopted to realise the objectives. The national and international legislation underpinning disability services is outlined. The rationale for the provision of disability services is discussed and the prevalence of disability and the extent of need for services in the future are described.

2.1.1 DEVELOPMENT OF INTELLECTUAL DISABILITY SERVICES

In the first half of the last century, the only public provision for adults with intellectual disability consisted of residential care in ‘mental hospitals’, as they were then called, and also in County Homes (Ryan, 1999). There were few agencies specifically serving the intellectually disabled and they tended to be institutions for children run by charitable trusts such as Stewarts’ Hospital (founded in 1869) or by religious orders. The Daughters of Charity agreed with the Commissioners for the Dublin Union in 1925 to convert their Home in Cabra, Dublin, to a centre exclusively for children with an intellectual disability. For many years, this was the only specialist publicly funded provision for children with intellectual disability. In both Stewarts’ Hospital and the Daughters of Charity’s Home, the lack of appropriate places for adults led to increasing numbers of children staying in these institutions beyond childhood. Other religious orders also started to provide services for children and adults from private funding.

In the 1950s, the County Homes stopped accommodating people with intellectual disability, while at the same time the mental hospitals experienced gross overcrowding and poor conditions. In response, in July 1953 the Department of Health sanctioned the creation of 1,000 publicly funded residential places for people with intellectual disabilities in the religious-run institutions. The Department also envisaged that, if necessary, ‘*new voluntary bodies be induced to enter this field*’.

Until the 1950s, all services, even for children with intellectual disability, were provided on a residential basis only. The first special national school for day pupils was not established until 1954 by a group of ‘Parents & Friends’, which later became known as St. Michael’s House (the Daughters of Charity’s residential school had already been designated as a special national school in 1947). Parents & Friends Associations throughout the country had, in many cases, started out as fund-raisers for residential institutions, but then began to follow the example of St. Michael’s House and entered into the area of direct service provision. The special national day-school model spread to other areas of the country and the Parents & Friends Associations progressed during the 1960s and 1970s from providing schools to providing adult day services, which largely took the form of training facilities and workshops. The Associations also started to provide residential services and eventually became significant providers of both day and residential services, in some instances rivalling or surpassing the religious-run institutions in size. For most of the 20th century, residential centres were provided in large buildings on campus settings. But in the last 20 years or so, the focus moved towards the development of domestic-style houses clustered together on campuses. More recently, the move to providing residential services in group houses in the community has gathered pace.

Many people with intellectual disability continued to reside in inappropriate psychiatric settings until the 1990s, when a programme of moving the remaining residents from these settings began. A total of 147 people remained to be transferred to more suitable residential accommodation at the end of 2010 (Kelly and Kelly, 2011).

2.1.2 DEVELOPMENT OF SERVICES FOR PEOPLE WITH PHYSICAL AND SENSORY DISABILITIES

During the 20th century, a well-established service infrastructure existed for people with physical and sensory disabilities provided by religious orders, such as the Christian Brothers, Daughters of Charity of St. Vincent de Paul and the Vincentian and Dominican Orders. Their services were largely educational, but they quickly, in many instances, became lifelong institutions, with people coming in at an early age and remaining into adulthood.

The National Council for the Blind (NCBI) in Ireland, founded in 1931, and the National Association for the Deaf (NAD), founded in 1963, were two of the earliest national lay organisations for people with sensory disabilities established in Ireland. The NCBI was modelled largely on the UK-based National Institute for the Blind.

The polio and TB epidemics sparked a significant organisational response, with the establishment of the Cork Polio and General Aftercare Association, the Polio Fellowship of Ireland, the Central Remedial Clinic and the Rehabilitation Institute. Also in the late 1940s, the National Association for Cerebral Palsy was established. These were community-based lay organisations, where the emphasis was on keeping people living and operating in the community, and were a significant departure from the earlier approach to service provision.

Since the 1960s, major growth has occurred in the number of voluntary organisations in the physical and sensory sector (principally in the physical area), the great majority of which provide services, supports, representation or advocacy for people with specific conditions. The number of service providers varies significantly across the country. Some former Health Board areas pursued an approach of funding a large number of smaller organisations, whilst some provided services directly. Activities by voluntary disability organisations are mostly community-based and include activities such as peer and family group supports, help-lines and other means of information dissemination, and co-working with persons to support them in accessing mainstream services. They also focus on prevention, early intervention and coping with the effects of the disability.

The 1980s saw the next development of voluntary organisations, which were characterised by a focus on supporting people with specific disabilities and conditions, and where the emphasis was on ensuring that people got access to services rather than being the total provider. At the same time, the earlier wave of organisations were to a greater or lesser extent becoming regarded more as cross-disability broad service-providing organisations. The 1990s was the decade of the independent living movement, with the establishment of a nationwide network of Centres for Independent Living.

2.2 VISION AND OBJECTIVES

State-funded disability services, in common with other care programmes, have operated under the umbrella of the vision and objectives which have applied to the health services as a whole. Broad objectives have been described, but were expressed in very general terms. These were not cascaded downwards into detailed objectives specific to the disability services provided by the health sector.

2.2.1 HISTORICAL OBJECTIVES

As mentioned above, the Daughters of Charity were the first publicly funded specialist intellectual disability service. Under the terms of their contract with the Commissioners for the Dublin Union, they undertook in 1930 to accept all ‘*mentally deficient and imbecile children*’ sent to them by the Commissioners and ‘*to support, clothe, maintain, educate and generally care for them*’ (Robins, 1992). Although the objective of the service was essentially custodial, it did at least contain a commitment to education as well. Over the following decades, society’s views of the objectives to be achieved by intellectual disability services developed, to the point where a 1994 Department of Health document on *Policy and Services for Persons with Mental Handicap* stated:

The objective of this service is to develop the person with mental handicap to the maximum of his/her potential. The principles which underlie the present provision of services are to ensure that:

- 1. People with mental handicap enjoy a life that is as normal as possible within the community for as long as possible.*
- 2. People with mental handicap have access to personalised programmes and their families have access to adequate support.*
- 3. People with mental handicap who can no longer live at home are cared for in a supportive and appropriate living environment.*

This seems to be the first attempt to formally state the objectives for the Disability Services Programme. It will be seen from the above that even in the mid-1990s residential services were still seen as being separate to community living.

2.2.2 CURRENT VISION AND OBJECTIVES

The current vision and objectives for services for people with disabilities have been described in the Social Partnership Agreement of 2006-2015, *Towards 2016* (Department of An Taoiseach, 2006), in the following terms:

33.1 Vision: *The parties to the 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.*

To achieve this vision, the Government and the social partners will work together over the next ten years towards the following long-term goals with a view to continued improvements in the quality of life of people with disabilities:

- Every person with a disability would have access to an income which is sufficient to sustain an acceptable standard of living;*

- *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 services;*
- *Every person with a disability would have access to public spaces, buildings, transport, information, advocacy and other public services and appropriate housing;*
- *Every person with a disability would be supported to enable them, as far as possible, to lead full and independent lives, to participate in work and in society and to maximise their potential; and*
- *Carers would be acknowledged and supported in their caring role.*

Towards 2016 envisaged that the achievement of these objectives would be through:

- the implementation of the National Disability Strategy;
- preparation for the implementation of the Disability Act 2005;
- the provision of appropriate supports and services to meet identified need;
- an increase in the capacity of the system to meet identified need and to respond to emerging and emergency need;
- the collection and analysis of information to underpin the planning, monitoring and delivery of services;
- the development and implementation of quality standards;
- partnership and cross-sectoral engagement with other agencies, both statutory and non-statutory, which have a role to play in supporting the individual with a disability in living a full and independent life;
- disability awareness training.

The national disability service objectives described in *Towards 2016* encompass mainstream services in the field of education, employment and training, public and social services, transport, housing and environmental services. An examination of these cross-cutting objectives, and how they are achieved, is outside the remit of this Review, but this is not to minimise their role in the lives of people with disabilities or the significant contribution made through partnership between statutory and non-statutory agencies in the delivery of these objectives.

2.2.3 OBJECTIVES OF THE DISABILITY SERVICES PROGRAMME

For the purpose of this VFM Review, the objectives that have pertained in recent years to two major components of the Disability Services Programme may be broadly expressed as follows:

Day services

- To support the individual with a disability as far as possible to participate in education, employment and society, and to maximise his or her potential.
- To ensure that the individual with a disability would, consistent with their needs and abilities, have access to appropriate health and personal social services.
- To support and acknowledge the role of carers in their caring role.

Residential and respite services

- To provide the individual with a disability, to the greatest extent possible, the opportunity to live a full and independent life with their family and as part of their local community.
- To provide residential services in a supportive living environment to the individual who can no longer live at home and, where possible, to provide these services in community-based residences.

OBJECTIVES

KEY FINDINGS

- ✓ The high-level objectives of the Disability Services Programme are derived from the National Health Strategy objectives and the vision and objectives in *Towards 2016*. [Finding 2.1](#)
- ✓ There are no explicitly stated national objectives for the Disability Services Programme funded from HSE Vote (40) nor are there a cascade of objectives for sub-programmes and service areas within the Programme. [Finding 2.2](#)
Recommendations on the re-articulation of objectives are outlined in Chapter 7.

2.3 POLICY DEVELOPMENTS

2.3.1 HISTORICAL POLICY DEVELOPMENT

In 1960, the Minister for Health published a White Paper entitled *The Problem of the Mentally Handicapped*, which was intended to set out the options with regard to further expansion of services. It announced the establishment of a commission to examine and report on all aspects of the '*mentally handicapped problem*'. The Commission of Enquiry on Mental Handicap was set up in February 1961 and reported four years later. It recommended that there should be clear obligations on health authorities to ensure that services were available for both adults and children with an intellectual disability. The report became the guide to the subsequent development of services to people with intellectual disabilities in areas such as prevention, early diagnosis and intervention, schooling, respite, family support, sheltered employment, challenging behaviour and staff training.

One of the Commission's recommendations was that services should continue to be provided through the voluntary bodies and that '*health authorities should accept responsibility for co-ordinating the activities of the various organisations involved and should encourage the development of voluntary organisations*'. From the foundation of the State to the present day, this policy of providing the bulk of services for both children and adults with intellectual disabilities through voluntary bodies has remained constant.

In recent times, policy development has been influenced by the recommendations of national equality and health strategy documents, together with the findings of working groups reporting on specific issues.

2.3.2 DEVELOPMENT OF CURRENT POLICY

Health policy for all members of society, including those with disabilities, is guided by the principles of equity, people-centredness, quality and accountability, as set out in the 2001 National Health Strategy, *Quality and Fairness – A Health System for You*. In the context of the planning and delivery of disability services, these principles underpin the philosophy that people with disabilities should be given the opportunity to live as full a life as possible and to live with their families, and as part of their communities, for as long as possible. The main policy and strategy reports covering disabilities are listed below.

Policy and Strategy Reports

- *Needs and Ability – A Policy for the Intellectually Disabled. Report of the Review Group on Mental Handicap Services* (1990)
- *Services to Persons with Autism* (1994)
- *Towards an Independent Future – Report of the Review Group on Health and Personal Social Services for People with Physical and Sensory Disabilities* (1996)
- *A Strategy for Equality – Report of the Commission on the Status of People with Disabilities* (1996)
- *Employment Challenges for the Millennium – Report of the National Advisory Committee on Training and Employment* (1997)
- *Enhancing the Partnership (incorporating Widening the Partnership) – Report of the Working Group on the Implementation of the Health Strategy in Relation to Persons with a Mental Handicap* (1997)
- *National Disability Strategy* (2004)

Mainstreaming

The Report of the Commission on the Status of People with Disabilities (1996), entitled *A Strategy for Equality*, recommended that services for people with disabilities should be provided by mainstream service providers, with appropriate supports – a policy later referred to as ‘mainstreaming’. The purpose of mainstreaming is to move from segregation to inclusion, by ensuring that persons with disabilities can take their place in mainstream society, that mainstream public services include people with disabilities and that mainstream public policies take into consideration their impact on people with disabilities. In terms of service provision, mainstreaming means that services for people with disabilities should be the responsibility of whichever Government department has responsibility for such services in general.

The Government made a commitment to the policy of mainstreaming in 2000, which was reiterated in the 2001 National Health Strategy, *Quality and Fairness – A Health System for You*.

Lifecycle framework

Towards 2016 developed a new framework within which to address key social challenges by assessing the risks and hazards which the individual person faces and the supports available to them at each stage in the lifecycle. Four key lifecycle stages were identified: children, people of working age, older people and people with disabilities. The lifecycle approach adopted the perspective of the individual as the centrepiece of social policy

development and aimed to support the evolution of policy and actions across relevant Government departments and agencies.

National Disability Strategy

The National Disability Strategy (NDS) was launched in 2004 by the Department of Justice, Equality and Law Reform. It is the focus for the overarching Government policy on people with disabilities and has five main elements:

- the Disability Act 2005;
- Education for Persons with Special Educational Needs (EPSEN) Act 2004;
- Sectoral Plans published in 2006 by six Government departments;
- Citizen's Information Act 2007;
- €900m multi-annual investment programme (allocated across a number of Government departments) to support the development of high-priority disability support services over the period 2006-2009.

The objective of the NDS is to put in place the most effective combination of legislation, policies, institutional arrangements and services to support and reinforce equal participation for people with disabilities. The Disability Act 2005 is a central element of the NDS and its focus on mainstreaming and social inclusion is given particular emphasis through the Sectoral Plan provided for in Part 3 of the Act.

The HSE has implemented the Disability Act from 1st June 2007 for children under the age of 5 years. The Act provides an Assessment of Need within defined timescales and also identifies the services that will be delivered within current capacity. This allows for the gap between assessed needs and delivery capacity to be identified and planned for. The Act also identifies the individuals who are regarded as having a disability and who require access to specialist disability services. The extension of the Disability Act to over 5-year-olds has been postponed.

Standards for the Assessment of Need process under the Disability Act were prepared by a sub-group from the Health and Education sectors, which included active participation by the HSE. The standards were subsequently approved by the interim Health and Information Quality Authority (HIQA), prior to the commencement of the Act in June 2007. There are six standards:

- person-centred approach;
- information;
- access to assessment;
- involvement of appropriate staff;
- coordination of assessment of need;
- monitoring and review.

Criteria are identified for each standard to indicate when the standard is being achieved. All clinicians who work on assessments of need under the Disability Act are required to be aware of the HIQA standards for assessments and undertake to adhere to these standards.

Multi-annual investment programme

The multi-annual investment programme (MAIP) sought to increase service capacity in order to reduce waiting lists for services, while at the same time improving services that fell below minimum standards or were delivered in inappropriate settings (see Chapter 4).

Office for Disability and Mental Health

The Office for Disability and Mental Health was established with responsibility for a range of different policy areas and State services that directly impact on the lives of people with a disability and people with mental health issues. The Office aims to bring about improvements in the manner in which services respond to the needs of these people by working on a cross-sectoral basis to develop person-centred services, focusing on the holistic needs of clients and service users, and actively involving them in their own care.

POLICIES

KEY FINDINGS

- ✓ A constant strand in the provision of publicly funded disability services has been the decision of State bodies, reiterated at various junctures, to provide services to people with disabilities by and large through voluntary agencies. [Finding 2.3](#)
- ✓ Current policies centre on the principle of mainstreaming and the lifecycle framework, together with the general policies outlined in the National Health Strategy. Cross-sectoral working is also a pivotal policy goal and resulted in the establishment of the Office for Disability and Mental Health. [Finding 2.4](#)
- ✓ Another strand in the provision of disability services has been the continuing requirement to create new and enhanced places to address service needs. Most recently, the multi-annual investment programme has invested substantial funds in the creation of new places and enhancement of existing places. [Finding 2.5](#)

Recommendations on the policy approach to future service development are considered in Chapter 7.

2.3.3 COMPATIBILITY WITH DEPARTMENT OF HEALTH POLICIES AND STRATEGIES: HEALTH SECTOR REFORM

The 2001 National Health Strategy, *Quality and Fairness – A Health System for You*, was designed to be a blueprint to guide policy-makers and service providers in achieving the vision of the health system. It identified four goals to guide activity and planning in the health system, namely:

- better health for everyone;
- fair access;
- responsive and appropriate care delivery;
- high performance.

In relation to people with disabilities, the National Health Strategy:

- reiterated the Government's commitment, made in 2000, to a policy of mainstreaming. It also committed to preparing an action plan for rehabilitation services – to set out a programme to meet existing shortfalls in services and to integrate specialised facilities with locally based follow-up services;
- stated that a national policy for the provision of sheltered work for people with disabilities would be developed;
- sought to put the patient at the centre in the delivery of care and encouraged healthcare workers to listen to and accommodate, as appropriate, the wishes of individual patients/clients;
- recognised that people with intellectual disability being cared for in psychiatric hospitals was not appropriate and stated that action would be taken to ensure that the care required was delivered in the appropriate setting.

The vision for the future of the health sector is set out in the current *Programme for Government* (Department of An Taoiseach, 2011) and also detailed in the Department of Health's (2012) *Integrated Reform Plan for the Health Sector 2012 to 2014*.

The *Programme for Government* states:

'We will ensure that the quality of life of people with disabilities is enhanced and that resources allocated reach the people who need them. To achieve this, we will reform the delivery of public services to bring about back office savings that will protect front-line services.'

The *Integrated Reform Plan for the Health Sector* contains the following commitments in respect of services for people with disabilities:

- publish a Value for Money and Policy Review of Disability Services and, based on its findings, implement reforms to the system of financing and delivering services, including the introduction of individualised budgets;
- enhance cost-effectiveness by introducing standardised funding bands for specific types of services for people with disabilities and developing a standardised needs assessment framework to ensure that levels/types of services provided are appropriate to people's needs.

HEALTH SECTOR REFORM

KEY FINDING

- ✓ The Department of Health is committed to using this VFM and Policy Review of Disability Services as a mechanism for implementing reforms to the system of financing and delivering disability services and enhancing the cost-effectiveness of those services. [Finding 2.6](#)

Recommendations on the efficiency and effectiveness of the Disability Services Programme are considered in Chapters 5, 6 and 7.

2.3.4 INTERRELATIONSHIP WITH OTHER DEPARTMENTS

In line with the policy of mainstreaming, responsibility for services to people with disabilities is vested in a range of Government departments, as detailed below.

Department of Justice and Equality	Lead responsibility for the coordination of the National Disability Strategy, the National Disability Authority and the UN Convention on the Rights of Persons with Disabilities. Liaises with other State bodies, including the Department of Health. Key interrelationship with Disability Services Programme: National Disability Office
Department of Education and Skills	Responsibility for education of children with disabilities. Liaises with the Department of Health on joined-up implementation of Disability Act 2005 and the Education for Persons with Special Educational Needs (EPSEN) Act 2004. Key interrelationship with Disability Services Programme: Disability services for children and young people
Department of Social Protection	Responsibility for disability-related payments and income supports, together with employment activation measures. Cross-Sectoral Group on Strategy for Employment of People with Disabilities to be re-constituted in 2012, jointly with the Department of Health, following transfer of relevant responsibilities from the former Department of Enterprise, Trade and Employment. Key interrelationship with Disability Services Programme: Day services
Department of the Environment, Community and Local Government	Cross-sectoral cooperation with the Department of Health and the HSE on development of a Housing Strategy for People with Disabilities, launched in 2011. Key interrelationship with Disability Services Programme: Residential services

2.4 NATIONAL AND INTERNATIONAL LEGISLATION

2.4.1 NATIONAL LEGISLATION

A number of pieces of legislation underpin the provision of services to people with disabilities:

Health Act 1970	Provides for the provision of training for employment of disabled persons and for placing disabled persons in suitable employment. It also provided for the payment of maintenance allowances to disabled persons over 16 years of age until responsibility for this payment was moved to the Department of Social Protection (<i>ref. Chapter 10 (Part 3) of the Social Welfare Consolidation Act 2005 as amended, and Chapter 5 (Part 3) of the Social Welfare (Consolidated Claims, Payments and Control) Regulations 2007, S.I. No. 142 of 2007, as amended</i>).
Equality Act 2004	Prohibits discrimination, harassment and victimisation on the grounds of gender, racial or ethnic origin, religion or belief, disability, age or sexual orientation in relation to employment and occupational and vocational training.
Education for Persons with Special Educational Needs Act 2004	Provides for the provision of education plans in an inclusive environment for students with special educational needs.

Disability Act 2005	<p>Supports the provision of disability-specific services and improved access to mainstream public services through:</p> <ul style="list-style-type: none"> • an independent assessment of individual needs, a related service statement and independent redress and enforcement for persons with disabilities; • imposition of obligation on public bodies to make buildings and services accessible to people with disabilities; • Sectoral Plans in key service areas; • requirement on public bodies to take positive actions to employ people with disabilities; • provides for the establishment of a Centre for Excellence in Universal Design.
Citizens Information Act 2007	<p>Established the Citizens Information Board in place of Comhairle and provides for the development of a Personal Advocacy Service for people with a disability.</p>

2.4.2 UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

The UN Convention on the Rights of Persons with Disabilities and its Optional Protocol entered into force on 3rd May 2008. Ireland signed the Convention in 2007 and is working towards ratification.

Article 1 sets out the purpose of the Convention: *'To promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.'*

Article 3 sets out its general principles:

- Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons.
- Non-discrimination.
- Full and effective participation and inclusion in society.
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity.
- Equality of opportunity.
- Accessibility.
- Equality between men and women.
- Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

The goals of achieving economic, social and cultural rights are qualified by two considerations – resource constraints (*take measures to the maximum of its available resources*) and the progressive, rather than immediate, realisation of these rights.

2.5 RATIONALE FOR DISABILITY SERVICES

2.5.1 ECONOMIC CASE FOR INTERVENTION

Rationale is concerned with establishing why a public policy intervention is necessary and requires consideration of the public policy objectives and the reasons for public sector provision. It is also linked to the concept of market failure, which applies when the private sector does not produce the optimal level of a good or service. In theory, in the absence of a specific market failure, the market delivers goods and services in quantities that best meet people's needs and preferences, given scarce resources. The public sector, in theory, should only intervene when markets are not efficient and when the intervention would improve efficiency. Therefore, the first condition for public sector intervention is evidence that a market failure exists.

There are four standard justifications identified by the Economic and Social Research Institute and quoted in the Department of Finance's (2007) *Value for Money and Policy Review Initiative: Guidance Manual* for the continued allocation of public funds to programmes; for example, where the service provided can be considered a public good and where there is a market failure to support the service. Markets may fail when the activity of the provider imposes a cost or benefit on the beneficiaries, but it is not possible or expedient to charge them. The Disability Services Programme satisfies both these criteria in that the marketplace is not in a position to make private provision for the needs of people with disabilities who have continuing support needs. The service is provided on the basis that it is a public good and that it serves the needs of those who could not otherwise afford to provide basic social and personal supports for themselves. In addition to public good, it can also be described as containing elements of both redistribution and a merit good.

The second condition for public sector intervention is that the intervention will make an improvement, which leads on to consideration of whether the programme in question is the most appropriate means of achieving the identified public policy objectives. This is explored further in Chapters 6 and 7.

A consideration of the public good also raises VFM-related questions:

- ***Do we need to provide the public good at a given level of service?***
Disability services require to be provided at a level that meets the individual's needs, assessed according to a standardised needs assessment methodology. The principle of standardised needs assessment is addressed in Chapter 5, while issues around the effectiveness, quality and type of services and supports required are addressed in Chapters 6 and 7.
- ***Are there any rationing/affordability issues?***
This Review is conducted in the context of the current economic climate and the prospect of continuing resource constraints into the foreseeable future. The current model of service delivery is not providing a sufficient quality and quantity of services at an affordable price. Section 2.5.2 below outlines the prevalence of disability in the population and the extent of current and future service needs. Chapter 4 discusses the trend in expenditure in recent years and the cost of providing services, while Chapter 5 analyses expenditure in more detail. Results show that the demand for services is growing and what people expect from disability services is changing. Cuts in the budget for disability services since 2009 are testament to the fact that the same level of service cannot continue to be provided at existing cost levels. The thrust of the recommendations throughout this Review are aimed at rectifying the situation.

- ***Can we achieve the same level of service at a lower level of cost?***

This question is addressed at length in Chapter 5 and the conclusions reached indicate that the same level of service can, and should, be provided at a lower level of cost. Chapter 7 looks at the issue from another angle, building on the work of the *National Working Group for the Review of HSE-funded Adult Day Services* (HSE, 2012a) and the *Report of the Working Group on Congregated Settings* (HSE, 2011), and proposes that the emerging trend towards the delivery of supports rather than services will produce a more effective service at a more reasonable cost.

- ***To what extent can we recover costs from service users?***

Virtually all residential service users would have limited financial means. Most are in receipt of the Disability Allowance (DA). Because of the current skill mix in residential services, many service users in Section 38 centre-based residential care are subject to the Class 1 or Class 2 charges based on the level of nursing care provided. Residents in Section 39 agencies are by and large subject to a similar level of 'voluntary' contribution. People who are in community-based residences with no nursing support generally pay for the necessities of everyday life, such as food, utilities, clothes and rent, leaving little disposable income from which co-payments could be levied.

There may be more scope in requiring day attenders to make co-payments, for example, for transport. Again, as most are in receipt of the DA and have the same living expenses as the general population, the level of payment they could reasonably be asked to pay would be small. Around 17,000 people with intellectual disabilities attend day centres. There is no information available on the number of day attenders who use transport provided by the health sector: some are transported by family members or use public transport, particularly in urban areas. If a notional 50% of the 17,000 day attenders were required to pay €5 per week (48 weeks per year) towards the cost of health sector-provided transport, the income accrued would come to just over €2 million. It could be argued that this would discriminate against service users who had access to public transport, since they would continue to travel without charge under the free Travel Pass Scheme (which is awarded automatically to all DA recipients).

RATIONALE

KEY FINDING

- ✓ The economic case for State intervention in the provision of disability services has been based on the criterion that the provision of services is a public good and could not be provided by the marketplace on a privately funded basis. This case remains valid. [Finding 2.7](#)

Recommendations on measures to increase the efficiency and effectiveness with which services are delivered are considered in Chapters 5 and 6.

2.5.2 DISABILITY PREVALENCE AND EXTENT OF NEED

Prevalence

Estimates of the number of individuals with disabilities in Ireland and internationally are problematic. Due to differences in the concepts and methods used to identify persons with disabilities, prevalence rates should not be compared across countries (see United Nations Disability Statistics Database: <http://unstats.un.org/unsd/demographic/sconcerns/disability/disab2.asp>).

Disability prevalence rises strongly with age. The average global prevalence of moderate and severe disability is estimated to range from 5% in children aged 0-14 years, to 15% in adults aged 15-59 years, and 46% in adults aged 60 years and over.

The prevalence rate of disability in Ireland is difficult to determine categorically since results may vary according to the definition of disability used, the methodology used to determine the prevalence rate and the types of disabilities included. For the purpose of this VFM Review, the definition of disability is taken from the Disability Act 2005:

'A substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment.'

This does not, however, resolve the issue of arriving at a consistent estimate of the numbers who fall within this definition. The results of the 2006 Census of Population suggested that between 323,500 and 328,200 people (or between 8.7% and 8.9% of the population in Ireland) had a disability. The disability prevalence rate according to the National Disability Survey sample was reported as 8.1% of the population, with people over the age of 55 making up 52% of the total number of persons with a disability. However, a recent report by the Department of Social Protection and the Economic and Social Research Institute estimated that between 16.8% and 20.4% of people (or between 1 in 5 and 1 in 6 of the population) has a long-term disability (Watson and Nolan, 2011).

For the purpose of this VFM Review, the relevant cohort is the group of people who are availing of, or requiring, specialist disability services provided by the health sector on the basis of a substantial restriction in their capacity to carry on the normal activities of daily life without support.

The target coverage for the National Physical and Sensory Disability Database (NPSDD) has been estimated by the HRB to be 44,594 people with a physical and sensory disability which causes them substantial restriction. The 2009 report of the NPSDD recorded a total of 29,749 persons registered, of whom 26,169 were aged 65 and under (HRB, 2010a). Because progress towards achieving target coverage for the NPSDD is uneven for several groups and areas, it is not possible to give a comprehensive picture of the number of people with substantial levels of disability. The figure for target coverage has been calculated by applying an estimated norm of 10.53 people with a disability per 100,000 to the 2006 Census, which gives a target figure nationally of 44,594. Based on this calculation, the NPSDD has captured data on 67% of the number estimated to have a physical and sensory disability.

The 2009 report of the National Intellectual Disability Database (NIDD), also managed by the HRB, recorded a total of 26,066 people with intellectual disability, representing a prevalence rate of 6.15 per 1,000 of the population (HRB, 2010b).

Further information on both the NPSDD and NIDD is given in Chapter 8.

Trend in level of service provision

Since the first report of the NIDD in 1996, there has been a significant rise in the level of provision of residential services, residential support services and day services, together with a change in the profile of services availed of (Kelly *et al*, 2010). Key developments during the period 1996-2009 include:

- an increase of 66% in the number of people with intellectual disability living full time in community group homes;
- a 71% reduction in the number of people with intellectual disability accommodated in psychiatric hospitals;
- a continued expansion in the availability of residential support services, particularly planned or emergency centre-based respite services, which have grown by a substantial 437%; 4,681 people availed of this type of service in 2009, allowing them to continue living with their families and in their communities;
- increased provision in almost all areas of adult day services and in the level of support services delivered as part of a package of day services to both children and adults.

Future service requirements

Both the NIDD and NPSDD report on the future need for services. Participation in both databases is voluntary. Data for the NIDD is collected through the disability service providers and is used in their funding discussions with the HSE so coverage is excellent, although a small number of service users or their families have refused to participate. Most people with physical and sensory disabilities do not have the same level of interaction with specialist providers, making data capture more difficult, and coverage of the NPSDD is estimated to be around 67% of the target cohort (*see Chapter 8 for further discussion on both national databases*).

The 2005 Report 52 of the C&AG cited concerns regarding the assessment of need in the NIDD and the NPSDD, namely that the assessment process to identify needs is not standardised nor is it independent (service providers make a judgement on the future needs of their current service users). It was noted that the assessment process *'has been criticised for the tendency to identify needs from a narrow perspective and in terms of capacity to deliver'* (C&AG, 2005, p. 20). The estimate of future residential needs has been reported as being only 50% accurate, with future need for multidisciplinary services being reported as 78% accurate (Craig, 2008).

In terms of linking needs to service requirements, the C&AG's (2010) report on *Accounts of the Public Services 2009* noted that *'although the databases record information for individual service users, they do not capture the level of service required by each individual, in terms of the number, type and grade of staff required'*.

Physical and sensory services

The 2009 report of the NPSDD (HRB, 2010a) reported on outstanding demand for rehabilitation and therapeutic services, such as physiotherapy, occupational therapy and speech and language therapy:

- 21,891 people (83.7% of all people registered on the database) were receiving therapeutic intervention and rehabilitation services. Of these, 5,308 people needed an enhancement to these services.
- 13,263 people (50.7%) required assessment for these services.
- 1,801 people (6.9%) were assessed and placed on a waiting list for these services.
- 113 people (0.4%) were assessed, but were unable to avail of these services for a variety of reasons; for example, the service location was not accessible by the individual.
- Just over half of people registered (13,812 people) were using day services and activities. However, 3,159 people (12.1 %) still registered a need for this type of support. A further 4,080 people registered on the database (15.6%) needed some change or alternative to their existing services.
- 6,121 people (23.4%) still required assessment for personal assistance and support services.
- 2.6% of people registered required residential supports.
- Demand for respite was higher, with almost 15% of people indicating a need for assessment for respite services.

Intellectual disability services

The 2010 report of the NIDD (HRB, 2010b) indicates that 4,539 new residential, day and/or residential support places will be needed to meet service requirements. The following services will be needed in the period 2011-2015 (most service needs were recorded as being immediate):

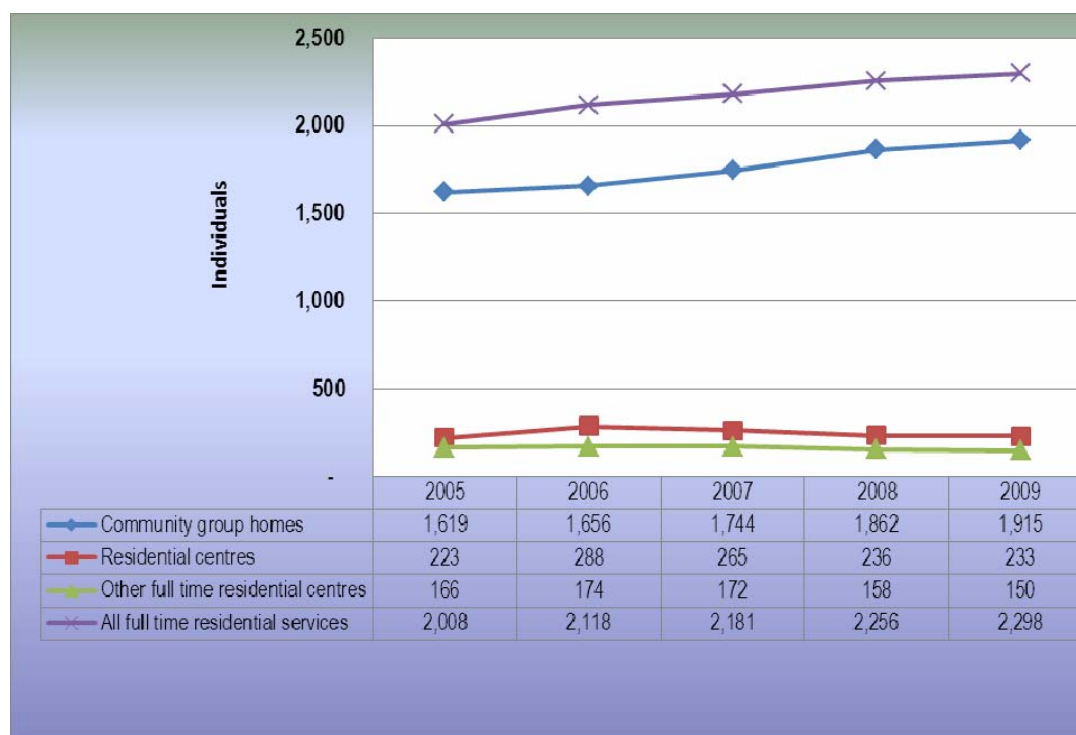
- 2,269 full-time residential placements (a slight decrease on the 2009 figure of 2,298, which was the highest number since the database was established – *see Figure 2.1*). The number of new full-time residential services required increased consistently following a slight downward trend during the years 2000-2002 and the latest small (1%) decrease in 2010.
- The demographic profile of people with intellectual disability in Ireland suggests that the number of people requiring full-time residential supports is likely to continue to increase over the coming years as those with a more severe disability and those who care for them advance in age.
- The 2010 NIDD report records a requirement for 2,045 residential support services (respite and regular part-time care). This represents a small decrease of 70 (3.3%) since 2009, and a cumulative decrease of 84 since 2008, but the level of demand is still higher than the years from 2005 to 2008 (*see Table 2.1*). This significant level of need persists even though there were over 5,000 people availing of residential support services in 2009.
- 209 day support places (this figure excludes multidisciplinary support services and services provided by early intervention teams). The number of new day places required has been decreasing since NIDD data were first reported in 1996 and is now at its lowest since the database was established. This number does not include the 908 young adults who, as they approach the age of 18, were preparing to leave the education system to take up a range of training and supported/sheltered employment opportunities which, traditionally have been funded by the health sector.

- 169 individuals who were living in psychiatric hospitals in 2009 have been identified as needing to transfer from these locations to more appropriate accommodation.
- Of those in receipt of services in 2009, 11,564 people required alternative, additional or enhanced services in the period 2010-2014, a decrease of 259 (2%) since 2008. This group included people who required an increased level of service provision, increased support within their existing services, transfer to more appropriate placements or a service change to coincide with transition periods in their lives, for example, movement from child to adult services, or from education to training and/or employment placements.

In summary, to address the required service changes for people with intellectual disability over the next 5 years:

- 9,998 people who are accessing day services will require a change of service or an enhancement in their existing service. Health-funded services are required by 6,934 individuals (69.3%), employment services are required by 1,279 individuals (12.8%), education services are required by 1,121 individuals (11.2%) and generic services are required by 664 individuals (6.6%). Of the 1,121 service changes required within education, 861 (76.8%) are requirements for an alternative service and 260 (23.2%) are requirements for an enhancement of the individual's existing service. A large proportion of the 1,449 individuals who were attending special schools in 2009 require adult day services within the period 2010-2014. Of this group, over one-quarter (395 individuals) require rehabilitative training, 329 (22.7%) require vocational training and 158 (10.9%) require activation programmes.
- 3,055 residential places will require changes or enhancements.
- 1,625 residential support places will require changes or enhancements.

Figure 2.1: Future full-time residential service requirements of individuals receiving no residential service, 2005-2009



Source: NIDD, 2005-2009

Table 2.1: Trend in future residential support service requirements of individuals receiving no residential support services, 2005-2009

Type of service required	2005 No.	2006 No.	2007 No.	2008 No.	2009 No.
Foster care	2	4	4	2	2
Lives independently	73	86	93	77	60
Living semi-independently	310	316	328	334	352
Holiday residential placement	164	180	172	166	152
Crisis or planned respite	1,039	1,102	1,255	1,290	1,272
Occasional respite care with host family	100	96	88	94	94
Shared care or guardianship	7	6	8	11	9
Regular part-time care (2/3 days per week)	29	30	19	16	16
Regular part-time care (every weekend)	12	9	9	11	10
Regular part-time care (alternate weeks)	11	12	10	10	8
Other residential service	83	101	84	98	115
Overnight respite in the home	10	12	18	20	25
All services	1,840	1,954	2,088	2,129	2,115

Source: NIDD, 2005-2009

Despite high levels of service provision in 2009, there remained a significant demand for new and enhanced multidisciplinary supports. Three-quarters (19,413 individuals) of the population registered on the NIDD require a new or enhanced multidisciplinary support service in the period 2010-2014. There was substantial demand for all the therapeutic inputs, in particular psychology, speech and language therapy, and occupational therapy.

The service demands identified in the 2010 NIDD report outstrip current resources. In the medium term, based on the profile of people currently in receipt of services, together with population growth estimates, it is expected that the increased demand for intellectual disability services will continue.

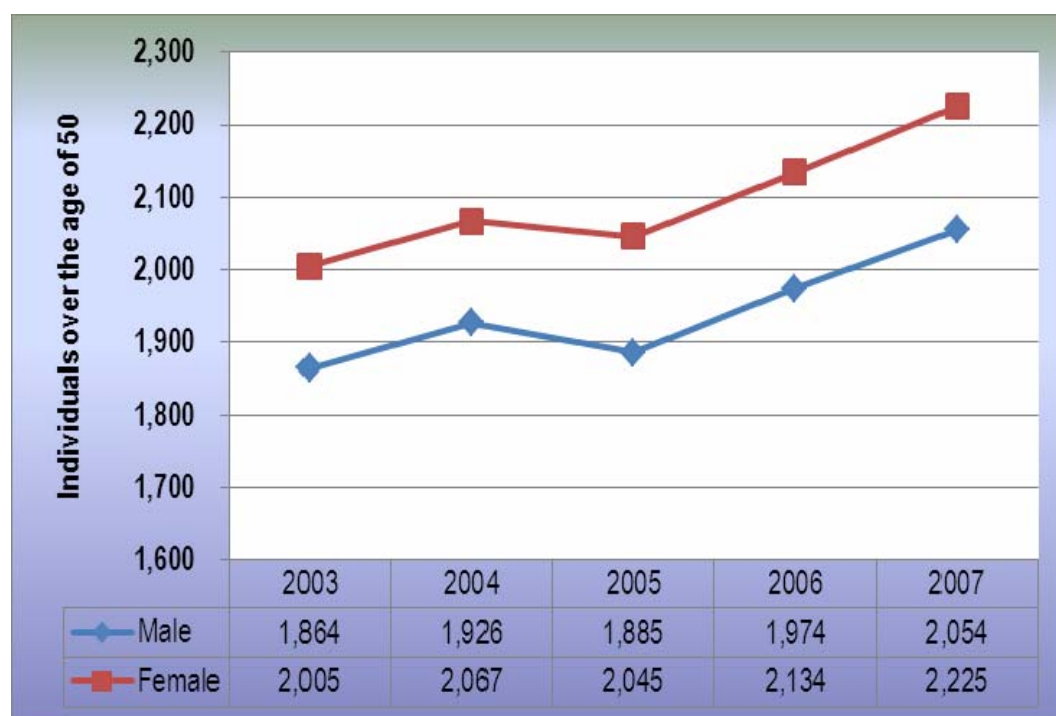
2.5.3 FUTURE TRENDS: AGEING AND POPULATION GROWTH

A HRB study by Kelly *et al* (2009) outlines key trends in specialised health service use and need by those aged 50 years and over who are registered on the NIDD. It includes data on demographics, service use and future need. Census data was used to compare life expectancy and morbidity in older age groups in the general population with those of people aged 50 years and over registered on the NIDD. The main findings from the analysis were:

- In the period 2003-2007, the number of people aged 50 years and over registered on the NIDD increased by 11% – from 3,869 in 2003 to 4,279 in 2007.
- Over the 5-year period 2003-2007, the number of males exceeded the number of females in every age group except for the 50-years-and-over group. In this cohort, the number of females exceeded the number of males by 8%, indicating that females with an intellectual disability are more likely to live into old age than their male counterparts (*see Figure 2.2*).

- In 2007, the proportion of people aged 65 years and over registered on the NIDD (3.8%) was significantly less than that in the general population (11%), which suggests that although people with intellectual disabilities are living longer, their life expectancy remains significantly lower than that of the general population.
- In 2003, just over one-fifth of the cohort was recorded as having both an intellectual disability and a physical/sensory disability; in 2007 this proportion had risen to one-third.
- The largest area of growth in full-time residential services between 2003 and 2007 was in the provision of community group homes. In 2003, 948 of the cohort were living in community group homes; this figure increased to 1,253 in 2007, a rise of almost 33%. This reflects policy trends in this area.

Figure 2.2: Number of people aged 50 years and over by gender, 2003-2007



Source: NIDD, 2003-2007

EXTENT OF NEED

KEY FINDINGS

- ✓ There are concerns about the accuracy of the assessment process and quantification of future need recorded in the NIDD and the NPSDD. [Finding 2.8](#)
- ✓ Even taking into account the estimated error levels in the quantification of future need, the level of need for day, residential and multidisciplinary services between 2009 and 2013 is substantial. At least 1,000 new residential places will be needed for people with intellectual disabilities and almost 400 for people with physical or sensory disabilities during the 5-year period. [Finding 2.9](#)
- ✓ Based on the profile of people currently in *receipt* of services, together with population growth estimates, it is expected that the increase in the level of demand for disability services will continue for the medium term. [Finding 2.10](#)

Recommendations on the future policy approach to addressing service development and assessed need are considered in Chapter 7. Chapter 8 outlines and evaluates the current data collection systems to support performance measurement, including the NIDD and NPSDD.

Chapter 3: Framework for the delivery of disability services

The purpose of this chapter is to outline the framework for the delivery of disability services at national, regional and local levels. The governance and accountability framework for service delivery is described, as well as coordination and management structures. The funding framework is explained, including the annual determination and resource allocation process. Funding arrangements between the HSE and non-statutory service providers are examined. The service delivery configuration is outlined, together with the processes for funding and developing new services.

3.1 GOVERNANCE AND ACCOUNTABILITY FRAMEWORK

3.1.1 GOVERNANCE

National governance

Political oversight for disability services lies with the Oireachtas and Minister, and is exercised through the Department of Health and the HSE. Statutory accountability mechanisms are provided for under the Health Acts of 2004 and 2007, and include a public complaints system administered by the HSE and the forthcoming regulatory framework of registration and inspection to be implemented by the Health Information and Quality Authority (see Section 3.1.4 below).

The HSE was established in January 2005 and is responsible for providing health and personal social services in the State within available resources. The Health Act 2004 charges the HSE with using the resources available to it in the most beneficial, effective and efficient manner to improve, promote and protect the health and welfare of the public. The HSE is required under Section 7 of the 2004 Act to have regard to the policies and objectives of the Government or any Minister of the Government to the extent that those policies and objectives may affect or relate to its functions.

Annual determination: Revenue, capital and staffing

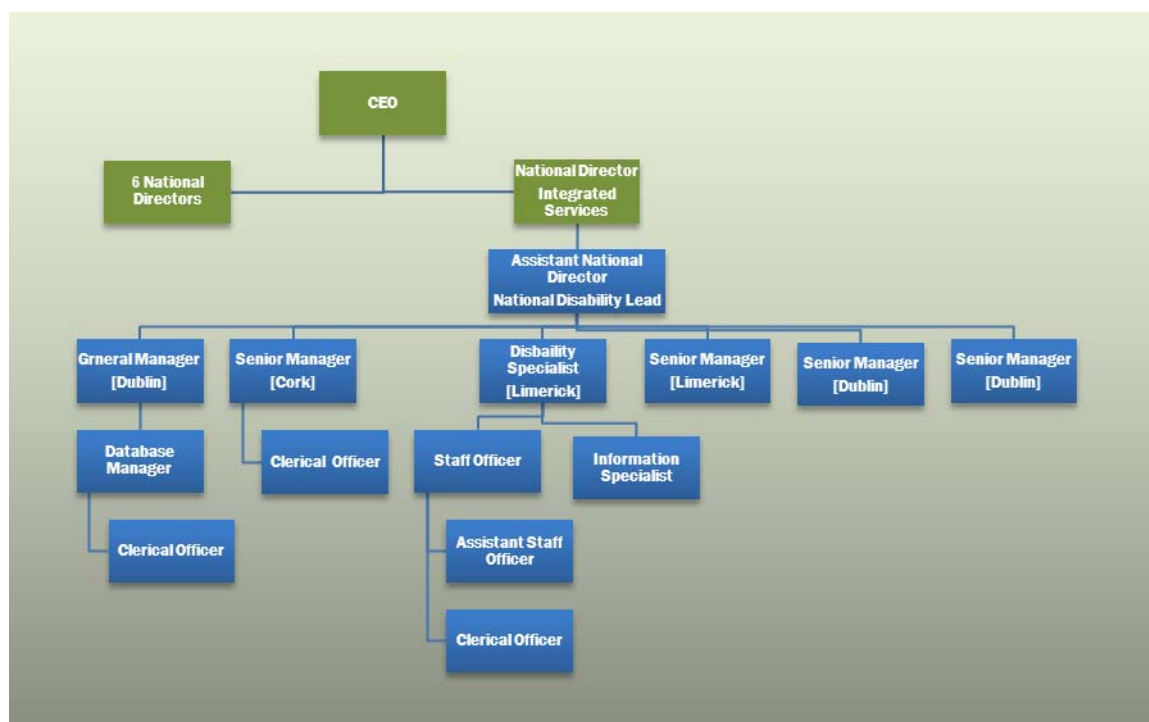
Government decides the level of financial resources available for the health sector, and overall employment policy and these resources are allocated through the annual estimates process. Numbers ceilings for the sector reflecting Government employment policy have also been set out in the employment control frameworks for the health sector.

Under the Health Act 2004, the HSE is obliged to produce an annual National Service Plan (NSP) that is consistent with the level of resources set in the estimates as published by the Government. The NSP is approved by the HSE Board and must then be approved by the Minister for Health, who is charged with ensuring consistency of the service plan with Government policies. The HSE's capital spending is subject to the approval of the Minister for Health, with the consent of the Minister for Public Expenditure and Reform.

3.1.2 ADMINISTRATIVE STRUCTURES: NATIONAL, REGIONAL AND LOCAL

The National Disability Unit is the HSE lead for the implementation of national disability policy and strategy, working collaboratively with all stakeholders to ensure the equal participation and inclusion of people with disabilities in society (see Figures 3.1 and 3.2).

Figure 3.1: National Disability Unit

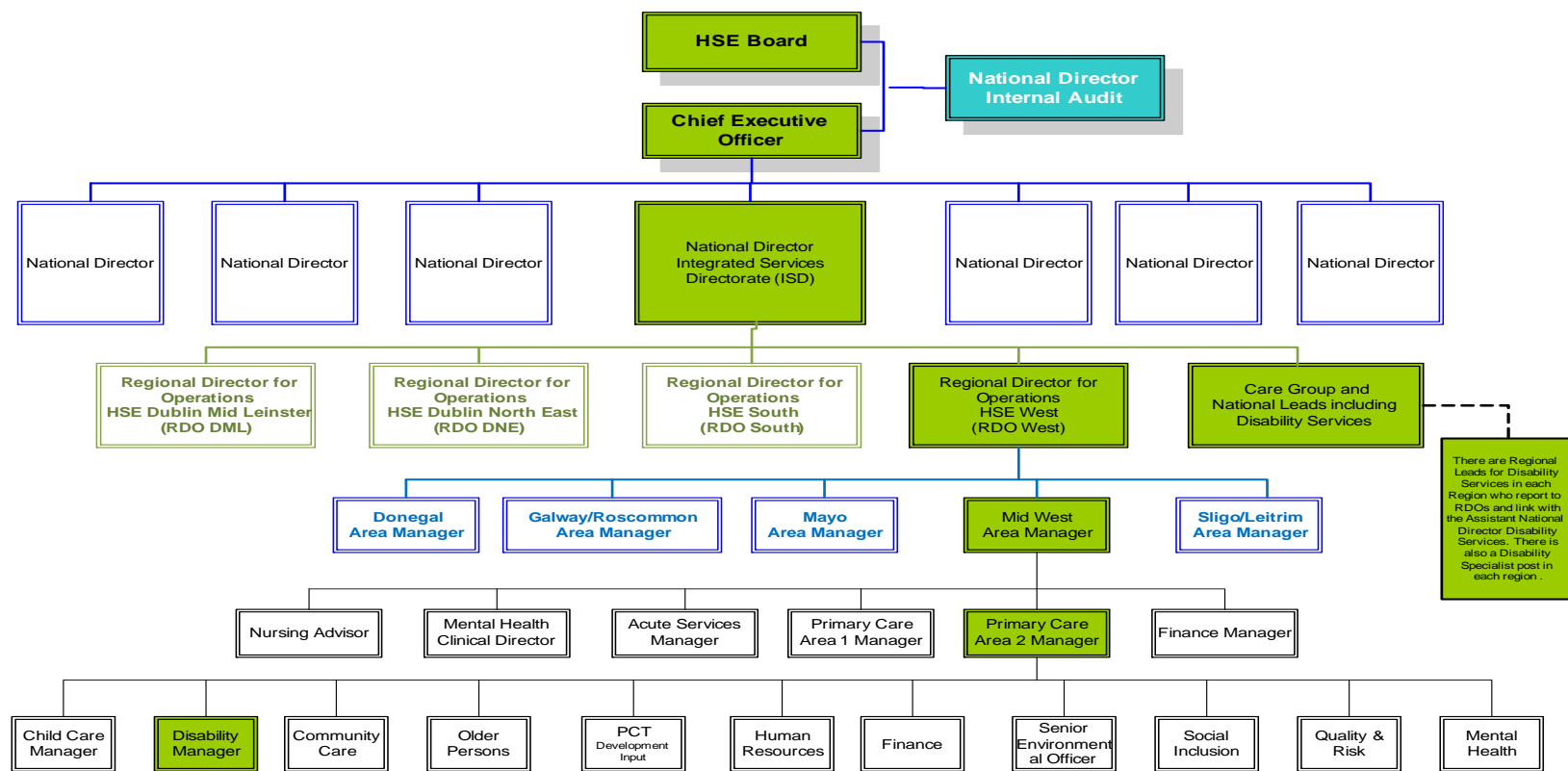


Note: These are not all whole-time equivalent posts.

National, regional and ISA-level (local) fora have been established to enable a collaborative framework to oversee the effective planning, coordination, delivery and monitoring of services to meet the needs of people with disabilities, within available resources.

Membership of the fora is representative of the major stakeholders: the HSE, other service providers and service users. The Department of Health is represented on the National Forum. The fora will establish sub-groups or task groups when required, which may include other appropriate representation, including statutory sector organisations or Government departments.

Figure 3.2: HSE organisational structure for Disability Services, using the Mid-West as an example (March 2012)



This is a general HSE organisational structure from CEO to Disability Manager in ISA. It must be noted that new structures are currently being put in place within individual Areas and HSE Regions and this chart shows the structure recently adopted in the Mid West ISA. Staff working in the disability service would report to the Disability Manager.

3.1.3 ALLOCATION OF RESOURCES

The period from 2004/2005 to 2009 was a development period in which substantial additional development resources were allocated in the annual estimates process to develop disability services and facilities, and to provide for additional staffing in disability services. This was the background against which the vision in the 2006 document, *Towards 2016*, was agreed.

The period from 2009 onwards was a period of retrenchment, necessitated by the emerging crisis in the public finances from mid-2008. Nonetheless, the employment control frameworks (ECFs) and annual sanction arrangements put in place sought to protect development moneys and development posts in so far as possible.

Allocation of revenue funding

The process of drafting the HSE National Service Plan (NSP) and determining the amount to be allocated to the Disability Services Programme at national and regional levels is heavily influenced by the previous year's funding levels, with appropriate adjustments, and is based on the principle of incremental budgeting. Decisions may also be made at Government level to allocate specific funds to specific programmes, including the Disability Services Programme, or to apply general increases or reductions to programmes, through the mechanism of the annual Estimates. At a local level, the HSE and the disability service providers negotiate the level of funding required by means of the Service Level Arrangement (SLA) process (see *Section 3.2.2 below*).

Concerns have been expressed by service providers that the incremental system for funding services does not necessarily reflect the needs of the individuals who are currently within their services at a given point in time (Irish Human Rights Commission, 2010). In some instances, the historical basis for determination of funding may date back to the time the services (or places) were first approved. For example, funding may have been originally allocated some years ago for a residential service for adults with intellectual disability but no significant additional care needs. Even the method of allocating the baseline funding may not have been directly linked to an individual assessment of need, but rather a global determination of resource needs based on a notional cost per place. Following the initial allocation, the client profile may have changed for many reasons over the years, not least because of the normal ageing process. The support requirements and resource needs of any given service may therefore vary considerably from the needs of the service users when the service was first established and its resource requirements first decided.

Allocation of capital funding

The HSE Capital Programme lists intended capital expenditure projects for the year and must be approved by the Minister for Health. The approved capital projects are also identified within the National Service Plan. Capital funding does not form part of the service level arrangement and service providers are required to make separate capital funding applications to the HSE for their capital requirements. The service level arrangement does, however, stipulate that service providers cannot undertake any capital project without the prior consent of the HSE.

Some service providers, through the establishment of housing associations, also receive funding from the Department of the Environment, Community and Local Government under its Capital Assistance Scheme (CAS). The CAS provides for the payment of a grant by the Department of the Environment to a local authority in respect of housing projects by approved housing bodies. The local authority then lends this money in the

form of a 30-year annuity mortgage to an approved housing association towards the approved costs it incurs in providing the dwelling. The approved housing association is the owner of the dwellings and is responsible for the management of the buildings and the operation of its letting policies (such as the fixing of rent) and providing adequate repairs.

3.1.4 STATUTORY OVERSIGHT

Health Information and Quality Authority

The Health Information and Quality Authority (HIQA) was established in May 2007, by means of the Health Act 2007, and is an independent statutory body responsible for setting and monitoring standards on safety and quality of healthcare services in the public sector, including the undertaking of investigations and the operation of accreditation programmes.

Following a public consultation process initiated by HIQA, proposed standards were formulated and the *National Quality Standards: Residential Settings for People with Disabilities* were published in May 2009. The current Programme for Government includes a commitment to put these standards on a statutory footing and to ensure that the services are inspected by HIQA. Discussions have begun between the Department of Health and HIQA to progress this commitment.

Provision for compliance with the HIQA standards is included in the Service Level Arrangements between the HSE and service providers in the disability sector. Service providers are required to have systems in place to assess quality and standards, and to specify the actions being taken to maintain and monitor quality and service standards. Examples of such monitoring actions could include audit tools appropriate to the service, service user evaluations and satisfaction surveys, and carer and service evaluations. Some service providers have already commenced a review of their services in the context of the HIQA standards.

For further consideration of the role of quality and standards in promoting and monitoring service effectiveness, please refer to Chapter 6.

GOVERNANCE AND ACCOUNTABILITY FRAMEWORK

KEY FINDINGS

- ✓ National governance and accountability structures for disability services are in a state of transition. [Finding 3.1](#)
- ✓ The practical application of statutory oversight at service user level will be realised from 2013 onwards, when the HIQA *National Quality Standards: Residential Settings for People with Disabilities* are put on a statutory footing. [Finding 3.2](#)
- ✓ Information on complaints that do not fall under Part 9 of the Health Act 2004 is not collated by care group within the HSE. [Finding 3.3](#)

KEY RECOMMENDATIONS

- ✓ A re-configured governance framework should be put in place to take account of the new model of services and supports outlined in Chapter 7 of this Review. The elements of such a governance framework include:
 - processes for assessing needs;
 - processes for allocating resources;
 - processes for procurement and commissioning;
 - quality assurance systems, including processes for managing risk;
 - processes for performance management, review and accountability;
 - appropriate information systems;
 - management structure.

Recommendation 3.1

- ✓ Information on complaints that do not fall under Part 9 of the Health Act 2004 should be collated at national level and be used by the National and Regional Disability Lead/Director to support the monitoring of service user outcomes.

Recommendation 3.2

3.2 SERVICE DELIVERY FRAMEWORK

3.2.1 SERVICE DELIVERY STRUCTURES

Non-statutory service providers

As outlined in Chapter 2, the structure of publicly funded service provision for people with disabilities has been shaped by the decisions of State bodies at various junctures to provide such services through non-statutory service providers rather than through direct service provision. The statutory basis for this is Sections 38 and 39 of the Health Act 2004, which are the primary legislative provisions under which funding is made to non-statutory bodies in the State by the HSE (the agencies funded under these provisions are described respectively as Section 38 and Section 39 agencies).

Section 38 of the Act provides that the HSE may ‘*subject to its available resources and any directions issued by the Minister under section 10, enter, on such terms and conditions as it considers appropriate, into an arrangement with a person for the provision of a health or personal social service by that person on behalf of the Executive*’. For each financial year, before entering into an arrangement for the procurement of services with a service provider, the HSE is obliged to determine the maximum amount of funding it proposes to make to the service provider and the level of services it expects to be provided for the funding. Because services provided under Section 38 are provided on behalf of the HSE, the Executive is obliged to include details of these services in its annual report (Section 37(2)(a) of the Health Act 2004).

Most staff in Section 38 agencies are encompassed by terms and conditions similar to those of HSE direct employees: they are bound by the Department of Health Consolidated Salary Scales, included in the HSE's employment control ceiling, and are members of one of the public sector pension schemes.¹ These pension schemes are defined benefit schemes under which benefits are currently payable based on the level of final salary at the date of retirement, with post-retirement increases being awarded in line with pay increases with the consent of the Minister for Finance.

Section 39 of the Act empowers the HSE to '*give assistance to any person or body that provides or proposes to provide a service similar or ancillary to a service that the Executive may provide*'. The support provided by the HSE may be given in a number of ways, including the provision of funding for premises, and may be subject to whatever terms and conditions the HSE sees fit to impose. Employees of Section 39 agencies are not included in the HSE's employment control ceiling, are not bound by the Department of Health Consolidated Salary Scales and are not members of a public sector pension scheme. This provides Section 39 agencies with the freedom to exercise greater flexibility in respect of staff recruitment, deployment, pay and conditions.

Structure of the voluntary sector

There are 200 diverse non-profit specialist disability service providers delivering disability services on behalf of the State (see Table 1.2). However, the core group of providers that deliver the majority of residential, day, respite and personal assistant services amount to approximately 75 organisations, which receive in excess of €1 billion revenue funding per annum from the HSE. The top 35 providers alone account for about 75%-80% of funding. Table 3.1 shows the distribution of HSE funding to providers by size of provider. There are a substantial number of smaller providers that receive minor payments for a variety of services; these can be one-off payments and may not necessarily represent year-on-year funding.

Table 3.1: Distribution of HSE funding by provider*

HSE funding (bands in €)	Percentage of providers %	Percentage of HSE funding (cumulative) %
0 – 250,000	34	0.4
250,000 – 1m	23	1.8
1m – 5m	20	6.4
5m – 10m	6	5
10m – 50m	15	59
50m – 150m	2	27.4
Total	100	100

* Some of these providers are branches of the same organisation.

Source: HSE, Agency Profile spreadsheet

¹ Most HSE employees are covered by the Local Government Superannuation Scheme (LGSS). Ministerial responsibility for the scheme as it applies to the health sector was transferred by the Health (Miscellaneous Provisions) Act 2009 from the Minister for the Environment, Heritage and Local Government to the Minister for Health. Other pension schemes include the Voluntary Hospitals (Officers) Superannuation Scheme, 1969 (as amended), the Nominated Health Agencies Superannuation Spouses' and Children's Contributory Pension Scheme, 1986 (as amended) and the Health Service Executive Employee Superannuation Scheme, 2010.

In addition to agencies whose core remit is the delivery of services and supports, there are a number of organisations whose primary function is the provision of representation or advocacy, although sometimes with some direct service provision as well. Ten organisations that are either umbrella/representative bodies or primarily provide support, information or advocacy services to people with disabilities and their families received grant assistance of €6.77m in 2009 (*see Table 3.2*).

Table 3.2: Funding to agencies that provide umbrella/representation, advocacy, information and support services

Annual HSE funding	No. of agencies
Less than €0.25m	2
Between €0.25m – €1m	6
Between €1m – €3m	2
Total	10

Source: Extracted from HSE Annual Report, 2010

The current structure of the voluntary sector reflects the origins of many of the providers as ‘Parents & Friends’ or other community-based organisations that were set up to address gaps in services (*see Section 2.1.1*). The multiplicity of providers and the ‘catchment area’ system of funding services by geographic location has increased the number of relationships and related administrative overheads that must be managed by the HSE as funder (full or partial) of their services. An analysis of the administrative costs of voluntary service providers is given in Chapter 4.

ADMINISTRATIVE FRAMEWORK

KEY FINDINGS

- ✓ While the National Disability Unit of the HSE has lead responsibility for the planning, monitoring and evaluation of the Disability Services Programme nationally, it has no authority over resource allocation matters or operational service delivery. Responsibility in these areas currently lies with the HSE Regional Directors of Operations and the Integrated Service Area Managers. [Finding 3.4](#)
- ✓ Regional and local partnership structures work within a collaborative framework and are representative of the major stakeholders in the region. [Finding 3.5](#)
- ✓ Catchment area structures are administratively more straightforward for the HSE at local area level, but do not facilitate regional and national service delivery planning or management. They also cause duplication of effort for those service providers that span more than one catchment area and restrict the ability of service providers to widen their service base. [Finding 3.6](#)
- ✓ A strong change management function will be required at national level to lead, coordinate and manage the implementation of the very significant body of recommendations in this Review, including progressing the further work recommended in Chapter 7. This will require a Director or Change Manager who is personally responsible for driving the process. [Finding 3.7](#)
- ✓ The delivery and funding of services through strictly enforced catchment areas restrict service user choice. [Finding 3.8](#)

KEY RECOMMENDATIONS

- ✓ A Director of Disability Services in the HSE should drive the implementation of the recommendations in this Review and should have sufficient decision-making authority to ensure that the necessary changes are implemented. He or she should have full accountability for all resources allocated to the disability sector.
[Recommendation 3.3](#)
- ✓ There should be a clear line of responsibility for decision-making at local, regional and national levels, which is consistent with levels of responsibility for the Disability Services Programme's budget. [Recommendation 3.4](#)
- ✓ A national disability function in the HSE requires to be strengthened in the following areas:
 - greater authority over the regional and local distribution of funding and service delivery matters;
 - resource monitoring;
 - greater role in identification and dissemination of best practice;
 - more 'hands on' commissioning, including management and direction of the market for provision of disability services;
 - the formulation of operational policy and administration of national/Government policy;
 - appropriate information systems;
 - research, development and implementation of innovative interventions.[Recommendation 3.5](#)
- ✓ A strong change management function should be put in place at national level to lead, coordinate and manage the implementation of the very significant body of recommendations in this Review, including progressing the further work recommended in Chapter 7. This would require a Director or Change Manager who is personally responsible for driving the process, and who has the qualifications, skills and experience necessary at senior management level for this task.
[Recommendation 3.6](#)
- ✓ Geographic-based service provision should be examined to minimise duplication of administrative effort by service providers, facilitate regional and local service delivery planning and management, and maximise service user choice.
[Recommendation 3.7](#)
- ✓ The role and funding of agencies that are wholly or substantially engaged in representation rather than direct service provision should be re-appraised having regard to the recommendations in this Review on the person-centred approach.
[Recommendation 3.8](#)
- ✓ The place of the Disability Services Programme should be appropriately situated within the newly emerging health management structures and the development of those new structures should be kept under close scrutiny in the short term.
[Recommendation 3.9](#)

3.2.2 RELATIONSHIP BETWEEN HSE AND SERVICE PROVIDERS

Service Level Arrangement framework

The Service Level Arrangement or Grant Aid Agreement between the HSE and service providers governs the funding relationship between the relevant bodies.

Report 52 of the C&AG on the *Provision of Disability Services by Non-Profit Organisations* (C&AG, 2005) identified the requirements for more robust service arrangements between the HSE and non-statutory disability service providers. In particular, the report identified the need to link funding provided to the quantum of service delivered. On foot of the report, the HSE engaged in a comprehensive process of developing new documentation for service arrangements to address the C&AG's concerns and in 2009 introduced a new governance framework to formalise its relationship with non-statutory service providers.

According to the HSE, *'The key benefits of the framework are that it formalises a relationship between both parties which seeks to address the needs of each in an open way. It ensures that agreements that are robust and equitable are put in place. They contain formal specification of services to be provided in return for funding and agree clearly defined service levels, outcomes and performance indicators thus enabling effective monitoring of performance'*.

The framework sets out 3 elements: the Section 38 Service Arrangement, the Section 39 Service Arrangement and the Section 39 Grant Aid Arrangement (for service providers that receive under €250,000 funding from the HSE). The Service Level Arrangement (SLA) process was introduced during 2009 and has thus been in operation for 3 years. No published assessment of the process has been made available to date, although it is understood that the HSE has conducted its own internal assessment. As far as the Project Team for this VFM Review is aware, the HSE has not collated SLA data at national level, except for the purposes of this Review.

Data obtained from the SLA process is analysed in Chapter 5, while Chapter 8 contains a discussion on the role of the SLA in performance measurement.

Service monitoring

The HSE monitors the performance of a service provider in accordance with the standards set out in the SLA, by generally accepted best practice and by reference to its Performance Monitoring Framework. The service provider, in turn, undertakes to maintain systems, procedures and controls that reflect the best practices of accountability in expending public funds and to fully cooperate with the Executive in any reviews of such practices required by the Executive.

The HSE, through the SLA framework, requires agencies to participate in a monitoring and review process, through submission of information to the HSE and attendance at review meetings. At each review meeting, consideration is given to various issues specified in the SLA, including financial, staffing, administrative and activity issues. As part of its monitoring arrangement with an agency, the HSE has 3-stage protocols to address non-compliance, the ultimate sanction being the immediate termination of the SLA in the event of a serious breach of its obligations by the agency. This sanction has not yet been invoked in respect of any disability service provider.

FUNDING FRAMEWORK

KEY FINDINGS

- ✓ The historical framework for funding disability services was a pragmatic approach, which should be seen within the context of the development and administration of public services generally. However, with the development of governance requirements, it must now be regarded as relatively inefficient. [Finding 3.9](#)
- ✓ HSE funding is based on an incremental determination process with relevant adjustments made to the previous year's baseline allocation. Resource allocation to the Disability Services Programme at national level is informed by the national disability databases (the NIDD and NPSDD) and other relevant data, and in particular the overall HSE Vote for the year. [Finding 3.10](#)
- ✓ Again, for historical reasons, funding has in general been provided for places rather than people. In more recent years, the funding of new places was made at local level on the basis of providing services to named individuals, but, once allocated, the funding did not remain associated with that individual but was absorbed into the agency's base. [Finding 3.11](#)
- ✓ Staff employed in Section 39 agencies are outside the HSE's employment control ceiling, are not bound by the terms and conditions of the Department of Health Consolidated Salary Scales and are not members of a public sector pension scheme. [Finding 3.12](#)
- ✓ The HSE has reported that value for money savings made by the Disability Services Programme from 2008 to 2011 were targeted at areas that did not immediately and directly impact on front-line services. [Finding 3.13](#)
- ✓ In common with other publicly funded health and personal social services, disability services, with few exceptions, have not been formally commissioned or procured. [Finding 3.14](#)
- ✓ The HSE has indicated that SLAs contain clearly defined outcomes and performance indicators, thus enabling effective monitoring of performance. These data are not collated at national level and do not contribute to national monitoring of performance. [Finding 3.15](#)
- ✓ While the implementation of the SLA process is a positive development, there has not as yet been any objective evaluation of its operation. [Finding 3.16](#)

KEY RECOMMENDATIONS

- ✓ Agencies that receive funding from the State for the delivery of services and supports to people with disabilities are accountable for that funding and the necessary systems and protocols should be put in place by the HSE to ensure full accountability and transparency on a standardised basis. [Recommendation 3.10](#)
- ✓ Resource allocation at national, regional and local level should be on the basis of programme budgeting, where the objectives, output and outcomes of each element of the budget are specified, rather than incremental budgeting based on the calculation of changes to the previous year's baseline. [Recommendation 3.11](#)
- ✓ The position of funding *places* rather than *people* should be reversed. [Recommendation 3.12](#)
- ✓ The commissioning process, whereby the HSE arranges for the provision of services, should be formally documented. Opportunities for procurement by competitive tendering should be explored wherever this would maintain or improve service user outcomes at the same or lower cost. The HSE should move beyond a model of commissioning services from individual providers to one where, even on a pilot basis, services are sourced using a competitive procurement process. [Recommendation 3.13](#)
- ✓ Gaps in the dataset collected at SLA level should be addressed, while continuing to exploit the simplicity and effectiveness of the Excel-based data collection mechanism. SLA data should be collated at regional and national levels. Data on outcomes and performance indicators should form part of the data collection process and be aggregated at regional and national level to allow effective monitoring of performance. [Recommendation 3.14](#)
- ✓ Summary SLA data should be collated and published annually. [Recommendation 3.15](#)
- ✓ The operation of the SLA process should be independently validated and audited. [Recommendation 3.16](#)

3.2.3 PROVISION OF NEW SERVICES

Commissioning and procurement

Commissioning of social care has been defined by the UK Audit Commission as '*the process of specifying, securing and monitoring services to meet people's needs at a strategic level*'.² Commissioning as a concept applies to services regardless of source, whether they are directly provided by the public health sector or other public bodies, or by the voluntary or private sector. Procurement is one specific aspect of the commissioning cycle and focuses on the process of buying services.

² See www.joint-reviews.gov.uk/money/commissioning/2-21.html#2-211

Using the above definition, the HSE may be deemed to commission services by means of the SLA process. By and large, the HSE's commissioning function is not proactive, but based on the continued provision of existing services by the established service providers. New services, too, are generally commissioned through a process of local negotiation with the established providers. New voluntary service providers have generally established a foot in the market through providing a service that was not available from an established source or through providing a service in a geographical region that had no existing service providers.

Some incidents of service procurement have been initiated by the HSE in recent years, usually in respect of a small number of places and in response to specific circumstances.

Development of new services

The provision of new service development funding to service providers is made on the basis of a nationally agreed average cost per place, a determination of individual need and the total amount of funding available. The indicative cost that has been used when planning for new residential places for persons with an intellectual disability is approximately €80,000. This is an average, applied across all models of residential services and dependency levels. At local level, efforts are made by the HSE to fund new services on the basis of costing individualised dependency needs and while there is some flexibility to fund places which cost more than, or less than, the average, the overall number of places created from a specified amount of funding is calculated broadly on the basis of an €80,000 average cost per place. Similarly, day places were funded on the basis of an average annual cost of €19,000, although this has been reduced to €14,000 in 2011. Chapter 5 provides more detailed analysis on the cost of day and residential places.

NEW SERVICE DEVELOPMENT PROTOCOLS

The Department of Health and the HSE created New Service Development Protocols to govern the allocation of new funding. The Protocols require that 70% of funding provided for any given year from any additional investment funding must be allocated to developing new residential services, while the remaining 30% is to be allocated to enhancing residential services for people who already have a service. The New Service Development Protocols also state that in respect of day service funding, priority must be given to the provision of day services for school-leavers. The HSE distributes the allocation for new development funding to its four Regional Offices on the basis of identified need.

Allocation of new or enhanced places

In 2004, Development Committees agreed on a prioritisation process in respect of allocating new service development funding for the provision of services to individuals. Under the prioritisation process, a service provider lists individuals within their service whom it considers require either a new place or an enhanced service. The prioritisation form outlines six criteria for prioritising service needs:

1. Sudden unavailability of primary carer, usually due to illness or death.
2. Those whose current service is deemed inappropriate due to risk to their own or others' personal safety or well-being, or because of concerns that they are experiencing neglect, emotional, physical or sexual abuse.
3. Those whose situation is known to be very difficult and at risk of breaking down within the next 12 months.

4. Those in service who have an immediate urgent need for a new element of service and as adults have been on a waiting list for 24 months, or in the case of children have been waiting for 12 months, or longer, for this specific service.
5. Those who are not in receipt of any service or whose current service is due to cease within the next 12 months.
6. Those whose health or well-being is seriously compromised in the absence of appropriate supports.

The HSE makes the final determination and allocation of the new development funding based on agreed local procedures. Provision of the requested services is dependent on the availability of funding.

Chapter 4: Inputs for the disability services

4.1 INTRODUCTION

The primary aim of this chapter is to examine the inputs of the disability services funded through the HSE Vote. The inputs consist of the financial and staffing resources used to run the services. In the following discussion, some background is provided on how the system is funded and on overall expenditure trends for the Disability Services Programme over the evaluation period by sector, region and disability type. The factors explaining the increase in expenditure in recent years are examined. The chapter also includes a profile of current pay and non-pay costs, and a brief look at the levels of management/administration costs. Resource allocation issues across geographical areas are discussed. Finally, some high-level examples are given of efficiency initiatives taken in recent years to control costs.

This chapter mainly addresses Term of Reference 6 of the Review, focusing in particular on identifying the level and trend of costs and staffing resources associated with the disability services.

It should be noted that much of the analysis of inputs presented here is the first time data have been analysed in this way and that some of the required data was not available from the HSE in the form needed for the purposes of the evaluation.

Detailed information on non-pay expenditure is contained in Appendix 2, Tables A2.2 and A2.3. Further details on staff numbers and pay are contained in Appendix 11, Tables 11.11 to 11.16.

4.2 FUNDING

This Review focuses on expenditure on the Disability Services Programme under the HSE Vote. There are other sources of funding supporting service delivery, which, although outside the scope of this Review, require examination in order to understand how the system is resourced.

A multiplicity of funding sources can potentially lead to risks of duplication of funding and double-funding of overheads, as well as causing difficulties in linking outputs to expenditure, as highlighted in a recent cross-cutting paper prepared in 2011 by the Central Expenditure Evaluation Unit (CEEU) of the Department of Public Expenditure and Reform (DPER) for the Comprehensive Review of Expenditure. This paper, entitled *Rationalising Multiple Sources of Funding to the Not-for-Profit Sector* recommends that the number of State-to-agencies transactions should be reduced, by rationalising both the number of bodies and the number of State interlocutors (CEEU, 2011).

There are also disadvantages for voluntary bodies in receipt of multiple sources of Exchequer funding since each Government department applies its own administrative and accountability requirements for funding provided. This increases the administrative burden for agencies. Further, there is an issue regarding the application of different sources of funding: if once-off or volatile sources of funding are used to fund mainstreamed services, this can lead to funding deficits if income from these sources reduces significantly.

The HSE does not currently maintain centralised, national records on the sources of funding for disability providers nor does it reconcile the sources of funding for an agency against annual accounts or performance

data. A data-gathering exercise was carried out by the VFM Project Team to ascertain the full extent of funding available for disability services in Ireland. This comprised two elements:

- a data request to other Government departments to determine other funds provided for specialist disability services;
- the inclusion of a separate question regarding funding sources in the non-pay questionnaire distributed to disability providers.³

Table 4.1 summarises the Government funding (current) for disability services. The data were sourced by the Department of Health through a data request circulated to Government departments since this funding data was not otherwise available. As can be seen, the majority of funding comes from the HSE, with approximately 4% of funding provided by other Government departments. The bulk of this is accounted for by FÁS, which provides funding to specialist training providers. The National Learning Network, a division of Rehab, receives the majority of this funding.

Table 4.1: Sources of Exchequer funding for gross current specialist disability services, 2009

Source of income	€m
HSE	1,789.0
Other Government departments	70.0
Transport, Tourism and Sport (including Arts Council and Sports Council)	4.4
Education and Skills	0.5
FÁS	55.6
Finance (charitable lotteries scheme)	7.9
Justice and Equality	1.6
Total	1,859.0

Note: Excludes client charges that derive from disability clients' social welfare entitlements.

Source: Data questionnaire distributed to Government departments, 2011

Some agencies derive funding from a large number of different sources. For example, one small provider of disability services received funding from 6 different Government sources.

In addition to public sources, providers also receive funding from private sources, such as donations and income from ancillary services. There is no central register or database of sources of funding for voluntary agencies including private sources. Agencies are required to submit annual accounts retrospectively, which may contain information on funding sources. However, there is no systematic analysis of funding sources based on annual accounts information. Ideally, funding information should be available prior to resource allocation to inform funding decisions.

For the purposes of this VFM Review, the Project Team also issued a questionnaire to voluntary agencies. One of the questions dealt with sources of funding. Responses were received from 73 providers, accounting for approximately €1.1 billion. The data show that non-Exchequer funding (i.e. private sources) amounted to approximately 5%-7% (assuming that client charges are mainly funded by social protection disability

³ It should be noted that non-pay expenditure is based on data questionnaire returns from 74 agencies and 13 HSE Local Health Offices; total expenditure for 2009 for these agencies amounted to €1.1 billion.

payments). For some smaller agencies, there can be a much higher proportion of funding deriving from non-Exchequer sources, but this reflects lower overall funding levels.

FUNDING

KEY FINDINGS

- ✓ The HSE does not maintain sufficient information on the sources of funding for voluntary providers because it does not systematically collect data on funding sources or reconcile these to annual accounts. [Finding 4.1](#)
- ✓ Non-Exchequer sources of funding are estimated to account for 5%-7% of total funding for voluntary agencies based on questionnaire data collated for this Review. [Finding 4.2](#)

KEY RECOMMENDATION

- ✓ Full transparency on all sources of funding (both Exchequer and non-Exchequer) for disability organisations is required. Sources of funding should be itemised by source of funding and reconciled to the total income for the organisation. This analysis should be mandatory by being made a condition of HSE Grant Aid Agreements and Service Level Arrangements. It should be provided as part of a standardised expenditure and staffing reporting template. This should be introduced for the allocation process from 2013. [Recommendation 4.1](#)

4.3 AGGREGATE EXPENDITURE TRENDS

4.3.1 OVERALL SPENDING TRENDS AND COMPARISONS TO HSE SPENDING

It should be noted that the estimation of annual expenditure for the Disability Services Programme for 2005-2009 required a dedicated analytical exercise by the HSE since accurate data are not available on an annual basis. The HSE's accounting system does not capture all HSE-funded expenditure relating to the Disability Services Programme. This is because some of the funding is not coded appropriately to the Disability Services Programme. For example, some funding is coded to a broader multi-care group coding structure, including other care groups as well as the Disability area. There are different financial systems, with different general ledger coding systems, in operation in different HSE areas. In addition, grants paid to some of the voluntary providers (particularly Section 39 agencies) are recorded as a single annual payment, with no further breakdown on pay or non-pay costs. Other deficiencies in the HSE's financial Corporate Reporting System (CRS) include:

- Data may not include certain services provided in Local Health Office settings that cross traditional care group boundaries, in particular, services provided via therapy grades which may be traditionally embedded in Primary (PRI) or Multiple (MUL) care group categories.

- There is little or no meaningful secondary costing mechanism (i.e. overhead cost apportionment) in the HSE local financial systems. Therefore, the opportunity to reflect a fully inclusive cost of service through secondary cost apportionment is limited.
- The CRS retains and hard-codes historical data, which will not then change when mapping changes occur; for example, moving costs from one care group mapping to another during a given year.

Expenditure on the Disability Services Programme accounts for approximately 12% of total gross expenditure. It has risen significantly in recent years. Total gross⁴ expenditure on the Disability Services Programme funded through the HSE Vote has increased by roughly 34% – from €1.34 billion in 2005 to approximately €1.789 billion in 2009. Expenditure for 2011 is estimated at €1.708 billion.⁵

The main drivers of the increased expenditure included:

- the introduction of the multi-annual investment programme (MAIP) for 2006-2009, comprising €900m, of which €680m was aimed at developing HSE-funded disability services;
- successive pay awards in national pay agreements (which applied to the public sector in general);
- increases in staff numbers;
- the general year-on-year incremental increase in allocations.

Pay costs are the main component of the disability services' budget, accounting for approximately 82%-85% (based on the data questionnaires and the DFB). In recent years, expenditure on disability services has declined due to pay reductions and the impact of the moratorium on recruitment. It is estimated that overall expenditure decreased by approximately 5.8% in 2010 and increased by 1%⁶ in 2011, amounting to an estimated cumulative reduction of roughly 5% from 2009 to 2011.

Table 4.2 compares the rate of growth in gross expenditure for disability services to the HSE generally. By 2009, the rate of increase in spending was broadly equivalent across disability services and the HSE in total. By 2011, spending on the Disability Services Programme was 27% higher than 2005 levels compared to 22% for the HSE overall. However, a comparison of net spending shows that spending on disability services was 31% higher in 2009, whereas HSE spending was 24% higher.⁷ A HSE analysis based on gross CRS expenditure alone (i.e. expenditure coded to the statutory sector and some Section 38 agencies, before any DFB adjustments) showed that expenditure on disability services as a proportion of total HSE expenditure increased from 9% to 12% over the period 2005-2009.

⁴ These figures are based on a costing exercise carried out by the HSE for the purposes of this VFM Review, which resulted in a financial dataset called the Disability Finance Book (DFB). Data consist of reconstructed data and not contemporaneous data. Core financial data relating to the Disability care group recorded in the CRS (the HSE's financial Corporate Reporting System) were augmented by inclusion of certain allowances not coded to disabilities and certain standard overheads. The data were also adjusted to reflect expenditure incorrectly coded to other care groups and were subject to validation and correction by regional health offices. The figures exclude appropriations, such as client charges and income associated with services. Appendix 2 sets out the limitations and caveats surrounding the data in more detail.

⁵ Based on trends in CRS gross expenditure figures for 2010 and 2011 applied to 2009 DFB data.

⁶ These percentage figures are taken from gross expenditure figures for statutory and certain Section 38 agencies as recorded in the CRS for 2010 and 2011. The DFB process of adjusting CRS data to improve accuracy (*see Appendix 2*) was not carried out by the HSE for 2010 and 2011. The HSE stated that this was due to the extensive regional validation work required.

⁷ Based on DFB and HSE CRS expenditure.

Table 4.2: Comparison of Disability Services Programme gross expenditure to HSE gross expenditure, 2005 to 2011

	2005 €m	2009 €m	% increase 2005-2009	2010 €m	2011 €m	% increase 2005-2011
Disability Services Programme	1,338	1,789	33.7%	1,684	1,708	27.1%
HSE Total Expenditure	11,000	14,695	33.5%	14,077	13,400	21.8%

Note: The gross expenditure figures for the Disability Services Programme are taken from the DFB. HSE total gross expenditure figures are taken from HSE Annual Reports. The HSE Annual Report does not outline the methodology for deriving gross expenditure.

Source: HSE Annual Reports; gross expenditure line, DFB

It is worth noting that the figure of €1.5 billion is commonly referred to as the annual expenditure on disability services for the 2009 period. This is a net figure that reflects expenditure after appropriations and income sources (e.g. allowances, pension levy, charges, income such as canteen income, etc) as well as other CRS adjustments (e.g. adding back expenditure coded to other care groups), which have the effect of reducing the net amount required to fund services. For the purposes of this VFM Review, gross figures are used (e.g. €1.789 billion in 2009) since these represent the actual levels of expenditure regardless of the income which finances a portion of this expenditure.

OVERALL SPENDING TRENDS

KEY FINDINGS

- ✓ The absence of an integrated financial data collection system was a significant barrier to the work of the Review. It was difficult to determine total spending on the Disability Services Programme and required significant additional work to derive expenditure totals. It is also clear that there are different organisational approaches to coding and recording expenditure, which make comparisons across agencies difficult. The fact that there is no line of sight over expenditure by cost type across all agencies makes it difficult to analyse spending for the disability sector. [Finding 4.3](#)
- ✓ Based on reconstructed data from the CRS system and an adjustment process (i.e. the DFB), gross expenditure on disability-related services has increased by 33.7% over the evaluation period 2005-2009. In recent years, expenditure has reduced by an estimated 5.9% from 2009 to 2011. Over the period 2005-2011, gross expenditure is estimated to have increased from €1.3 billion to €1.7 billion. This estimate is based on DFB data and CRS expenditure trend estimates for 2010 and 2011. [Finding 4.4](#)

KEY RECOMMENDATION

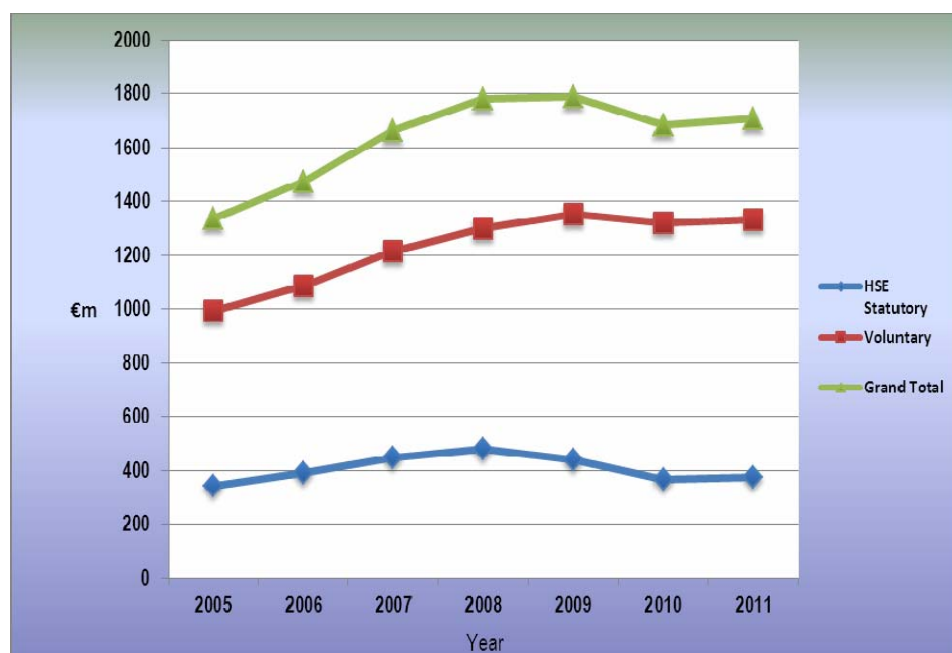
- ✓ As a medium-term priority (1 to 2 years), a common system of recording and reporting expenditure should be developed by the HSE and implemented across the sector, subject to budgetary constraints. This should include common general ledger coding for cost elements across disability providers.

[Recommendation 4.2](#)

4.3.2 EXPENDITURE BY SECTOR

Expenditure on disability services is delivered mainly through voluntary agencies and the HSE. Figure 4.1 illustrates that the proportionate increase in funding for the voluntary sector over the period 2005-2009 was greater than that for the statutory sector.

Figure 4.1: Trend in gross annual expenditure on disability services, 2005-2011 (estimated)



Notes:

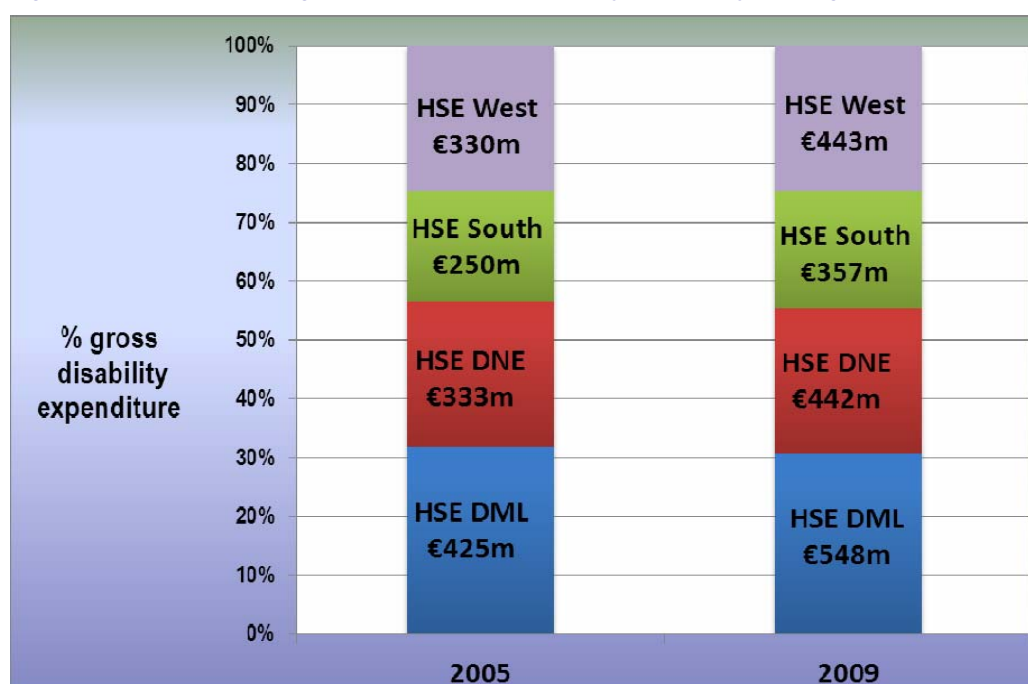
- Data for 2005-2009 is based on a HSE methodology that draws on core financial reporting systems and allowances payments.
- Total spending for 2010 and 2011 is estimated, based on gross CRS data provided by the HSE.

Source: HSE, Disability Finance Book, 2011

4.3.3 REGIONAL EXPENDITURE TRENDS

The regional breakdown of expenditure has not changed significantly over the period 2005-2009 (see Figure 4.2).

Figure 4.2: Distribution of gross expenditure for disability services by HSE region, 2005 and 2009



Source: HSE, Disability Finance Book, 2011

Data provided by the HSE for 2011, based on core CRS information, show that the distribution of spending has not changed over the period 2009-2011.

The distribution of regional expenditure by sector (statutory *versus* voluntary) is more varied within each region. In all regions other than the Dublin Mid Leinster (DML) region, 25%-29% of regional expenditure is incurred by statutory services. In the DML region, only 15% of all regional expenditure is directed at statutory services. The reason for this variance is most likely due to historical factors related to the emergence of voluntary services in this region.

An important issue in assessing the regional distribution of spending is how resource allocation is linked to regional demand for services and whether or not there is an equitable distribution of resources based on need. A recent report on resource allocation by Vega *et al* (2010), entitled *Towards the development of a resource allocation model for primary, continuing and community care in the health services*, found that there is currently no systematic approach to resource allocation generally in the HSE. The geographical distribution of funding is considered further in Section 4.7 below.

A more detailed analysis of regional expenditure by Local Health Office (LHO) area is not feasible since services may often be delivered to clients in neighbouring areas and LHO disability budgets may relate to multiple areas. This is a deficiency which needs to be addressed to allow for detailed area by area comparison of disability resource allocation and requires mapping of expenditure to the location of clients receiving services.

REGIONAL EXPENDITURE TRENDS

KEY FINDINGS

- ✓ The proportional regional distribution of expenditure has not changed significantly over the period 2005-2011. [Finding 4.5](#)
- ✓ It is difficult to map regional expenditure by LHO area since budgets may relate to multiple areas. [Finding 4.6](#)

KEY RECOMMENDATION

- ✓ The HSE should match Disability Services Programme expenditure with individual administrative areas to facilitate a comparison of resource allocation across different geographical areas. One way to facilitate this would be to track geographical spending using a client identifier that is linked to address information. [Recommendation 4.3](#)

4.3.4 TRENDS BY DISABILITY TYPE

There is no trend information available on spending by programme type (e.g. residential, day services, etc.). Similarly, there is no routine information on expenditure by type of disability across the broad categories of intellectual disability and physical and sensory disability. Analysis was carried out on a selection of the larger voluntary providers using management information provided by the HSE (data taken from the HSE's annual financial statements). Table 4.3 shows the pattern in disability spending by disability type. There was little major change in percentage distribution of spending over the period 2005-2009, although it should be noted that this analysis is based on partial data and is not representative of all voluntary agencies. An analysis based on a smaller dataset for the period 2005-2009 also shows no major change in the distribution of spending by disability type.

Table 4.3: Distribution of expenditure on disability services by disability type, 2005-2009

	2005	2009	% change
Physical and sensory disability	10%	10%	–
Intellectual disability	74%	73%	-1%
Mixed	14%	15%	+1%

Notes:

- Excludes some larger agencies.
- The data do not include payments relating to capitation.

Source: HSE, Project Team's analysis based on AFS data, 2011

TRENDS BY DISABILITY TYPE

KEY FINDING

- ✓ There is no information readily available to track the trend in spending by disability type for the period 2005-2009 or 2010-2011. However indicative data on voluntary providers derived from HSE management information show no major change in spending by disability type over the period 2005-2011.

[Finding 4.7](#)

4.3.5 CAPITAL SPENDING

In addition to current funding, the HSE also allocates resources for capital funding. Although the scope of this VFM Review relates to current spending, it is useful to note the expenditure on capital spending as contextual material. The overall level of capital funding has decreased significantly in recent years, reflecting Exchequer constraints. Spending fell from €27m to €9m over the period 2005-2009.⁸ Over 80% of capital funding over the same period was allocated to 18 individual providers. Annual allocations ranged from €0.1m to €7m. The majority of capital funding for agencies comes from other Government departments, e.g. Environment, Community and Local Government. No data are available regarding the intended purpose of capital funding by the HSE and it is not possible to identify the main results of capital spending or the types of projects funded.

This Review was unable to determine the extent to which capital funding amounts mentioned above incorporate multi-annual investment programme (MAIP) allocations. The HSE was requested to provide information on the distribution of MAIP capital spending by type of output. Although the HSE provided trend capital spending information, it was not able to categorise spending by type of MAIP output or project.

4.4 EXPENDITURE DRIVERS

4.4.1 MULTI-ANNUAL INVESTMENT PROGRAMME

The multi-annual investment programme (MAIP) 2006-2009 was announced as part of the Budget Day package in December 2004. It outlined the Government's commitment to a temporary initiative of revenue and capital expenditure for specific disability support services, amounting to a cumulative total of approximately €900m, of which €680m was targeted toward HSE-funded services (€500m current expenditure and €180m capital). The MAIP aimed to deliver additional residential services, day services, respite services, multidisciplinary supports and personal assistant hours across the intellectual and physical/sensory disability sectors. Approximately €425m has been spent to date (i.e. up to end 2011) on disability services under the MAIP by the HSE.

⁸ Based on Capital Grants expenditure information provided by the HSE.

Section 4.1.1 of the Sectoral Disability Plan for the Department of Health identifies measures to monitor MAIP expenditure. These include agreed protocols governing the implementation of and reporting on the MAIP and regular reports to the Cabinet Committee on Health and Children on progress by the HSE in achieving the targets set. Despite this, it has been difficult to identify the link between MAIP spending and service level improvements. This is in part because a proportion of the MAIP funding was aimed at enhancing services (e.g. improving the quality of residential places for existing clients, transfers from inappropriate places), as well as generating additional places for more clients. This means that separating development funding for new places from development funding affecting pre-existing baseline services is complex. It is also complicated by the fact that the specific nature of service ‘enhancements’ has not been formally defined for the different services. In addition, although physical and financial targets were set for increases in particular outputs, the targets were not categorised by new or enhanced services. For planning purposes, a flat rate (€80,000) was used as the cost per residential and respite place, and similarly a flat rate was used as the cost for a day service place. Neither the HSE nor the Department of Health have provided an explanation as to how these costs were arrived at.

In addition, the HSE did not effectively monitor or collect data regarding the delivery of outputs under the MAIP. Although some data were collected and submitted for the purposes of this VFM Review (e.g. aggregate data on new places funded), they were not sufficiently robust for analytical purposes. In particular, it was not possible to definitively relate trends in MAIP spending to changes in net outputs. MAIP spending by service/programme type was also not reported. Furthermore, there is a lack of clarity regarding the methods used to collect data to monitor MAIP delivery and how this data was validated.

Ultimately, responsibility for the deficiencies in the collection and reporting of performance data for MAIP is shared between the Department of Health and the HSE. The Department of Health did not adequately specify the performance data requirements for MAIP to a sufficient level of detail and the HSE did not monitor the implementation of MAIP to allow for assessment of the impact of the MAIP on overall numbers receiving services and service outputs.

MULTI-ANNUAL INVESTMENT PROGRAMME

KEY FINDING

- ✓ As part of the evidence-gathering work for the Review, it emerged that although some data on new places were collected, overall there was insufficient reporting by the HSE, on an agency-by-agency basis, regarding the impact of MAIP investments at service setting level and how agencies used MAIP money for their clients in terms of new services, existing services, financing core deficit funding and additional staff. Although the HSE sought returns from agencies, these were not sufficient in terms of information headings to adequately report on the use of MAIP funds. [Finding 4.8](#)

KEY RECOMMENDATION

- ✓ Any future development funding should be coded separately on SLA agreements to allow for an assessment of the impact of development funding relative to baseline levels of output. This should be introduced for the next iteration of the SLA agreements (i.e. 2013) (*see also recommendations in Chapter 8*). [Recommendation 4.4](#)

4.4.2 PAY COSTS

The HSE does not have available data regarding the total pay bill for disability services delivered by the voluntary and statutory sectors because pay details for all disability service providers are not accounted for on one system. The Section 39 agencies and certain Section 38 agencies⁹ are outside the scope of HSE accounting systems. The closest estimate can be derived by using pay data provided by agencies through the Service Level Arrangement (SLA) process. In 2009, the estimated pay bill amounted to approximately €1.2 billion. The HSE estimates that the pay bill for the HSE and certain Section 38 agencies increased by 35% from 2005 to 2009. Based on the same data, pay for disability services was €662m in 2009, falling to an estimated €616m by 2011 or 7%. This does not include Section 39 agencies.

The increase in the pay bill over the period 2005-2011 is due to:

- increase in pay rates;
- increase in staff numbers;
- possible changes in staff mix by type of staff;
- the extent of staff at higher grades for a given staff type.

It is difficult to disaggregate the impact of the various factors. The most important factors are pay rate and changes in staffing numbers. The increase in pay rates derives from national pay agreements.

The HSE could not provide any trend data relating to the pay/non-pay split for all disability spending. It did, however, provide the pay and non-pay split for statutory services and certain voluntary agencies (former ERHA region Section 38 agencies). Figures from the DFB indicated an 83.5%:16.5% split. Data sourced from a questionnaire distributed for the purposes of this VFM Review showed that pay costs were, on average, 79% of total expenditure in 2005, compared to 85% in 2009 for Section 39 providers.¹⁰ It should be noted that the distribution of total expenditure by pay/non-pay can be an arbitrary distinction because some costs which are more related to pay can be categorised as a non-pay cost (e.g. agency costs).

The national distribution of pay and non-pay costs can also mask variations by service type and by agency. There may be valid reasons for differences in the pay cost percentage due to the model of service deployed. An analysis of agencies in the former ERHA region showed the pay cost percentage to be in the broad range of 70%-84%. In the absence of sufficient data about clients' needs and demand for resources in different care settings, it is difficult to determine the reasons for variations in pay and non-pay percentages.

⁹ Those agencies outside the former ERHA region (e.g. Brothers of Charity, Daughters of Charity, Sisters of la Sagesse and Sisters of Bon Saveur).

¹⁰ According to the data provided by Section 39 agencies on the questionnaires, these 53 agencies accounted for approximately €380m of expenditure and €326m pay cost (or roughly 25%-30% of total pay cost for the disability services). Overall, the non-pay questionnaire covered 71 agencies, with related 2009 expenditure of over €1.2 billion.

4.4.3 PAY RATES

Increases in pay rates based on national pay agreements have also contributed to the overall increase in expenditure on disability services. The impact of national pay agreements and various other pay awards on overall pay levels during 2005-2009 range from 17%-25% across the main staffing categories. Table 4.4 provides some examples of pay rate increases for selected staff types over that period. It should, however, be noted that there have been subsequent pay reductions over the period 2010-2011.

Table 4.4: Percentage increase in pay scale, 2005-2009 (selected grades)

Staff type	% pay increase
Social Care Worker (professionally qualified)	16.6 – 20.2
Clerical Grade 7	18.8 – 19.8
Staff Nurse/CNM1/CNM2	18.8 – 19.3
Health Care Assistant	20.8
Consultant	25

Source: HSE, Pay Movement Analysis, 2011

4.4.4 STAFF NUMBERS

There are difficulties in analysing the total number of staff working across the voluntary and statutory sectors in the disability services. The HSE maintains a HR Staff Census, which includes Section 38 agencies and HSE services but does not include staff working in Section 39 agencies. The best estimate of total staff in disability services can be sourced from the 2009 SLA data, which showed a total staff of 23,866.

However, the HSE's HR Staff Census is the only existing secondary source to assess trends in staff numbers, despite the data gaps for Section 39 agencies. Table 4.5 shows the trend of staffing numbers by staff type for the HSE and voluntary sector (excluding agencies not captured in the HR Staff Census, i.e. Section 39 agencies). There are important limitations with this information due to the difficulty in allocating staff by care group and the incompleteness of the HR Staff Census due to the lack of Section 39 data (*for details, see 'Notes' to Table 4.5*).

Table 4.5 shows that overall staffing levels increased by 25% in 2005-2009 (approximately 3,200 staff over the period 2005-2009), before falling by roughly 700 by the end of 2011. The 'Other patient and client care' category accounted for the largest percentage increase in staffing numbers. Over 60% of the increase in staff over the period 2005-2009 took place in the voluntary agencies. However, more of the staffing reductions in recent years have also taken place among these providers. In 2005, staff in the voluntary agencies constituted 84% of the total staff in disability services as measured by the HR Staff Census; by the end of 2011, staff in these agencies made up approximately 78% of total staff.

Table 4.5: HR Staff Census – trend in total staff numbers by staffing type for HSE and certain voluntary providers, 2005-2011

Staffing type	2005 No.	2009 No.	2011 No.	% 2005-2009	% 2005-2011
Medical and Dental	75	135	71	80	-5
Nursing	3,301	4,095	4,131	24	25
Health and Social Care Professionals	2,405	3,154	2,896	31	20
Management/Administration	1,151	1,322	1,094	15	-5
General support	1,303	1,351	1,222	4	-6
Other patient and client care	4,691	6,111	5,999	30	28
Total	12,926	16,168	15,413	25	19

Notes:

- Prior to 2009, the HSE could not report on care groups. But care group reporting was reconstructed for this VFM Review by mapping agencies in their entirety to a care group. This was not possible in all cases since some agencies provide services under more than one care group.
- The HSE's HR Staff Census methodology changed in 2007 and data were not reconstructed for previous years according to the new methodology.

Source: HSE, HR Staff Census, 2011

Based on the figures in Table 4.5, the overall mix of staff types across total staff in the HSE and the selected voluntary agencies has remained stable in percentage terms between 2005 and 2011. The results of the non-pay questionnaire show that the mix of staffing in Section 39 agencies is broadly similar to the mix for Section 38 agencies for some categories (management and health/social care professionals) but there are differences in the distribution for the support services and nursing categories.

There was little change in the mix of staff type within the HSE and voluntary sector based on available data for 2009 and 2011, as seen in Table 4.6.

Table 4.6: Mix of staff by type, 2009-2011 (HSE and certain voluntary agencies)

Staffing type	2009 HSE %	2009 Voluntary %	2011 HSE %	2011 Voluntary %
Medical and Dental	0.12	0.7	0.7	0.4
Nursing	33.3	23.2	37.8	23.9
Health and Social Care Professionals	11.5	21.5	8.8	21.3
Management/Administration	9.8	7.9	7.4	7.1
General support	3.6	9.6	6.0	8.8
Other patient and client care	40.6	37.0	39.4	38.5
Total	100	100	100	100

Source: HSE, HR Staff Census, 2009 and 2011 (based on end-Quarter 3 data for 2011).

The results of the data questionnaires issued to voluntary agencies for the purposes of this VFM Review showed that over the period 2005-2009 Section 39 agencies experienced a small reduction in the percentage of nursing staff employed (from 21% to 18%) as a percentage of total staff, and an increase in the number of support staff (from 36% to 41%). Overall, the non-pay questionnaires showed that total staff increased by 35% over the same period.¹¹

STAFF NUMBERS

KEY FINDING

- ✓ Data from the HSE HR Staff Census show that staff numbers in the statutory and certain Section 38 agencies increased by 25% over the evaluation period – from approximately 12,900 in 2005 to 16,200 in 2009. Staff numbers decreased by an estimated 5% by 2011, compared to 2009. There is no national mechanism for monitoring staff numbers in Section 39 agencies on an ongoing basis and there are no national benchmarks for the distribution of staff by type across similar groups of provider or types of services, in line with best practice. [Finding 4.9](#)

KEY RECOMMENDATION

- ✓ Staff numbers in Section 39 agencies should be monitored as part of a more comprehensive information-gathering and performance-monitoring system across the sector, i.e. potentially through the mechanism of the SLA process. A consistent periodic HR dataset on Section 39 agencies should be available by end Quarter 2, 2013. [Recommendation 4.5](#)

4.5 PROFILE OF PAY AND NON-PAY COSTS

4.5.1 PROFILE OF PAY COSTS

Average salary levels

Based on 2009 SLA data, the average salary of staff working in the Disability Services Programme is €54,000 per annum. Of the staff groupings, the Medical and Dental category has the highest average salary, at €120,000. The Management and Administration, and Health and Social Care Professionals categories have virtually identical averages, at €61,000, followed by Nursing at €55,000. The lowest average salary is in the Support Staff category, at €38,000.

¹¹ The non-pay questionnaire was issued in 2010 and covered the reference period 2005-2009. As a result, up-to-date data for 2010 and 2011 are not available. This represents an ongoing problem for staff monitoring.

In the Management and Administration group, the average management salary is €82,000 per annum, while the average salary of Clerical and Administrative staff is €44,000. The average management salary in the HSE is €71,000, but this is not a fair comparison with the other two sectors on the basis that it does not take into account senior management costs, such as Chief Executive Officer (CEO), Finance Officer, etc., which would be included in the figures for Section 38 and Section 39 agencies. Clerical and administrative structures would be more comparable across agency types, and here the HSE figure is mid-way between that of Section 38 and Section 39 agencies.

In order to meet the remit of this Review, the analysis was necessarily focused on areas of greatest expenditure (see *Chapter 5*) and the data collection and analysis targeted at the contribution of gross salaries, across a range of staff grades, to overall unit costs. As the contribution of CEO salaries to unit costs (in the context of total pay expenditure of €1.2 billion) was minimal, the Review concentrated on total management and administration costs. Moreover, the information collected for the Review on foot of SLA Schedule 3 forms was not designed to capture pay at the level of the individual employee. However, the HSE separately appraised SLA data on the level of remuneration paid to CEOs under the Disability Services Programme. Based on the SLA data and appraisal, a total of 28 Section 38 and Section 39 providers indicated that their chief administrative officer was graded at CEO level, of whom 25 were paid at the standard rate on the Department of Health Consolidated Salary Scale for the CEO grade – approximately €150,000 per year (although Section 39 agencies are not specifically tied to this scale). Three CEOs were paid at a lower rate. In only one case (a Section 39 agency) was the CEO found to be paid over and above the Consolidated Salary Scale rate. Other agencies indicated that they were managed by administrators who were not graded at CEO level and were paid at a lower rate. The SLA returns showed that the highest administrative grade in agencies that did not have CEO equivalents were pitched at a variety of levels, including Functional Officer/General Manager grade (mid-point €82,058), Grade VIII (mid-point €76,706) or Grade VII (mid-point €57,208). No analysis was carried out of any salaries paid in whole or in part from sources outside the Disability Services Programme since this was outside the remit of the Review.

In all staff groupings except Nursing, the average salary in Section 38 agencies is higher than that in either the HSE or Section 39 agencies. The average nursing salary in the HSE, at €57,000, is marginally higher than the average for Section 38 and Section 39 agencies. The average nursing salary figures include premium and overtime payments, and it would be necessary to examine service user characteristics and other factors to determine whether this is a fair comparison on a like-for-like basis or whether there are specific factors to explain this divergence in average nursing salaries.

Average salaries in Section 39 agencies are lower than those in either the HSE or Section 38 agencies, or both, for all categories of staff.

It should be borne in mind that all average salary data are based on 2009 rates and will have changed in the intervening period.

AVERAGE SALARY LEVELS

KEY FINDINGS

- ✓ Based on the 2009 SLA data, average salaries in Section 39 agencies are lower than those in either the HSE or in Section 38 agencies, or in both, for all categories of staff. [Finding 4.10](#)
- ✓ There are a multiplicity of grades and pay rates across the disability sector, as shown in the SLA data-gathering experience of the National Disability Unit. [Finding 4.11](#)

KEY RECOMMENDATIONS

- ✓ For agencies that derive over 50% of their income from the State, CEO salaries should be capped at Consolidated Scales CEO level. The salary level should also be commensurate with the size and complexity of the agency, so that the CEO of a medium or small provider should receive less than the CEO of a major agency. This requirement should also encompass the senior management of agencies. The remuneration of the senior management team should not be set at levels in excess of equivalent senior management scales in the HSE. These requirements should be conditions of HSE funding and should be introduced as part of resource allocation from 2013. [Recommendation 4.6](#)
- ✓ As a medium-term priority, opportunities for rationalising grade structures and creating flatter organisational models should be explored across disability providers, taking account of the work practice and skills mix flexibility measures under the Croke Park Agreement. [Recommendation 4.7](#)

Staff mix

Table 4.7 shows the current distribution of staff across the main staff categories, based on the SLA returns. There are inconsistencies between data in this table and data contained in the questionnaires relating to staffing in Section 39 agencies in terms of the distribution of staff by type. In particular, nursing accounts for 6% of staff for Section 39 agencies according to questionnaire data, whereas the SLA data show nursing staff of 15% of total staff. This will require further investigation in the context of future revised data collection arrangements for staffing levels in the disability services.

Table 4.7: Distribution of staff by category, 2009

	HSE	Section 38	Section 39	Total	% of total
Health and Social Care	615	2,876	1,785	5,276	22.1%
Management and Administration	383	1,051	844	2,278	9.5%
Medical and Dental	27	66	4	97	0.4%
Nursing	1,291	3,262	382	4,935	20.6%
Support Services	1,833	5,883	3,564	11,280	47.3%
Total	4,149	13,138	6,579	23,866	100%

Source: HSE, SLA 2009

The care of people with disabilities is provided by professionally qualified staff to a significant extent: 43% of staff is in nursing grades or social care / therapy professional grades. Approximately 47% of staff is involved in support services, which include a mix of staff ranging from drivers, catering staff, attendants, personal assistants and home helps. This grouping contains the highest number of staff. It should be noted that these staffing types are spread across front-line and administrative staff categories. For example, personal assistants and home helps provide an important contribution to service delivery. Given the quantum of staff involved, a more extensive analysis of staff in this category is warranted. However, there are no available SLA data that illustrate the breakdown of the 4,935 support services staff as between front-line services and administrative staff. Analysis of equivalent, more detailed data from the HSE HR Staff Census shows that over 80% of support services could be classified as front-line service staff.¹²

The SLA data show that for every 10% change in staffing mix, from professional nursing care or social care to non-professional personal care, the overall cost of providing care reduces by €3.5m.¹³

STAFF MIX

KEY FINDING

- ✓ Based on an indicative analysis of 2009 SLA salary data, pay costs could be lowered by substituting care staff for professionally qualified staff, e.g. for every 10% change in staff mix from professional care to non-professional care, a saving of €3.5m could be achieved. [Finding 4.12](#)

¹² This is based on a categorisation of home helps, nurses' aides and care assistants as front-line service staff, and drivers, porters, maintenance, household services and catering staff as administrative staff (based on October 2011 HSE data).

¹³ This is based on 10% of the approximately 5,000 nurses (500) multiplied by the difference between the average nursing salary (€43,000) and the average care assistant salary (€36,000), the result being €3.5m. It should be noted that the figure of €55,000 previously mentioned as the average nursing salary also includes nursing management grades. The figure of €43,000 is used here because it represents the average salary midpoint of a typical nurse engaged in service delivery.

KEY RECOMMENDATION

- ✓ The HSE should begin the process of substituting non-professionally qualified care staff (e.g. care assistants) for professionally qualified care staff to achieve pay savings both in the statutory and voluntary sectors. This will also be consistent with the new person-centred model envisaged as the future direction of disability policy (see Chapter 7). [Recommendation 4.8](#)

Additional pay cost elements

An analysis of the aggregate pay cost components for the HSE and selected Section 38 agencies is provided in Table 4.8. It shows that between 14% and 20% of the pay bill for selected staffing categories relates to additional pay elements such as overtime, allowances, agency, arrears and night duty costs.

Table 4.8: Distribution of pay costs as between basic and non-basic components by sector, 2009 (for selected categories)

	HSE (national)		Section 38 (DML and DNE)	
	€m	%	€m	%
Basic	165	80%	290	86%
Additional pay components	41	20%	46	14%
Total	206	100%	338	100%

Notes:

- This analysis excludes employers' PRSI.
- DML = Dublin Mid Leinster; DNE = Dublin North East

Source: HSE, SLA 2009

The figures in Table 4.8 mask significant variations between agencies and between the statutory regions and across selected Section 38 agencies. This may be due to service-related reasons and client characteristics, but other staffing factors could also play a role, such as rostering and staff assignments. Nursing is the main staff category where a significant percentage of pay is composed of non-basic elements. Table 4.9 sets out non-basic pay costs by HSE region for statutory services. Even allowing for potential differences in the profile of services and clients across different regions, the HSE DML region spends a higher proportion of the disability pay bill on non-basic pay elements compared to other regions. It should be noted that many of the additional pay components are currently treated as fixed pay components (e.g. arrears, night duty and weekends) and as such are not considered discretionary pay elements. Nonetheless, the distribution of pay costs as presented in Table 4.8 highlights the extent to which the pay bill comprises non-basic elements and the variation in those elements across regions.

Table 4.9: Non-basic pay costs by region for HSE statutory services, 2009

HSE region	Total pay €m	Non basic pay €m	% of pay costs relating to non-basic elements
HSE DML	37.8	12.1	32.0%
HSE South	42.0	6.4	15.2%
HSE West	62.1	8.9	14.3%
HSE DNE	64.7	13.4	20.7%

Notes:

- This analysis excludes employers' PRSI.
- DML = Dublin Mid Leinster; DNE = Dublin North East

Source: HSE, Disability Finance Book, 2011, p. 15,2,3

4.5.2 PROFILE OF NON- PAY COSTS

Non-pay costs account for approximately 15%-17% of total expenditure across the statutory and voluntary sectors (based on 2009 data). However, there are variations in the non-pay cost percentage per provider. DFB analysis of statutory and ERHA Section 38 providers showed that the non-pay cost percentage was in the range of 12%-23%. The data questionnaire showed non-pay cost percentages varying from 7% to 25%. Non-pay cost percentages may vary for valid service-related reasons.

Table 4.10 presents the main non-pay cost elements across the different sectors based on DFB data. The cost drivers for non-pay costs depend on the types of services provided and the care requirements for clients. The distribution of non-pay costs by cost type vary between the statutory and voluntary services; for example, the statutory side carries a disproportionately high cost of medical and surgical supplies, a cost which is not incurred to the same degree by the former ERHA voluntary agencies. Conversely, for the voluntary agencies, there is a high cost for maintenance. This could be due to older buildings held by these agencies. However, not all maintenance costs could be properly coded to disability services. Proportionately more expenditure is also incurred on transport in the voluntary sector.

Table 4.10: Distribution of top 10 non-pay cost elements by sector (excluding Section 39 and non-ERHA Section 38)

Former ERHA S.38 agencies		HSE	
Cost type	%	Cost type	%
Maintenance	15.3	Medical/surgical	12.7
Office expenses/rent	11.0	Professional Services	10.5
Catering	10.8	Office expenses/rent	9.5
Miscellaneous	10.0	Miscellaneous	9.1
Heat, power and light	8.6	Catering	7.9
Cleaning and washing	5.7	Transport (patient)	7.6
Insurance	4.7	Maintenance	7.4
Travel and subsistence	4.1	Heat, power and light	5.5
Education and training	4.0	Suppliers and contracts	5.0
Transport (patient)	4.0	Education and training	4.9

Source: HSE, Disability Finance Book, 2011, p. 19

The Terms of Reference for this VFM Review required analysis of specific types of overheads and costs, such as advertising and profile-building. The HSE's accounting systems do not record non-pay costs in a way that aligns with these cost headings. In addition, the HSE do not maintain non-pay information for Section 39 providers or Section 38 providers outside the former ERHA region. The data questionnaire, previously mentioned in this chapter, was issued to collect data to address these gaps. Analysis of non-pay information submitted to date by voluntary providers (covering approximately €230m of non-pay costs) for the purposes of this Review shows that maintenance costs, catering, utilities and rent are the most important categories of non-pay cost.

Certain categories of non-pay costs are specifically mentioned for analysis in the Terms of Reference:

- administrative costs;
- management structures;
- research, advertising;
- profile-building (i.e. public relations);
- infrastructure costs.

The combined total of advertising, staff recruitment, research costs and public relations accounted for less than 1% of total non-pay costs across the voluntary agencies that participated in the survey (*see Appendix 3 for a more detailed breakdown of these costs*).

The total level of expenditure on research is €0.2m. There are no available data regarding the types and purposes of the research, i.e. whether this research relates to public policy or specific scientific health research issues. The NDA and HRB also carry out research related to disabilities. The NDA focuses on policy issues, whereas the HRB publishes reports related to activity levels and demand for services. In this context, it should be noted that there is scope for overlap and duplication. A background paper, entitled *Cross-cutting Issues in relation to Science, Technology and Innovation (STI)*, prepared by the CEEU for the Special Group on Public Service Numbers and Expenditure Programming in 2009, recommended that '*there is scope for greater coordination in order to bring greater efficiency to STI expenditure*' (CEEU, 2009).

The relevant non-pay costs for the Terms of Reference, as sourced from the data questionnaires, are highlighted in *italics* in Table 4.11.

Table 4.11: Main (top 15) non-pay costs for voluntary agencies and selected ToR-related costs as reported in data questionnaires

No.	Cost element	Selected voluntary agencies € m
1	General maintenance	24.2
2	Catering and Food	19.2
3	Rent/leasing accommodation	16.5
4	Utilities	16.5
5	Other	15.8
6	Service user transport	10.9
7	Office equipment, services, supplies	9.8
8	Insurance	8.9
9	Laundry and cleaning	7.5
10	Medical/Surgical Equipment, Services & Supplies	6.8
11	Professional Services	6.4
12	Vehicle maintenance and running costs	5.9

No.	Cost element	Selected voluntary agencies € m
13	Drugs/medicines	5.8
14	Household equipment and supplies	5.3
15	Service user payments	4.9
ToR	Advertising	0.7
ToR	Public Relations	0.3
ToR	Research	0.2

Note: Data extracted from €197m of non-pay costs for voluntary agencies returning questionnaire data.

Source: Non-pay data questionnaires, 2011

Transport is also an important cost element for providers. A significant amount of money is invested in own-delivered service user transport, particularly by the Section 38 agencies. The rationale for investment is that there is no alternative transport system available and that, in some cases, public transport is not suitable for all people with disabilities. According to the non-pay data questionnaires, voluntary agencies spent €23m on all transport-related costs in 2009, mainly on service user transport and vehicle running costs.

Infrastructural costs for questionnaire respondents amounted to €57m. The key expenditure headings are general maintenance, utilities and rent/leasing.

PROFILE OF NON-PAY COSTS

KEY FINDINGS

- ✓ The distribution of non-pay costs by cost type varies between the voluntary and statutory sectors. [Finding 4.13](#)
- ✓ Expenditure on research, advertising and profile-building (PR) is negligible in the context of non-pay spending. [Finding 4.14](#)

KEY RECOMMENDATIONS

- ✓ The HSE should agree upper limits on non-pay percentages for the most important key cost element headings, differentiated by services where appropriate, as a useful addition to the ongoing accountability framework for voluntary providers. This should be concluded by end Quarter 1, 2013. [Recommendation 4.9](#)
- ✓ Agencies should be required, and facilitated, by the HSE to explore opportunities to share services, including clinical, therapeutic and back office services (e.g. leasing buildings) as appropriate. This requirement should be mandatory and made a condition of Exchequer Grant Aid Agreements and Service Level Arrangements from 2013. [Recommendation 4.10](#)
- ✓ Agencies should introduce formal tendering arrangements for services, including professional services, where these arrangements do not currently exist. Joint procurement mechanisms at national level should be used. For example, the

HSE should investigate the potential savings of central HSE procurement of significant items of expenditure for the agencies through the NPS (e.g. energy costs) or HSE purchasing frameworks. Service arrangements currently require funded agencies to utilise HSE contracts, but the HSE should publish information illustrating the extent of take-up by voluntary agencies of HSE and NPS central purchasing frameworks by end Quarter 1, 2013 to ensure best value is achieved in procurement expenditure. [Recommendation 4.11](#)

- ✓ As a medium-term measure, public transport should be used in all circumstances where it is an option. This can have benefits in terms of personal development for the service users and is also more efficient. This VFM Review is aware of some day services where almost all service users avail of public transport to attend services. Since clients in receipt of Disability Allowance are automatically entitled to the Free Travel Pass, there should be no additional cost burden at the individual level. [Recommendation 4.12](#)
- ✓ Similarly, service providers should examine the possibility of sharing transport resources on a cost-neutral basis with other local service providers/community groups, taking into account the recent announcement of plans by the Department of Transport to integrate local transport services. [Recommendation 4.13](#)
- ✓ The introduction of charges for transport to services (in the form of fares linked to distance) should be considered, even at a minimum contribution level. [Recommendation 4.14](#)
- ✓ As a general rule, policy or scientific research funded by agencies through HSE allocations should be commissioned directly by the HSE. In deciding research priorities, the HSE should be informed by a 'whole of Government' perspective, consistent with the recently published *Research Prioritisation Plan* (i.e. taking account of research underway at university, agency and hospital levels). Research not commissioned by the HSE as part of the SLA process should not be funded through HSE allocations from 2013. [Recommendation 4.15](#)
- ✓ To ensure that duplication across the NDA, HRB and publicly funded disability agencies is avoided, the HSE should engage with these bodies to determine research priorities and needs. In particular, research commissioned by the HSE (if any) in this way from the HRB and NDA from 2013 onwards should not be remunerated, but rather funded through their ongoing revenue allocations. [Recommendation 4.16](#)

4.6 ADMINISTRATION

A common measure of efficiency is the level of administration cost. This normally comprises pay (management/administration staff) and non-pay costs (administrative overheads). An attempt was made to develop an analysis of total administration costs (pay and non-pay) by provider and the administration cost percentage. However, this proved not to be possible due to the difficulty of collating non-pay administration costs through the non-pay questionnaire. The questionnaire attempted to apportion non-pay costs by direct and indirect cost headings, but an overall analysis extracting administration costs was not feasible since cost apportionment was not completed in a consistent way by all providers. The remaining analysis focuses on pay cost only. Table 4.12 shows the range in HSE management/administration pay costs by region across its own services for 2009. There is no data source that captures both pay and non-pay administration costs. Data are available regarding pay administration costs for the HSE and certain Section 38 providers. As seen in Table 4.12, HSE DNE reports the lowest percentage management/administration costs (6%), whereas HSE South records almost three times as much (17%). Overall, the total management/administration pay cost for all regions is 10% of the total pay bill.

Table 4.12: Distribution of HSE management/administration pay costs by HSE region across statutory services, 2009 (excludes corporate administration costs)

Pay cost type	HSE DML %	HSE South %	HSE DNE %	HSE West %
Nursing/medical/dental	51	54	55	46
Maintenance/technical	1	1	2	2
Support services	39	28	37	41
Management/administration	9	17	6	11
Total	100	100	100	100

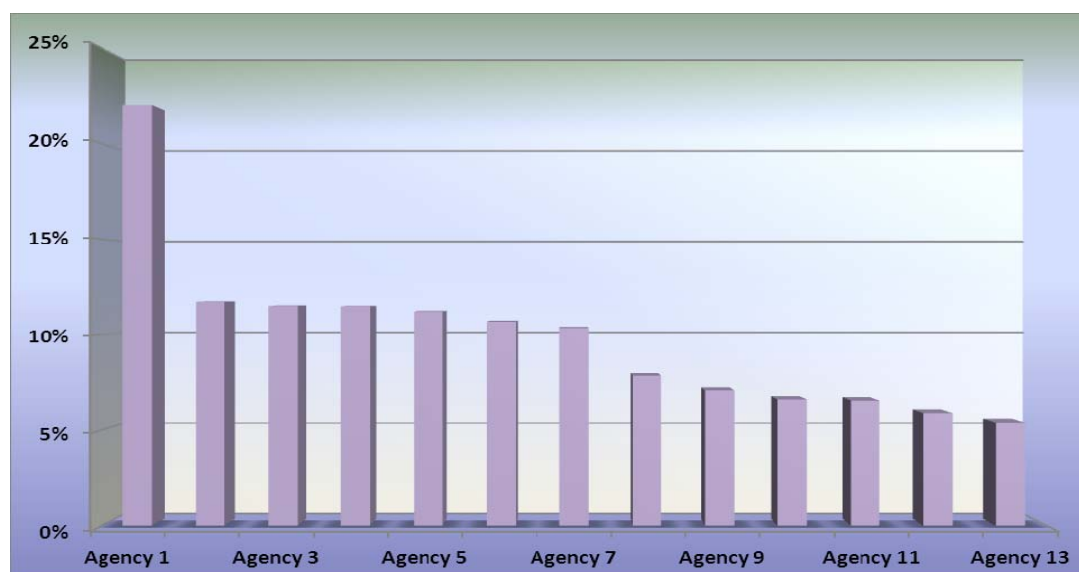
Notes:

- Management/administration pay costs do not include HSE corporate management costs.
- Excludes superannuation income.

Source: HSE, Disability Finance Book, 2011, p. 12(2)

Similar variation in management/administration pay costs may be observed for the voluntary sector where the same type of data is available (certain Section 38 agencies). Figure 4.3 shows the management/administration pay costs as a percentage of total pay costs for a number of agencies. The percentages range from just over 5% to over 20%, although a large number of agencies are clustered in or around 10%-12%. Ideally, management/administration pay costs should be minimised in favour of spending on front-line supports. Changes in management structures and efficiencies in administrative staffing levels (e.g. better use of IT) can contribute to this.

Figure 4.3: Management and administration pay costs for Section 38 agencies in the former ERHA region



Notes:

- Management/administration pay costs do not include HSE corporate management costs.
- Excludes superannuation income.

Source: HSE, Disability Finance Book, 2011, p. 12(2)

Data on management/administration pay costs is also available from the non-pay questionnaires. However, this data is heavily qualified since the full range of management costs (including CEO costs) may not be included if these are funded from fund-raising or other sources. Further, it is not clear if data on senior management costs contained in the SLA data fully reflect actual remuneration levels since the SLA represents HSE funding only.

The data support the contention that the percentage of pay spent on management/administration declines as the size of the organisation increases, as set out in Table 4.13. It should be noted that some organisations will have proportionately higher management costs because of their model of service. Management costs are best compared within relevant peer groups.

Table 4.13: Management, clerical and administration pay as percentage of total pay by size of agency, 2009

Expenditure band	Management		Clerical/Administration	
	%	€	%	€
Under €5m	7.4	€7,424,076	9.8	€9,799,392
€5m – €10m	6.4	€2,694,252	4.2	€1,774,065
€10m – €25m	5.2	€9,528,697	7.9	€14,543,717
€25m – €50m	4.4	€6,893,133	8.7	€13,545,030
€50m – €75m	4.2	€2,568,247	6.7	€4,088,096
€75m – €100m	2.7	€4,677,475	5.2	€8,986,252
Over €100m	3.7	€12,252,867	5.2	€17,201,107
Total	4.4	€46,038,748	6.7	€69,937,659

Source: HSE, SLA 2009

Table 4.14 shows the average management/administration cost percentage for agencies banded by total pay expenditure and by disability agency type (as a rough proxy for care setting). The management/administration percentage appears to be higher for P&S services overall. For example, the average percentage for management/administration costs of total pay costs is 21% across all P&S agencies compared to a figure of 11% across all ID/Mixed agencies.

Table 4.14: Average management/administration pay costs percentages by type of agency, 2009

Expenditure band	No. of agencies	ID/Mixed agencies	P&S agencies	Average for all types
Under €5m	35	13%	18%	14%
€5m – €10m	9	11%	34%	17%
€10m – €25m	12	9%	19%	11%
€25m – €50m	6	11%	19%	12%
€50m – €100m	1	10%		10%
Over €100m	3	7%		7%
Total	66	12%	21%	13%

Notes:

- It should be noted that the management/administration cost percentage for certain bands are based on a small number of observations.
- Agencies with pay expenditure less than €1m are excluded from this table (approx. 43).

Source: HSE, SLA 2009

There are options to reduce administration costs at the broad sectoral level. For example, agencies can amalgamate to reduce support costs. However, there are disadvantages with this approach in terms of potentially reduced consumer choice and the difficulties in merging organisations with different service locations and property portfolios. One-off costs can arise and savings may not be achieved for some time.

To date, there has been little evidence of mergers of voluntary agencies in Ireland. In the UK, there are more mergers of charities in general. Since 2009, the Charity Commission's Mergers Unit has seen a 150% increase in the cases it deals with. For example, the National Centre for Independent Living, Radar and Disability Alliance have announced that they will merge to form the UK's largest disability organisation, led by disabled people themselves.

An alternative to mergers involves collaboration, by sharing resources and staffing. In the absence of details about the extent of efficiencies achieved through collaboration and shared services, it is difficult to draw any conclusions about the best approach to generation of administration savings. Savings may vary on a case-by-case basis.

ADMINISTRATION COSTS

KEY FINDING

- ✓ There is wide variation in the percentage of the pay bill spent on management/ administration costs across the regional statutory services and, to a lesser extent, across some voluntary providers where data are available and also in different care settings. [Finding 4.15](#)

KEY RECOMMENDATION

- ✓ The HSE should investigate whether or not there are transferable best practice lessons from the low administration costs in the HSE's statutory services in the DNE region. [Recommendation 4.17](#)

4.7 GEOGRAPHICAL DISTRIBUTION OF RESOURCES

Section 4.3.3 outlined the regional allocation of expenditure. This section provides more detailed analysis on the distribution of staffing, agencies and expenditure by region. Table 4.15 shows the distribution of agencies by region and size. The DML and DNE regions contain more of the larger agencies compared to the other regions. An analysis of agency distribution by region is an important consideration for any future policy changes designed to increase client choice (*see Chapters 5 and 7*). Ideally, this should be at Local Health Office (LHO) level, but robust data at this level are not available (*see Section 4.3.3*). The availability of other agencies offering similar services in a given area will influence the level of practical choice for clients, as well as the potential for contestability of services in the short term.

Table 4.15: Number of voluntary providers by HSE region and total pay cost, 2009

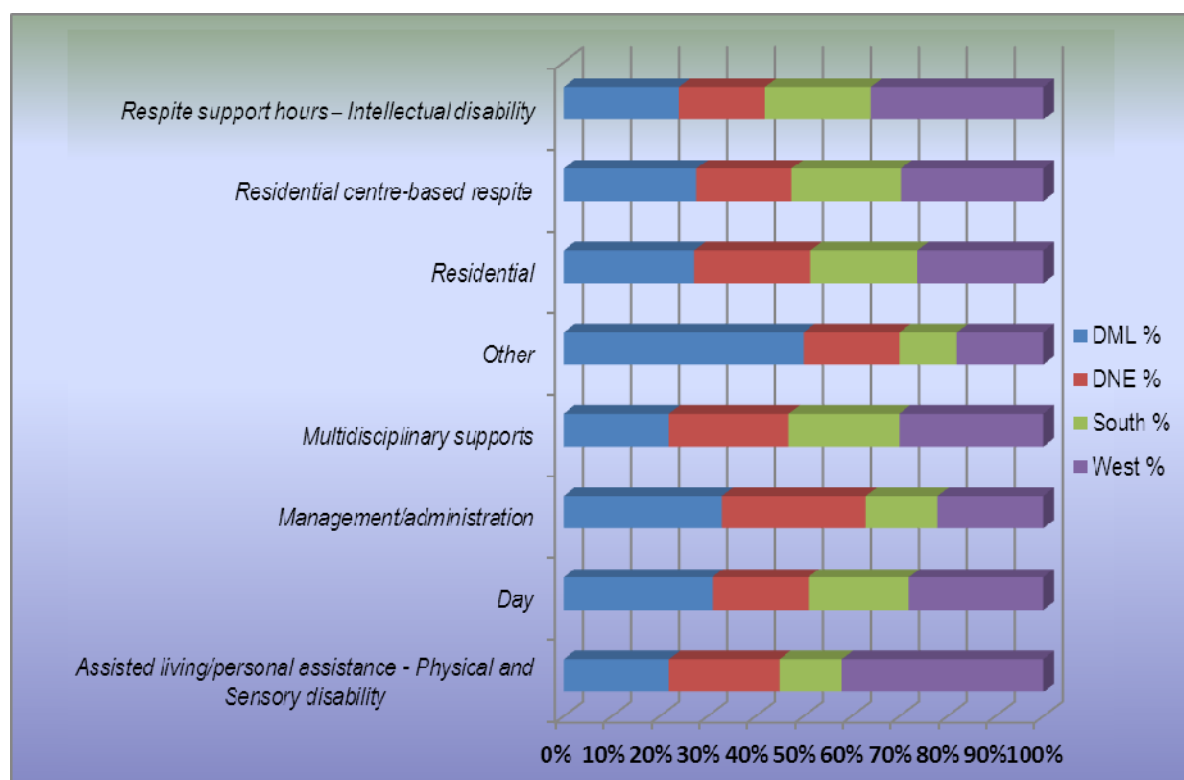
HSE region	€50m+	€20 – €50m	€5 – €20m	€1 – €5m	> €1m	Total
DML	1	5	8	15	23	52
DNE	3	1	3	11	16	34
South	1	1	10	10	8	30
West	1	3	5	7	21	37
Total	6	10	26	43	68	153

Note: In order to analyse the number of agencies that operate in each of the regions, Table 4.15 does not count agencies in the same way as in Table 1.1. In Table 4.15, agencies that operate across regions are counted separately within each region and the total pay cost is the cost within that region. Agencies with more than one SLA within a region are counted once within the region.

Source: HSE, SLA 2009

Figure 4.4 outlines the distribution of different services by region by looking at the percentage distribution of staff, regardless of sector, across the different services in each region. There is a lower proportion of staff working as ALS/PA (Assisted Living Service/Personal Assistance) in the HSE South region, although total staff is low for this category (927). There is also a lower proportion of all administration staff working in the HSE South region. DML absorbs the highest proportion of day services-related staff. It is not possible to explain these variations without more background information and given the potential biases in the data (e.g. staff in the category labelled 'Other').

Figure 4.4: Percentage distribution of all WTE staff (voluntary and HSE) by HSE region and programme type, 2009



Notes:

- Agencies may be counted twice in the above numbers since they operate across regions.
- There was a lower completion rate of SLAs in the South region, with €24m or approximately 7% of gross regional expenditure not accounted for through the SLA process for the purposes of the VFM Review.

Source: HSE, SLA 2009

Ideally, a comparison of demand for disability services and actual services provided would be based on the number of clients receiving services and those on waiting lists, compared to patterns of service delivery. Such data are not available. Instead, Table 4.16 shows general data on the general population as a proxy for potential demand and WTE staff as a proxy for service provision. There seems to be less disability staff assigned in the HSE DNE region and more in HSE West than would be expected given the local population and assuming relatively similar levels of disability prevalence across the regions.

Table 4.16: All disability staff per capita of population 2006, by HSE region

	HSE DML	HSE South	HSE DNE	HSE West
WTE staff 2009	7,105.81	5,546.04	4,845.56	6,370.97
Census of Population 2006	1,216,848	928,619	1,081,968	1,012,413
Population per WTE staff	171.25	167.44	223.29	158.91

Note: Population data from Census 2011 is not yet available by HSE region. Census 2006 data have been used instead.

Source: Census 2006 and HSE, SLA 2009

A common approach to considering efficiency is an examination of capacity compared to actual service delivery. The SLA data do not facilitate an analysis of capacity against actual for any of the services apart from residential services. Table 4.17 outlines an analysis of capacity for residential services based on the data provided.

Table 4.17: Capacity compared to actual for residential services, 2009

	Totals
Capacity in WTE places	8,674
Actual users	8,790
Percentage	101%

Source: HSE, SLA 2009

It should be noted that there are significant reliability issues associated with the figures in Table 4.17. For example, the information regarding actual users represents point-in-time data as at 28th February 2009, whereas the capacity information represents WTE places available over the year. In addition, since the HSE did not issue detailed guidelines with the SLA template explaining how the various fields were to be completed, it is not clear how agencies completed the fields (e.g. agencies may have calculated WTE places in different ways). Therefore, the comparison of capacity and actual is not useful for drawing conclusions. This highlights the need for improved data collection as part of the SLA dataset (*see Chapter 8*).

GEOGRAPHICAL DISTRIBUTION OF RESOURCES

KEY FINDING

- ✓ There are variations in regional resource allocation in terms of WTE staffing, which warrant further investigation. [Finding 4.16](#)

KEY RECOMMENDATION

- ✓ The HSE should be able to match resource allocation to the location of clients so that a proper assessment of geographical resource allocation (at Local Health Office level) can be made. This would address the problem where funding routed through one LHO relates to clients located in neighbouring regions. The HSE should attach a geographical marker to client identification numbers to facilitate this analysis. [Recommendation 4.18](#)

4.8 EFFICIENCY INITIATIVES

The preceding sections relating to non-pay costs and administration costs have highlighted areas of expenditure where cost control and economy are important. As allocations for voluntary agencies have reduced in recent years as a result of budgetary consolidation at national level, some of these agencies have taken initiatives to reduce costs. As part of a pilot questionnaire exercise relating to trend performance data, participating agencies were asked to give instances of efficiency measures taken and how savings were achieved to demonstrate the extent of their efficiency improvements. Although insufficient data were gathered to provide evidence for a detailed case study, the main types of efficiency measures taken are summarised in Table 4.18.

Table 4.18: Efficiency initiatives taken by voluntary agencies

Initiatives	
Management	<ul style="list-style-type: none"> Reduction of senior management headcount and restructuring. Reassignment of management duties. Introduction of lean management system.
Staff	<ul style="list-style-type: none"> Review of all staff rosters leading to efficiencies. Pay savings owing to strict application of the sick leave scheme. Reduced bank holiday double pay hours in the Care Centre. The negotiation of flexible contracts of employment with staff. Outsourcing of specialised clinical supports. Non-payment of increments. Significantly lower non-pay benefits, e.g. significantly lower paid sick leave entitlement, lower premium rates for anti-social hours and a standard 25 days' annual leave. Covering maternity leave and sick leave from existing staff. Freezing a number of non-service delivery posts. Non-replacement of staff and re-organisation of staff activities. Putting all staff in the organisation on fully vouched out-of-pocket expenses only. Reduction in the mileage rates paid by agencies to rates below those paid to staff working in the civil service. Travel management protocols implemented to identify non-essential travel and encourage use of carpooling/public transport. Significant reduction in training costs through participation in the Skills VEC programme. A review of the utilisation of staff resources throughout the 24-hour day was undertaken, with a particular focus on identifying critical times of the day. This has led to changes to rosters, staff roles and location, and generally a change of mind-set, which has seen much greater flexibility and an openness to change. Use of Community Employment Schemes and volunteers.

Initiatives	
Administration	<ul style="list-style-type: none"> • Implementation of integrated it system for HR – Personnel, Time & Attendance, Rostering, Payroll and Business Intelligence. Also consolidation of a number of administrative functions, such as Accounts, Payroll and HR into Central Office. • Centralised procurement in relation to various headings of expenditure, e.g. information technology, rents on leased properties, waste services, energy costs, stationery, office goods, health and safety, vehicle fuel, lift servicing, fire equipment, cleaning and sanitation supplies. • Implementation of incident and accident monitoring, resulting in lower insurance costs. • Zero Based Budgeting System. • Ongoing monitoring of all costs, including insurance costs, catering, cleaning, utility costs and suppliers, IT contracts. • Introduction of initiatives in relation to tele-conferencing, tele-working, reduced expenditure on postage and stationery through use of e-mailed pay slips, internal email, online forms, etc.
Facilities	<ul style="list-style-type: none"> • Moving from rented accommodation by consolidating services in own premises. • Linking into the Government VPN network for telecommunications pricing with Eircom and Vodafone, which has resulted in substantial cost savings. • Sharing office and other facilities with other organisations. • Outsourcing of buildings' maintenance and cleaning services and IT support. • Leasing of vehicles and renting of properties, as opposed to purchase of same. • Comprehensive review of transport provision and fleet size. • Renewable energy and heat efficiency measures. • The use of vehicles from the services fleet towards staff travel.
Shared	<ul style="list-style-type: none"> • Continuing and developing the shared service initiative with another service provider around the provision of resources.

Source: Trend questionnaires pilot process, 2010

EFFICIENCY INITIATIVES

KEY RECOMMENDATION

- ✓ Some examples of efficiency initiatives across the statutory and voluntary sectors have been brought to the attention of the VFMPR Project Team. The HSE should select some examples of efficiency improvements and develop the evidence base relating to the extent of efficiencies achieved and how these were achieved, and publish a summary document by end 2012.

[Recommendation 4.19](#)

Chapter 5: How efficient are disability services?

The purpose of this chapter is to provide a broad description of service provision, define service outputs, discuss how these outputs may be analysed and costed, and consider trends in output delivery. A methodology for producing unit costs is defined and applied to the Service Level Arrangement (SLA) data received from the HSE. The data are analysed under a number of headings. Potential factors influencing cost variations are examined and conclusions drawn where possible.

5.1 OUTPUTS

5.1.1 OVERVIEW OF SERVICE PROVISION

Service provision is diverse and multi-faceted because of the nature and extent of the Disability Services Programme. In line with the high-level objectives of providing people with the support to live normal lives and maximise their potential, the response of service providers to this need is necessarily as diverse as the individuals who avail of those supports. Services also encompass the full gamut of an individual's life, in a different and more extensive way than services provided by any other part of the health sector.

Services have evolved in an ad hoc fashion for a variety of historical reasons, described in Chapters 2 and 3, and are currently in progression from the traditional more institutionalised model to an emerging more personalised model, the essential difference being a move from the provision of services to the provision of supports. This evolutionary process is a continuum and agencies are at different stages of their journey along that continuum.

This paradigm shift from providing services to providing supports has proved difficult for the VFMPR Project Team to address and consider in relation to its efficiency. The collection of data for the Review was challenging and some outputs could not be readily defined (*see Section 5.2.2 and Appendix 6 on 'Units of Output'*). The quantification of complex outputs (including respite, early intervention service, home support, personal assistance and multidisciplinary therapies) and outcomes was not feasible within the resources available to the Review. These complex outputs comprised 27% (€332 million) of total pay expenditure (€1.2 billion), whereas better defined outputs (in particular residential services and, to a lesser extent, day services for people with intellectual disabilities) accounted for 64% (€781 million). The remaining 9% (€112 million) was expended on management and administration (*see Appendix 11, Table 14 for expenditure breakdown*). As a result, the Review concentrated on the collection and analysis of data on outputs that represented the bulk of the funding. This was a pragmatic decision taken out of necessity and does not represent a judgement call on the services and supports not analysed. The identification of services and supports that are not currently defined, measured and costed on a national basis is, in itself, a useful finding (*see Chapter 8 for recommendations*).

5.1.2 GRANTS TO SMALLER PROVIDERS (GRANT AID AGREEMENTS)

Grant Aid Agreements (GAAs) are signed with service providers when the grant is less than €250,000. GAAs are generally signed with smaller niche organisations. Details of the funding provided and the type of services funded are given in Tables 5.1 and 5.2. In view of the amount expended on foot of GAAs, the diverse nature of the services provided and the large number of agencies involved, it was not feasible to examine the efficiency and effectiveness of the GAA process as part of this Review.

The HSE provided details of 204 GAAs signed in 2009, with a total allocation of €11.96m.

- The lowest grant given on foot of a GAA was €282.
- The total number of agencies with GAAs was 131. There were multiple agreements with some agencies. In some cases, the combined total which an agency received on foot of GAAs exceeded €250,000.
- There are agencies with both GAAs and service level arrangements (SLAs).

Table 5.1: Summary of Grant Aid Agreement funding, by child/adult service, by HSE region, 2009

Child or adult service	Region	Total no. of service users	Total funding	No. of Grant Aid Agreements
Adult	DML	187	€696,340	12
	DNE	465	€1,596,751	13
	South	496	€3,038,716	30
	West	1,030	€3,112,824	43
Total		2,178	€8,444,631	98
Children	DML	58	€198,131	4
	DNE	266	€236,554	9
	South	687	€545,051	10
	West	398	€356,123	33
Total		1,409	€1,335,859	56
Mixed adults and children	DML	389	€470,951	12
	DNE	5,504	€570,390	14
	South	2	€675,511	5
	West	607	467,589	19
Total		6,502	€2,184,441	50
Grand Total		10,089	€11,964,931	204

Source: HSE

Table 5.2: Summary of services funded by means of Grant Aid Agreements, 2009

Programme detail	Total no. of service users	Amount of HSE funding received	No. of services funded
ALS/PA Support	189	€743,395	5
Day Activation programme	97	€195,360	1
Day Care/Day Activation Programme	192	€639,968	10
Day Child Education and Development Centre	27	€142,952	4
Day Community Participation Programme	56	€112,408	3
Day Rehabilitative Training	31	€386,364	3
Day Sheltered Programme	62	€547,365	5
Day Special Pre-school	444	€364,944	8
Home Support	5	€25,457	2

Programme detail	Total no. of service users	Amount of HSE funding received	No. of services funded
Management/Administration	5,378	€726,919	9
Multidisciplinary Early Intervention	10	€144,000	1
Multidisciplinary Support Other	1,060	€1,017,292	12
Pre-school Support	24	€83,270	17
Residential 5 day Community House	1	€43,468	1
Residential 7 day Community House	26	€718,507	9
Residential 7 day Institutional/Residential Centre	51	€1,014,817	9
Residential 7 day Other	13	€1,881,968	14
Residential Respite Centre-based	5	€1,269	1
Summer Camp	1	€14,000	2
Other*	2,417	€3,161,210	88
Total	10,089	€11,964,933	204

* Services provided under 'Other' include advocacy, counselling, information help lines, support programmes, education supports and sport clubs.

Source: HSE

GRANT AID AGREEMENTS

KEY RECOMMENDATIONS

- ✓ The practice of signing multiple Grant Aid Agreements and/or Service Level Arrangements should be phased out as the HSE is re-organised. This will reduce administrative burden on both the HSE and service providers, and give the HSE oversight, at national level, of all funding provided by it to each service provider. [Recommendation 5.1](#)
- ✓ The governance arrangements in place to support Grant Aid Agreements were not examined as part of this Review. The HSE should apply the governance recommendations in this Review to GAAs where appropriate. [Recommendation 5.2](#)

5.1.3 PROVISION OF SERVICES BY PRIVATE FOR-PROFIT PROVIDERS

This Review has found that €21.7m (or 1.25% of the net expenditure on disability services) was paid in 2009 to 105 private for-profit providers for the provision of a variety of services, including residential, day, home support and respite (see *Table 5.3*).

- Payment amounts ranged from €407 to €4.5m.
- 6 providers received payments of over €1m.
- 15 service level arrangements (SLAs) were in place.
- The average payment was €206,725; the median payment was €56,703.

Table 5.3: Expenditure on private for-profit providers by HSE region, 2009

HSE region	Expenditure	No. of providers per region
DML	€10,265,499	48
DNE	€6,725,948	24
West	€3,041,612	33
South	€1,673,168	10
Total	€21,706,227	115*

* The total number of for-profit providers nationwide was 105. Some providers provide services for more than one HSE region.

There is significant variation in the use of private for-profit providers between HSE regions, ranging from 48 providers in DML to 10 in the South. The average cost also varies considerable, from just over €92,000 in HSE West to €280,000 in DNE. Five providers are in Northern Ireland and the UK.

Information is not available on the number, age or disability of clients who are receiving services from private for-profit providers, the service provided or the outcomes for the service users. It is therefore not possible to comment on the efficiency or effectiveness of the services provided. However, most of the service providers are described as nursing homes and it is reasonable to assume that they are providing residential services. One advantage of this is that private nursing homes are subject to HIQA inspections and people residing in them are currently the only people with disabilities whose residential service is subject to any statutory standards and inspection.

There are no clear guidelines or protocols for deciding when to use private providers or for contracting them once it is decided to use private provision. It is notable that only 15 service level arrangements (SLAs) are in place. However, it should be noted that a review of SLA documentation was carried out in 2011 and that the National Standard Suite of Governance documentation now includes a service arrangement for use with commercial for-profit organisations providing personal health and social services.

PRIVATE FOR-PROFIT PROVIDERS

KEY FINDINGS

- ✓ A small, but significant amount of the disability budget is used to buy services from private for-profit providers. It is not possible to comment on the efficiency or effectiveness of the services provided in the absence of information on the nature or quantum of the services provided. [Finding 5.1](#)
- ✓ Private for-profit nursing homes providing residential services to people with disabilities are subject to inspection by HIQA. [Finding 5.2](#)

KEY RECOMMENDATIONS

- ✓ Commissioning, market-shaping and capacity-building expertise should be developed within the HSE (*see also Chapter 3*). [Recommendation 5.3](#)
- ✓ A national protocol to govern the use of private for-profit providers should be drawn up by the HSE and robust service level arrangements should be put in place with each service provider. [Recommendation 5.4](#)
- ✓ The HSE should develop protocols and practices to ensure that private for-profit providers are required to provide the same level and quality of service as applies to the statutory and voluntary sectors, and should be subject to all relevant recommendations in this and other relevant reports. [Recommendation 5.5](#)
- ✓ Sufficient information should be collected by the HSE on services that have been commissioned or procured to allow cost-effectiveness to be analysed and monitored on an ongoing basis. [Recommendation 5.6](#)
- ✓ The resource allocation model recommended in this chapter should be applied by the HSE to private for-profit providers (*see Section 5.2.2*). [Recommendation 5.7](#)

5.1.4 SPECIFICATION OF OUTPUTS

Outputs are classified into programme types and sub-types for the purpose of data collection and analysis, although an individual service user may receive services and supports from more than one programme or sub-programme.

The programme types collected on the SLA Schedule 3 form are Residential; Day; Residential Centre-based Respite; Assisted Living and Personal Assistant Service; Multidisciplinary Supports; and Other.

Residential services

Residential care is available where it is not possible for a person with a disability to live independently or with his or her family. Residential services are provided to almost 8,500 people through approximately 1,200 service units (i.e. individual locations). They are provided in a variety of settings, such as independent and semi-independent living, community group homes and residential centres on a 5-day, 7-day or shared care basis, with high, moderate, minimum or low support.

Expenditure in 2009 on residential services for people with intellectual disability amounts to €371m, while expenditure on residential services for people with physical and sensory disability totals €59m. Within residential services, the largest grouping of service users are those who avail of high support 7-day residential services (1,537 people living in 282 service units) and absorbs most funding (€191m). The numbers availing of 5-day residential services has been decreasing and now totals a little over 300 people in 57 service units, at a cost of €11m. The bulk of expenditure is now on 7-day services and is equally divided between the larger institutional facilities and the more domestic-scale community houses.

Respite services

Respite care supports people to live with their families in the community and can be provided in residential and non-residential settings. It may include recreational and social activity programmes, summer camps, holiday or family breaks. Centre-based respite was provided in 2009 to around 8,000 people nationwide by over 100 agencies and 1,000 WTE staff, at a total pay cost of €52m. Information on the quantum of service provided to each person, or at each location, was not collected through the SLA process and so did not allow an assessment of cost-efficiency to be made at agency level. All that could be deduced on the basis of the SLAs was that the total pay cost per service user in centre-based respite averaged €6,500. This was not a particularly useful finding since the quantum of service received by each of the 8,000 people who availed of centre-based respite (and hence the cost per service user) would have varied widely due to a combination of individual need and local resource availability.

To fill in the gaps, questions on respite were included in the pilot trend and non-pay questionnaires issued by the VFMPR Project Team to 25 service providers. Although some useful data were received, there was insufficient detail provided to determine the comparability of the information received, whether all indirect pay and non-pay had been apportioned to the services, and if so, the apportionment methodology used. It was clear from this process, and from talking to service providers, that in general they did not keep their records in a way that would lend itself to answering the type of questions posed in the questionnaires. After careful consideration, the Project Team took the view that it would not be productive to include questions on respite services in the revised questionnaire to all agencies following the pilot exercise.

Efforts were also made to match respite data from the NIDD with SLA data, concentrating on Galway and Limerick, but due to differences in the way in which agencies and locations were recorded in both sources, it did not prove feasible to match the data in most cases. Where the data could be matched, it confirmed that the quantum of respite ranged from 7 nights per service user per year at one location, up to an average of 49 nights per person per year in one of the larger service providers. The average cost (*pay only*) of the agency that provided the 49 nights' respite per user was approximately €13,000 per person (or €260 per night). This level of cost suggests that other methods of respite provision – such as the HSE's pilot *Respite/Residential Care with Host Families in Community Settings* project (HSE, 2012b), currently providing respite to almost 600 children and adults – could prove more cost-effective than traditional centre-based respite and should be pursued.

Day services

Day services are provided to approximately 18,000 adult service users by 81 organisations, including the HSE, through more than 800 service units (some service users may access more than one type of day service or activity). Services that come under the generic heading of 'day services' are also a key component of the support services that enable clients to live within the community. Services include day activation, special high-support and special intensive day services for adults, and developmental day care for children. Work-like programmes provide a range of opportunities that include work activation, supported work in the community, personal and social development. Specialist services are provided for persons with Autistic Spectrum Disorder and those with Acquired Brain Injuries. Increasingly, a range of support services are delivered in the community to people with physical and sensory disabilities. Personal assistance services are of particular importance in enabling people with disabilities to live normal, independent and self-directed lives in the community.

Community-based therapy services

A range of community-based therapy services are provided to people with disabilities, including occupational therapy, speech and language therapy, physiotherapy and psychology.

Because of the breadth of this Review, it was not possible to examine the efficiency or effectiveness of community-based therapy services. While data on staffing numbers and locations were available to the Review, there was no common definition of what constituted a unit of output for therapy services and no regional or national database that collated or summarised data on service delivery. As a result, findings in relation to these services are necessarily high level.

In respect of factors that impinge on the cost of therapy services, virtually all therapy staff have professional qualifications and in each of the therapies provided there are more staff at senior grades than at entry level. There are almost 2 senior occupational therapists for every basic grade occupational therapist; 1.6 senior speech and language therapists for every basic grade therapist; and almost 3 senior physiotherapists for every basic grade physiotherapist. The number of therapy assistants is miniscule: about 1% of occupational therapy staff,

2% of speech and therapy staff, and 4% of physiotherapy staff. Therapy assistants are also concentrated in the HSE DML and DNE regions. There is no national training programme for therapy assistants.

This Review found that there are no national benchmarks for therapy workloads and no nationally implemented IT system to assist therapists with managing and monitoring their workloads. In the absence of national caseload benchmarks and performance measurement and management tools, any assessment of the efficiency and effectiveness of therapy services will always be problematic.

Home-based nursing supports

Home-based nursing supports are part of a range of services provided to families funded by the HSE and other service providers for children with life-limiting conditions. Approximately 1,300 children are currently affected. Many of them availing of these services also avail of other specialist hospital and community health supports and disability services.

This Review has noted the 2010 report *There's No Place Like Home – A cost and outcomes analysis of alternative models of care for young people with severe disabilities in Ireland*, which was commissioned from the Centre for Health Policy and Management, TCD, on behalf of a service provider. The report asserts that the service provided by the voluntary agency concerned is significantly cheaper than hospital-based care. It is also noted that the HSE agreed that there is no dispute about the cost of hospital *versus* home-based services. The HSE indicated that where a child needs hospitalisation, this service will be provided, but that there is no question of providing continuing care to children in an acute setting if this is not required. The HSE's policy is that children should be at home whenever they can. The costs relating to a 24-hour acute medical service will always show an unfavourable cost when compared to a home-based support service, which is an entirely different type of service provided to families for a specified number of hours.

The relevant comparison in this case is not between the cost of home support and the cost of an acute hospital place, but rather between the cost of an individual service or support provider and a similar support provided by the HSE, which has been costed at €23 per hour in the context of the HSE home care nursing package.

Other services include:

- Early Childhood/Family Support Services for children with developmental delay.
- Rehabilitative training, which provides foundation-level personal, social and work-related skills to enable participants to progress to greater levels of independence and integration.
- Specialist services for persons with Autistic Spectrum Disorder and specialist day and residential brain injury services for people with Acquired Brain Injury.
- Aids and appliances, and other aids to performing activities of daily living.
- Home Support Services to assist persons to continue to live at home and to provide respite for carers, including personal assistant service, home care assistant service and home help service.
- Other support services, which include counselling, advisory, advocacy, information and general support services.

Further details on the range of services provided to people with disabilities are given in Appendix 4.

SPECIFICATION AND MEASUREMENT OF OUTPUTS

KEY FINDINGS

- ✓ Units of output were not defined for many forms of service provision and proved to be a major obstacle to the collection of comparable information across service providers. [Finding 5.3](#)
- ✓ Therapy services are professionally provided, with a significant number of staff at senior grades. [Finding 5.4](#)
- ✓ There is insufficient information available to the HSE at regional or national levels to monitor the provision of therapy services or assess their efficiency. There is no national benchmark for therapy workloads and no nationally implemented IT system to assist therapists with managing and monitoring their workloads. [Finding 5.5](#)

KEY RECOMMENDATIONS

- ✓ Common definitions of units of output should be developed by the HSE, supported by detailed business rules, to ensure that the same information is collected in the same format across agencies. Once a firm basis for data comparison and analysis has been identified, the HSE should examine the value for money, relevance and continued fitness for purpose provided by services which could not be addressed by this Review, such as respite services, multidisciplinary services, early intervention, home support, assisted living/personal assistance, and community-based support services such as the provision of information and advocacy, peer support, intermediary and enabling activities. [Recommendation 5.8](#)

- ✓ Methods of community-based respite care provision should continue to be explored by the HSE as an alternative to residential centre-based respite. [Recommendation 5.9](#)
- ✓ A targeted study into the efficiency and effectiveness of multidisciplinary and therapy services, including grade structures and workloads, should be considered by the HSE on completion of this VFM Review. This study should build on the work of the National Coordinating Group on the re-structuring of children's disability services, and the Report of the National Reference Group on Multidisciplinary Services for Children aged 5-18. [Recommendation 5.10](#)
- ✓ The recommended study on therapy services (*see above*) should investigate the degree to which the wider use of therapy assistants may support a more efficient and effective service, and whether there is a requirement for a national accredited therapy assistant training programme (or programmes). The study should also consider the feasibility of adopting national caseload benchmarks and the role of IT systems in performance measurement and caseload management. [Recommendation 5.11](#)

Trends in output delivery

The Terms of Reference of this VFM Review required that conclusions were reached regarding performance trends in outputs. Trends in the following outputs were identified as requiring analysis: number of places available, number of places occupied, staff/client support ratio, and cost per place. Three potential sources of data were identified: the HRB, HSE and voluntary service providers. A comprehensive dataset for the years 2005-2009 was provided by the HRB, drawn from the NIDD. Data were also provided from the NPSDD, but because of coverage issues (*see Chapter 8*) the data were not sufficient to support an analysis of outputs for relevant services.

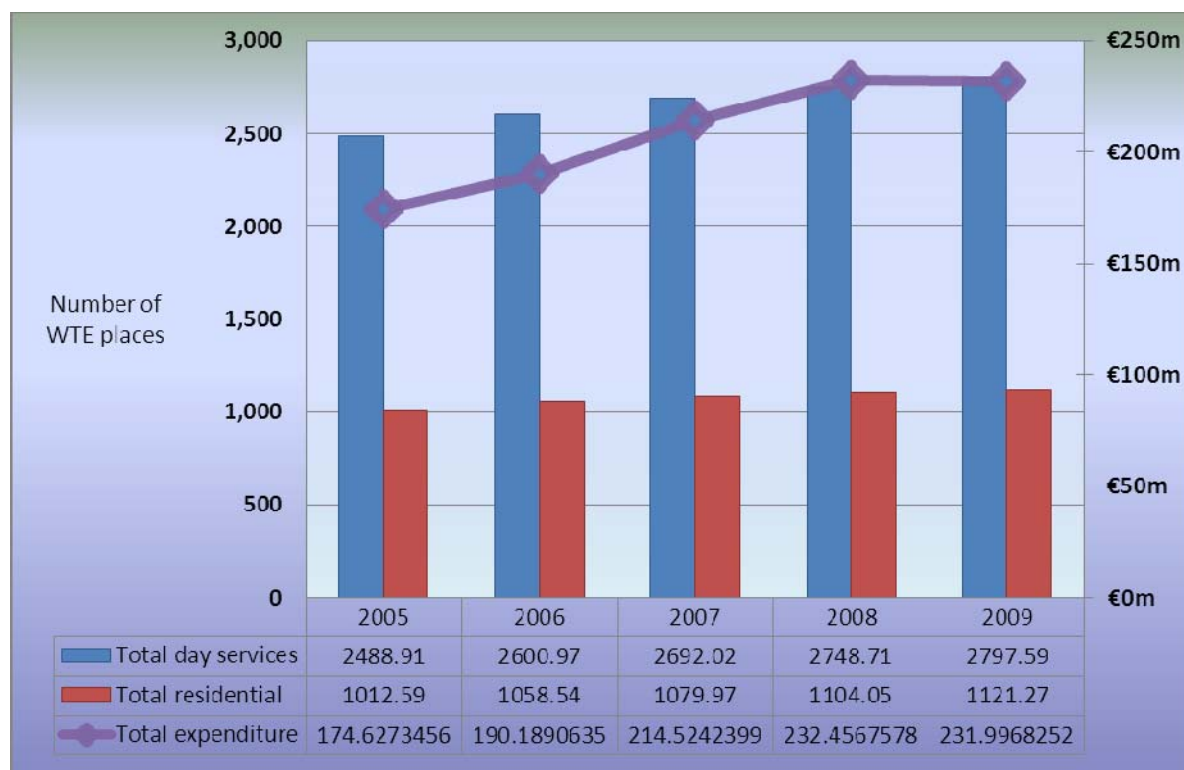
A pilot exercise was conducted to investigate the feasibility of obtaining data directly from voluntary agencies. Following the pilot, the original questionnaire was re-designed and a questionnaire seeking current (2009) data and some trend data (2005-2009) was circulated to all agencies.

The original pilot questionnaire included a question seeking quantitative information on the trend in outputs across the main output headings (i.e. day places, residential places, residential respite overnights, respite hours, multidisciplinary hours and home support hours). There was insufficient comparable information across all providers to enable a comprehensive analysis. In addition, this information did not take account of quality issues. For example, output levels may have remained static over a given period but the quality of services could have improved due to increased expenditure. For these reasons and due to the limited resources available for the Review, it was decided not to seek output information from all voluntary providers.

However, some trend output information did emerge from an analysis of pilot questionnaires submitted. Figure 5.1 compares the trend in outputs for day and residential places to the increase in annual expenditure for six providers where data was available for the main output types. The chart shows that the proportional increase in spending was greater than the rate of increase in the level of outputs provided. Without further information regarding the quality of outputs, the intensity of care requirements of clients or issues relating to baseline service provision, it is not possible to draw any definitive conclusions. But this exercise serves to

illustrate the type of trend analysis that should be carried out by the HSE in future years as a bank of trend SLA data develops.

Figure 5.1: Trend in outputs compared to trend in expenditure for six providers



Notes:

- The data relate to a sample of providers only and may not be representative of all voluntary providers.
- The data do not include all output headings for the agencies concerned.

Source: Pilot trend data questionnaire issued by VFM Project Team

Table 5.4 shows the trend in the number of service users accessing different services as reported by 77 agencies in response to the questionnaire. The data show an increase of 33,148 in the number of service places being accessed in the period, but this figure should be treated with caution because some service users would access more than one type of service or place (for example, one individual could be receiving a standard day service, multidisciplinary therapies and respite service). The main growth in numbers has been delivered by the Section 39 agencies, with the Section 38 and HSE services showing smaller levels of increase. This reflects the analysis of the trend in expenditure shown in Figure 4.1 in Chapter 4, which demonstrated that the HSE expenditure showed little change over the period, while non-statutory agencies (Section 38 and Section 39) increased.

The main increase in services provided was in the area of multidisciplinary therapies, respite services and day services.

Table 5.4: Trend in number of service users accessing day, residential, respite and other services, 2005-2009 (based on 77 questionnaires)

Service	2005	2006	2007	2008	2009	Change 2005-2009
5-day residential service	397	416	413	443	449	52
7-day residential service	5,563	5,708	5,904	5,990	6,369	806
Day services	12,361	12,860	16,286	18,628	19,344	6,983
Multidisciplinary therapies	15,964	17,101	22,078	23,904	32,686	16,722
Residential respite	3,790	4,109	4,326	4,449	5,165	1,375
Other respite services	2,171	2,326	2,607	3,002	6,891	4,720
Other services	-	-	-	2,604	2,503	2,503

Caveat: The increase in number of service users may not be directly proportional to an increase in outputs as service users may use variable amounts of output, and one service user may access multiple service types.

Source: Trend data questionnaire issued by VFM Project Team

The number of people with physical disabilities who accessed Personal Assistance services increased three-fold, from a low base of 600 people in 2005 to 1,967 people in 2009. According to the results of the questionnaire, the increase was almost entirely in Section 39 agencies, as shown in Figure 5.2. There was no increase in numbers accessing this service in Section 38 agencies during the years in question, according to the questionnaires returned.

Figure 5.2: Trend in number of service users with physical and sensory disabilities accessing Personal Assistance services, 2005-2009 (based on 77 questionnaires)



Source: Trend data questionnaire issued by VFM Project Team

5.2 EFFICIENCY

5.2.1 OVERALL APPROACH TO EFFICIENCY MEASUREMENT

The purpose of carrying out unit cost analysis was to develop findings that satisfy the Terms of Reference in relation to efficiency and cost-effectiveness (ToRs 5, 6 and 7) and to enable the following:

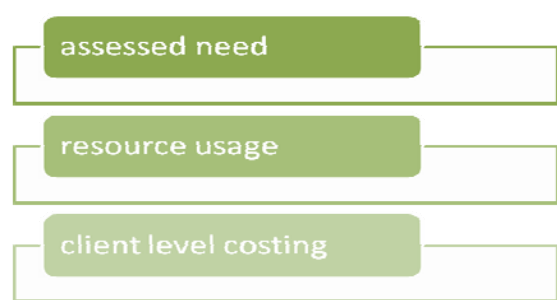
- Comparison between the relative efficiency of the statutory and non-statutory sectors for similar services.
- Development of a high-level understanding of certain cost drivers of disability expenditure and the cost behaviour of different types of disability costs.
- Demonstrate the gap between the most cost-efficient and least cost-efficient services, and the potential for resulting savings.
- Assessment of the relative cost-efficiency of different forms of service provision within programmes.
- Establishment of cost parameters for different service activities, together with a foundation for further work on resource allocation models in the future.
- Provision of an input into cost-effectiveness assessment.
- Identification of a core dataset and indicative baseline that can be refined and used as the basis for work on resource allocation and usage.

This is the first time that unit costing to this level of detail has been undertaken on a national basis in respect of the Disability Services Programme. Data on SLA Schedule 3 forms have been collected down to service unit level, where service units are defined as *'discrete physical locations where a specific type of service is provided, or where services are administered'*. The collection of data at this level is a significant addition to the body of existing information on disability service provision and will provide the foundation for further work in this area. Variations at local and regional level have been identified and avenues highlighted for further investigation. The potential factors that drive costs (including age, region, service unit size and agency size) have also been examined within the parameters of the data available.

There are many factors that drive costs and that might explain variations in costs. Not all contributory factors could be quantified for the purposes of this Review because of difficulties in identifying and collecting relevant data. The data available to the Review does, however, allow reasonable costs to be identified against which the cost of a range of service types can be assessed.

5.2.2 UNIT COSTS – OVERVIEW

There are three elements to consider in determining the efficiency with which services or supports are provided:



The type of services or supports required by the individual (**assessed need**) in order to achieve the desired outcome.

The amount of services received or supports utilised (**resource usage**).

The cost of providing services to that individual (**client-level costing**).

Assessed need

There are no objective and independent common assessment methodologies in use to allow a nationally consistent dataset to be collected on an individual's current service requirements. The NIDD was established for the purpose of informing regional and national planning, but it does not contain data to this level of operational detail (see also Chapter 8). As the NIDD Committee in its Annual Report for 1998/1999 states: *'The database was established on the principle that minimum information with maximum accuracy was preferred, hence it incorporates only three basic elements of information: demographic details, current service provision and future service requirements. The objective is to obtain this information for every individual known to have an intellectual disability and assessed as being in receipt of, or in need of, an intellectual disability service'* (HRB, 1999).

Moreover, it is a fact of life that the needs of an individual change as they get older, in line with the general population. There is also empirical evidence of the increased health needs of people with disabilities (McCarron *et al*, 2011), discussed further in Chapter 6. There is no mechanism for taking this developing need into account in national resource allocation decisions and no information is routinely collected about the impacts of the ageing process on resource usage.

Considerations of efficiency and effectiveness are inextricably linked and will be addressed in more detail in Chapter 6. Both efficiency and effectiveness are factors in the achievement of satisfactory outcomes since it is futile to measure the efficiency of a process if it is not delivering the required result to the required quality. Some disability agencies already set outcome targets for the people who avail of their services and incorporate these into the individual's person-centred plan. There are, however, no commonly agreed national outcome indicators associated with either the individual's initial assessment of need or their ongoing person-centred requirements, and consequently no assessment of outcomes achieved. The HSE has begun to address this area, although plans to introduce one or more outcome-based indicators in their 2012 National Service Plan on a pilot basis did not prove feasible. The HSE has now scheduled a comprehensive review of performance indicators to be completed by the 4th Quarter of 2012 (see also Chapter 8 on *'Performance indicators'*).

The International Classification of Functioning, Disability and Health (more commonly known as the ICF) is the World Health Organization's framework for measuring health and disability at both individual and population levels, and has been adopted by all WHO members as the international standard for this purpose.

The WHO's ICF framework uses two domains: a list of body functions and structure, and a list of domains of activity and participation. Since an individual's functioning and disability occurs in a context, the ICF also includes a list of environmental factors. Since 2004, the NPSDD has been collecting information on a Measure of Activity and Participation (MAP) in respect of people with physical and sensory disabilities, based on the ICF classification. Among the advantages of collecting this information is that it provides the ability to compare the participation and functioning experience of individuals before and after they receive services and supports. Efforts to expand the coverage of the NPSDD are continuing and will provide an invaluable record over time of the effects of service provision on service user outcomes for people with physical and sensory disabilities. For the purposes of this Review, however, the data have not been collected for enough of the population with disabilities to be useful in quantifying assessed need.

People with intellectual disability were universally classified in the past according to their level of IQ and were categorised as either borderline, mild, moderate, severe or profound. This categorisation, which is used in the NIDD, is based on criteria set out in the International Statistical Classification of Diseases, 10th Revision (ICD-10), which categorises degrees of disability on a scale ranging from mild to moderate to severe to profound (WHO, 1990). In more recent years, it has been recognised that this categorisation does not always correlate well to an individual's level of functional ability or adaptive behaviour, nor to the type of support an individual needs or the amount of resources that he or she will consume.

The American Association on Intellectual and Developmental Disabilities (AAIDD) defines intellectual disability as *'a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18'* (AAIDD, 2010). 'Intellectual functioning' refers to general mental capacity and one method of measuring this is by means of an IQ test. 'Adaptive behaviour', which can also be measured by standardised tests, comprises three skill types: conceptual (including literacy and numeracy), social and practical (activities of daily living).

While the IQ test is still a major tool in determining intellectual disability, an assessment of a person's level of disability now takes adaptive behaviour into account, together with a range of other factors, such as community and cultural factors, the availability of social supports and the degree to which a person's skills deficits are counter-balanced by their strengths. The AAIDD stress that *'the overarching reason for evaluating and classifying individuals with intellectual disabilities is to tailor supports for each individual, in the form of a set of strategies and services provided over a sustained period'* (see www.aaidd.org/content_104.cfm). Neither the SLA Schedule 3 forms nor the NIDD capture information on adaptive behaviour, thus the information was not available to this Review in trying to analyse the factors behind service usage.

Resource usage

Based on feedback from the HSE and discussions with individual agencies, it is clear that there is no standard methodology employed by disability service providers to quantify the amount of resources which an individual service user actually uses. Potential determinants of resource usage include age, gender, health status, physical or mental disability, level of intellectual functioning, adaptive behaviour and the level of personal and community supports required (Noonan Walsh *et al*, 1990; Knapp *et al*, 2005). The multiplicity of factors that influence resource usage means that service users with similar personal goals may require vastly different levels of resources to reach those goals.

There are various methods for determining resource usage. These tend to centre on ways of measuring actual client/staff interaction as precisely as possible, sometimes on an hour-by-hour basis. Such methodologies are useful for pilot projects, research or short-time use, but are resource-intensive and may not be practical for long-term use. A major service provider, St. Michael's House, has developed its own more straightforward resource usage model, which is in the process of being implemented in all its service units. The model has been demonstrated to other service providers in recent months and interest has been shown in adopting it for wider use.

Previous research by St. Michael's House found that the most significant cost drivers in its residential service units were *challenging behaviour*, *medical issues* (such as epilepsy) and *mobility*. The model uses (i) the actual pay cost of a service unit and (ii) the percentage of staff time used by service users in that unit over the course of the previous year. A standard percentage is applied to all service users and, where appropriate, a percentage for additional support needs on a person-by-person basis, classified under one or more of the following headings: challenging behaviour, medical, mobility, and other. An example of the results from one residential service unit is given in Tables 5.5 and 5.6, demonstrating the effects of the cost drivers (in this case *challenging behaviour* in particular) on the division of staffing resources, and hence costs, in this service unit.

Table 5.5: Percentage of unit time/resources utilised per service user in a sample service unit

	Challenging behaviour	Medical	Mobility	Other	Standard	Total
Service User A	15%	5%	–	–	10%	30%
Service User B	10%	–	–	–	10%	20%
Service User C	5%	–	–	–	10%	15%
Service User D	5%	–	–	–	10%	15%
Service User E	–	–	–	–	10%	10%
Service User F	–	–	–	–	10%	10%
Total	35%	5%	0%	0%	60%	100%

Table 5.6: Cost per service user in a sample service unit (*figures used are illustrative*)

	Challenging behaviour	Medical	Mobility	Other	Standard	Total
Service User A	€75,000	€25,000	–	–	€50,000	€150,000
Service User B	€50,000	–	–	–	€50,000	€100,000
Service User C	€25,000	–	–	–	€50,000	€75,000
Service User D	€25,000	–	–	–	€50,000	€75,000
Service User E	–	–	–	–	€50,000	€50,000
Service User F	–	–	–	–	€50,000	€50,000
Total	€175,000	€25,000	–	–	€300,000	€500,000
Average cost						€83,333

Note: It cannot be assumed that Service Users E or F on their own could be provided with services for the 'standard' cost.

Client-level costing

The basic building block for resource management is the cost of providing a single unit of service or support. Since the focus of service provision is to provide a package of services and supports to individuals (albeit often delivered in a group setting), aggregating costs by individual service user is the most useful way in which to plan, monitor and control costs. Client-level costing is fundamental to an assessment of the efficiency with which services or supports are provided since it takes into account both the unit cost of each 'bundle' of services provided to an individual and also the quantum of services provided. There is no national client-costing methodology in use in disability services and no evidence that a methodology is in use, except in a very few individual agencies.

Some agencies are piloting the use of resource allocation, usage and costing systems. Menni Services, which is part of the St. John of God Hospitaller Order, has introduced the use of the Supports Intensity Scale (SIS) system in some units and is now proposing to extend it to other units throughout the Order. The HSE in the South East region is piloting the In Control system, which is similar in purpose to the SIS (*see also section below, 'Basis for funding decision – Existing places'*). Some other providers operate their own client-level costing systems, but in general client-level costing is not universally performed. In the services that are piloting resource allocation methodologies, they are being used (at least in the initial phases) to identify and monitor resource usage retrospectively, rather than to allocate resources prospectively.

On a regional and national basis, there is no common coding system for uniquely identifying agencies or locations so that costs and other relevant data may be aggregated and disaggregated as the need arises. On the one hand, codes have been allocated to agencies, and occasionally to service locations, at a national level for specific purposes (such as for the NIDD), while, on the other hand, agencies have their own means of identifying cost-centres at local level. There is no common ground between them on fundamental matters, such as definitions, formats or applicability.

Client costing – VFM

For the purpose of this VFM Review, lack of data at service user level militated against the identification of precise resource usage markers. The only practical source for service user information available to the Review was the SLA Schedule 3 returns, which record data at service unit level. Staff resources were recorded at service unit level and it was not possible from the available data to determine the proportion of the service unit's resources that were utilised by each individual service user. The schedules do record some service user profile data, but only in a 'free text' field which was not in a format that could be statistically analysed. The only reasonable option, given the limitations of the data, was to operate on the basis that all service users within a service unit used an equal amount of the resources of that unit. On that basis, the staff/client support ratio was used as a proxy for each individual's resource usage. An added complication was that there was no designated staff/client ratio information collected on the SLA schedules for people with physical and sensory disabilities, which further restricted an analysis of data for this cohort using resource usage as a variable.

MEASURING THE COST OF PROVIDING SERVICES

KEY FINDINGS

- ✓ There is no national standard client assessment methodology in use in the disability services and no methodology for linking service needs with target outcomes. [Finding 5.6](#)
- ✓ There is no standard classification of functional ability in use on a national basis that predicts the amount of resources which an individual is likely to require, and no classification that indicates with any degree of precision the amount of resources which an individual actually consumes. [Finding 5.7](#)
- ✓ There is no common method of uniquely identifying service locations for costing purposes. [Finding 5.8](#)
- ✓ Client-level costing is essential to the assessment of efficiency. There is no national client costing methodology in use in disability services and no evidence that any methodologies are in use in individual agencies, except in a small number of cases. [Finding 5.9](#)
- ✓ There are no standard procedures, practices and data sources used across the board by disability service providers (including the HSE) that would facilitate an assessment of all the key determinants (services required, services provided and cost of services) of efficiency on a national scale. Current service provision and future service need are recorded in the NIDD, but are not linked to funding and are not an objective independent assessment of current need. The NPSDD does not cover enough of the target population to provide an accurate assessment of client need. [Finding 5.10](#)
- ✓ There may have been inconsistencies in the allocation of staff to service units in the original SLA forms. The HSE validation process trapped and corrected as many errors as possible, but some may remain. [Finding 5.11](#)

KEY RECOMMENDATIONS

- ✓ A common assessment method should be developed or adopted by the HSE and implemented by disability service providers on a national basis to determine the services that are required by an individual (*see Chapter 8 for the implications of this for the NIDD*). This process should take into account any relevant developments taking place in the wider Primary Care context, such as the work being undertaken in Services for Older People, and also the experience of implementing the assessment process under Part II of the Disability Act 2005. [Recommendation 5.12](#)
- ✓ The assessment process should identify clearly the outcomes to be achieved through the provision of the services or supports. Any measure of the degree to which assessed needs have been met should include an assessment of the outcomes achieved. [Recommendation 5.13](#)

- ✓ An adult's requirements for supports and services should be re-assessed at the individual's request, at key transition periods or following a change in the individual's health or personal circumstances, but in any event not less than once every 3 years in order to ensure that services are responsive to the changing needs of the individual. This re-assessment process should be practical and capable of being integrated into an agency's person-centred planning and manpower utilisation and deployment planning processes. [Recommendation 5.14](#)
- ✓ Providing for the changing needs of service users over the lifecycle should be recognised as an intrinsic part of the resource allocation process. A phased approach will be required to the implementation of a cyclical assessment process, given the capacity constraints of the present system to support such a model. Providing for the changing needs of service users will be subject to the same affordability constraints and resource prioritisation requirements that will apply to all resource allocation decisions. [Recommendation 5.15](#)
- ✓ The HSE should require service providers to implement a common method for assessing the amount of resources which an individual consumes (*see also recommendations in Chapter 4*). [Recommendation 5.16](#)
- ✓ National guidelines should be drawn up by the HSE on an activity-based costing methodology to facilitate client-based costing. [Recommendation 5.17](#)
- ✓ A method of uniquely identifying service providers and service locations should be implemented by the HSE in order to facilitate unit costing in the context of the SLA process. [Recommendation 5.18](#)
- ✓ Pending the introduction of more comprehensive data collection processes, the Department of Health and the HSE should agree on a revised SLA Schedule 3 dataset specifically for disability services for implementation as soon as possible, and in particular to collect information on key cost drivers identified by the VFM process, build on the dataset collected by the HSE for the purpose of this Review, and incorporate the lessons learnt through the VFM process. Data should be collected for all directly provided HSE services on the same basis as for non-statutory agencies. [Recommendation 5.19](#)

5.2.3 UNIT COST METHODOLOGY

There were four main steps involved in carrying out the unit cost analysis (*see also Appendix 5*):

1. establishing and aggregating the units of analysis (outputs);
2. calculating unit average costs;
3. testing and refining costs;
4. grouping and comparing unit costs by aggregating them into groups with similar characteristics, described as 'resource usage groups'.

Data on units of outputs were derived from the SLA Schedule 3 dataset and are described in Appendix 6. In the case of such services as multidisciplinary services, assisted living and personal assistant services, respite services and early intervention, using a count of service users as the output metric would not give an accurate result due to variations in the quantum of service consumed. For example, two different individuals in receipt of multidisciplinary services could consume different types and quantities of services – one person might be in receipt of one speech and language therapy session a month and another may receive two or more different therapeutic services weekly. Similarly, one individual may receive respite for one weekend a month in a residential centre and another may receive respite in a family setting for 4 weeks in the year. As a result, the focus of output analysis in this Review was on residential and day services since these consume most resources and have the most comparable units of output.

The unit cost methodology employed in Steps 2-4 above are described in more detail in Appendix 5. In Step 4, in order to produce a manageable set of data to work with, services that shared similar characteristics were grouped together into 'resource usage groups'.

There are a number of caveats to bear in mind when considering the unit cost data:

- SLA schedules record the services provided from HSE funding only. As indicated in Chapter 4, data on other sources of funding were sought by means of questionnaires issued directly to service providers. However, there was no evidence on the basis of the questionnaires to suggest that funding from non-HSE sources would materially affect unit costs.
- Staff/client ratio is an average descriptor (in practice, many service units contain clients of mixed staffing requirements), but there was no information available to the VFM Project Team to quantify the amount of resources used by individual service users. (It should be noted that staff/client ratios reflect the service providers' assessment and historical practice, rather than an objective definition of actual client need.)

Analysis of Unit Costs – Overview

A summary analysis of national resource usage groups is given in Table 5.8. The data are further analysed in Tables 5.10–5.15 to determine whether there are geographical variations in the cost of services, whether costs are affected by an agency's legal status (either HSE, Section 38 or Section 39) or by other characteristics such as agency size, service unit size, service user characteristics or service type.

The overview shows that the single most expensive type of residential place is an **Intellectual Disability 7-day Residential High Support** place (€140,000). This resource usage group also has more residential service users than other groupings, giving an overall cost of €191m per annum for providing services to over 1,500 service users in 283 separate locations. While the highest cost for a day place is an **Intellectual Disability Adult Activation and Day Intensive Support** place (€70,000), the relatively low number of people availing of this service means that the day service absorbing the most funding is the **Intellectual Disability Adult Activation and Day High Support** place (at a total cost of €75m), followed closely by the **Intellectual Disability Adult Activation and Day Moderate Support** place (at a total cost of €69m).

Calculation of Comparator Costs

NOTE: All costs used in this chapter as the basis of comparison (referred to as ‘comparator costs’), unless otherwise stated, have been calculated using a two-step process:

- (i) The average cost of a service user place in an individual service unit is obtained by dividing the total cost of the unit by the number of service users in that unit.
- (ii) The results are then averaged across service units.

The purpose of this is to take account of the variable number of service users per unit, which can vary widely due to the nature of the services being provided. For example, in Table A5.2 (*in Appendix 5, ‘Unit Cost Methodology’*), the number of service users receiving intensive day activation supports varies from 1 person per unit to a maximum of 44 people in a unit.

An alternative approach would be to average service costs across all service users on a national basis, regardless of service unit. However, this would not be an accurate reflection of the actual incidence of cost behaviour at service unit level.

Using an extreme example for the purpose of illustration, consider a category which has only two units, A and B:

Service Unit A:	2 service users	Total cost = €150,000,	Average cost = €75,000 per person
Service Unit B:	10 service users	Total cost = €2,500,000,	Average cost = €250,000 per person

giving a total of 2 service units with 12 service users at a combined cost of €2,650,000.

If we want to compare the costs of these units on a fair and equitable basis, the simple average cost rounds up to €221,000 (€2,650,000 divided by 12), whereas the two-step average is €162,500 (€75,000 plus €250,000 divided by 2). Using the simple average of €221,000 as the basis for comparison makes the cost per place in Service Unit B look closer to the norm and relatively efficient, *whereas because of its size it has, in effect, unduly influenced the norm*. Using a two-step process that results in a comparator of €162,500 gives a fairer picture of the relative costs of Service Unit A in comparison to Service Unit B by giving equal weight to both service units in influencing the average.

An example of how the process works using an extract from an actual set of data is given in Table 5.7. Here, the divergence between the simple average and the two-step average is not as extreme as in the example above, but nevertheless the same principle applies, i.e. the two-step average is the fairer figure to use as the basis for comparison. A more detailed example is given in Table A5.2 (*see Appendix 5*), using the full list of service units that comprise the first ‘Resource Usage Group’ in Table 5.8 (i.e. Intensive Support, Day Services for Adults with ID: Activation and Day Support).

Table 5.7: Demonstration of method of calculation of comparator cost

Support ratio = ID Day Intensive (1 to 1 or above)	Count of service units	Total No. of service users	Total cost	Average cost per service user (Total cost/ Total service users)
Service Unit 1	1	10	€216,501.87	€21,650.19
Service Unit 2	1	3	€15,170.75	€5,056.92
Service Unit 3	1	1	€47,408.61	€47,408.61
Service Unit 4	1	1	€51,176.63	€51,176.63
Service Unit 5	1	1	€47,408.61	€47,408.61
Service Unit 6	1	1	€23,704.30	€23,704.30
Service Unit 7	1	1	€59,260.76	€59,260.76
Service Unit 8	1	4	€176,073.17	€44,018.29
Service Unit 9	1	6	€417,150.66	€69,525.11
Service Unit 10	1	5	€403,665.17	€80,733.03
	10	33	€1,457,520.53	€449,942.45
Simple average cost per place (total cost divided by total no. of service users)			€44,167.29	
Comparator cost per place (average cost per service unit totalled, then divided by the number of service units)				€44,994.25

Both averaging methods are valid and the choice of method depends on the purpose of the analysis. In this chapter, the purpose of the averaging exercise is to take account of the range of cost levels at the most detailed level of service setting available, i.e. the service unit. It is not the intention of the analysis to generate the average costs which are most typical or the level of costs which pertain for the majority of service users (as distinct from the majority of service units). The purpose of the exercise is to reflect average unit costs of relevance for resource allocation decisions.

Using the two-step methodology, a summary analysis of data on national resource usage groups is given in Table 5.8.

Table 5.8: National resource usage groups – Summary analysis

Resource usage groups		No. of service users	No. of service units	Total cost (pay and non-pay)	Comparator cost
ID = intellectual disability P&S = physical and sensory disability					
Day services for adults with ID: Activation and Day support	Intensive Support	482	54	€16,737,589	€69,718
	High Support	2,537	167	€74,909,762	€33,386
	Moderate Support	3,537	154	€69,384,846	€25,293
	Low Support	1,907	59	€20,525,287	€14,674
	Minimum Support	55	2	€505,179	€8,101
Day services for children with ID	Intensive Support	138	8	€3,512,084	€61,587
	High Support	640	36	€17,752,502	€34,618
	Moderate Support	588	16	€4,015,442	€14,006
	Low Support	251	6	€1,695,074	€8,681
Day services for adults with ID: Work-like activities	Intensive Support	91	7	€1,940,067	€39,126
	High Support	310	17	€6,553,277	€23,933
	Moderate Support	1,640	86	€32,182,360	€21,731
	Low Support	3,633	121	€46,159,438	€17,227
	Minimum Support	35	2	€376,036	€22,877
Day services for people with P&S disabilities only		2,568	80	€16,155,232	€12,181
5-day residential services for people with ID	High Support	59	12	€3,233,499	€62,402
	Moderate Support	46	9	€3,150,378	€69,136
	Low Support	197	33	€4,657,395	€32,244
	Minimum Support	9	3	€222,388	€33,624
7-day residential services for people with ID	High Support	1,542	283	€191,256,643	€139,739
	Moderate Support	1,336	251	€99,092,759	€84,205
	Low Support	1,369	259	€61,984,879	€53,034
	Minimum Support	237	60	€7,314,449	€35,086
Residential services for people with P&S disabilities only		717	51	€58,848,698	€103,283

Note: The costs used in this table as the basis for cost comparison have been calculated using a two-step calculation process. See 'Calculation of Comparator Costs' in Section 5.2.3, Table 5.7 and Table A5.2 in Appendix 5 for further details.

Percentile analysis

A percentile analysis was performed on the data summarised in Table 5.8 to identify the spread of data above and below the average. The results are documented in Table 5.9 and Figure 5.3.

A percentile is the value below which a certain percentage of results fall. In Table 5.9, the 25th percentile is the value below which 25% of the costs may be found, while the 50th percentile is equal to the median (i.e. 50% of costs are above and 50% are below this value). For 7-day High Support Residential Services, the average cost is €139,739, the median (50th percentile) is €119,545, while 5% of costs are above €312,511.

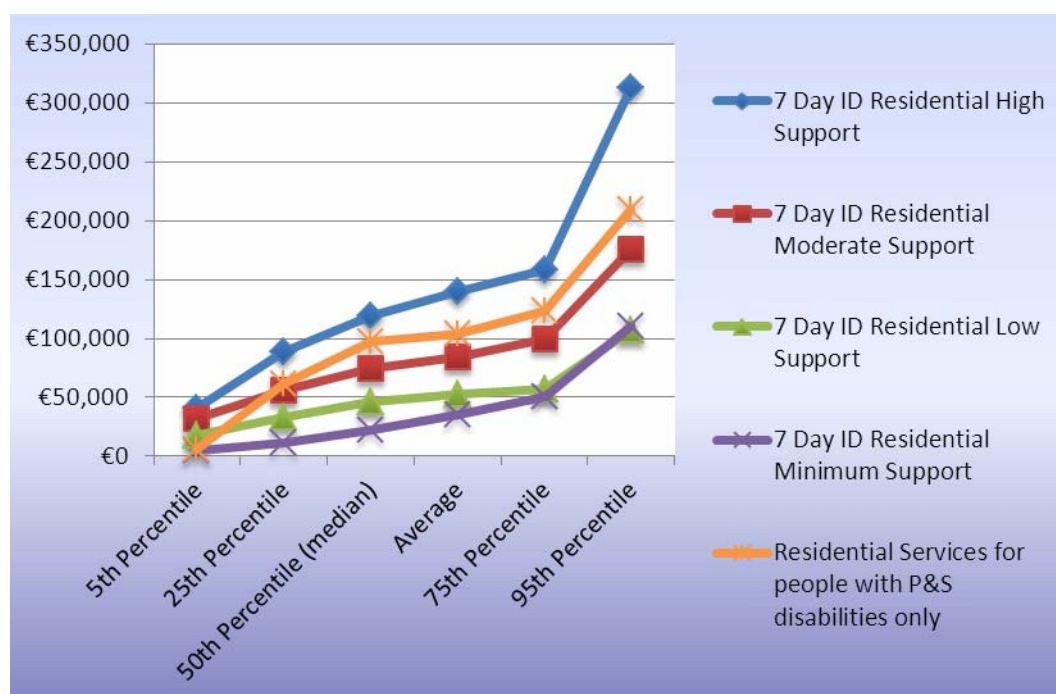
Table 5.9: National resource usage groups – Percentile analysis of 7-day residential services

Resource usage groups		Average annual cost per service user (in €), direct and indirect pay/non-pay							
ID = intellectual disability P&S = physical and sensory disability		No. of units	No. of service users	5th Percentile	25th Percentile	50th Percentile (median)	Average	75th Percentile	95th Percentile
7-day residential services for people with ID	High Support	283	1,542	€40,329	€88,838	€119,545	€139,739	€158,269	€312,511
	Moderate Support	251	1,336	€31,885	€56,098	€74,159	€84,205	€99,283	€175,267
	Low Support	259	1,369	€18,001	€32,821	€46,034	€53,034	€57,344	€107,062
	Minimum Support	60	237	€5,339	€11,356	€22,259	€35,086	€50,816	€110,800
Residential services for people with P&S disabilities only		51	717	€6,175	€61,172	€96,891	€103,283	€123,577	€209,621

Source: SLA Schedule 3 data (analysis by DoH Information Unit)

The percentile data illustrates the spread of costs which are above and below the average. Further work is required to understand and explain the outliers at either end of the spectrum, and these should be investigated by the HSE in the first instance to confirm that they are correct. Having established the accuracy or otherwise of the data, there is much to be gained in studying costs that are much higher or lower than the average to gain an understanding of cost behaviour, identify cost drivers and identify practices which contribute to greater cost-efficiency, and equally, to greater inefficiency.

Figure 5.3: National resource usage groups – Percentile analysis of 7-day residential services



Source: SLA Schedule 3 data (analysis by DoH Information Unit)

COST VARIATIONS

KEY FINDING

- ✓ There are significant variations in costs (from highest to lowest) in all resource usage groups. [Finding 5.12](#)

KEY RECOMMENDATION

- ✓ Costs substantially below the average should be examined by the HSE to (i) ascertain if they are correct; (ii) identify whether there are any common characteristics (such as unit size, client mix or staff mix) that have contributed to the low cost; and (iii) having established whether the costs are accurate and due to efficiencies, and looked at whether the quality is acceptable, what lessons can be learnt. Similarly, costs that are extremely high should be examined to confirm the figures are correct and if so, the reasons why they are so high (*See also Recommendation 5.36*). [Recommendation 5.20](#)

Cost drivers

As noted above, there are many factors that drive costs and explain variations in costs. The data cannot be used to demonstrate conclusively that some agencies, sectors or geographical areas are more or less efficient than others overall. On the whole, most agencies are efficient when compared to others for some of the services they provide and less efficient for others. This finding is not unique to the present study or to the Irish disability services. A large-scale research project conducted in the UK by Emerson *et al* (1999), with the aim of examining the quality and costs of residential supports provided to people with learning disabilities, concluded: *'We found a wide variation in the costs associated with residential provision. This variation occurred not only between the three accommodation models, but between individual organisations and, in many instances, individual settings. Thus, for example, accommodation cost per resident week varied between £356 and £1,720 in village communities, £532 and £1,086 in residential campuses, and £132 and £1,719 in dispersed housing. The costs of providing accommodation and associated care were dominated by staffing costs, whatever the specific staffing arrangements within the facility.'*

The same report also stated that *'Few studies have satisfactorily accounted for the wide variations in costs which clearly exist. The most consistent finding is that higher service costs are related to greater user needs ... However, it is also clear that there are no simple economies of scale associated with larger or more centralised residential services'*.

Unit costs – Geographical variations

There are significant regional variations in costs, but no clear pattern emerges that pinpoints one region as having higher costs across the board. Instead, a region that has the highest cost for one service type is lower or lowest for another (see Table 5.10).

Table 5.10: 7-day Residential Support Services – average annual cost per service user (including overheads), by HSE region

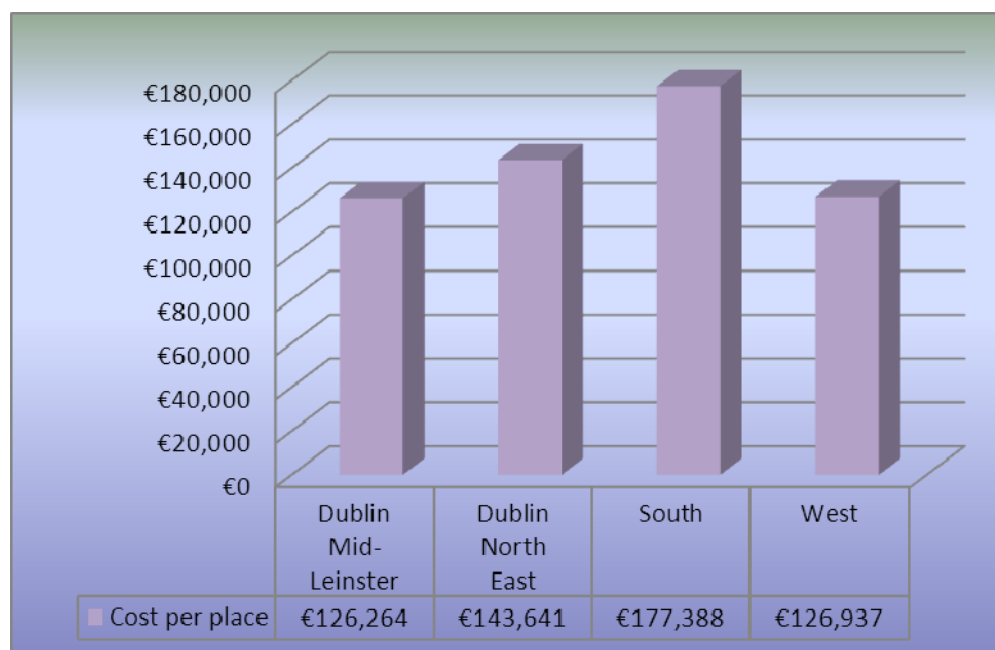
Resource usage groups		ID: Residential High (2 staff on duty plus on duty night staff)	ID: Residential Moderate (2 staff on duty plus sleep in)	ID: Residential Low (staff on duty most of time plus sleep in)	ID: Residential Minimum (no sleep in)	P&S: Residential services for people with P&S disabilities only
ID = intellectual disability; P&S = physical and sensory disability						
DML	No. of service users	479	417	323	47	332
	No. of service units	80	79	54	15	19
	Average annual cost per person	€126,264	€88,626	€62,543	€63,303	€118,198
DNE	No. of service users	345	289	183	42	163
	No. of units	54	52	36	7	8
	Average annual cost per person	€143,641	€96,226	€63,367	€28,008	€75,421
South	No. of service users	305	228	421	42	60
	No. of units	55	32	67	16	7
	Average annual cost per person	€177,388	€72,143	€47,427	€20,787	€127,112
West	No. of service users	413	402	442	106	162
	No. of units	94	88	102	22	17
	Average annual cost per person	€126,937	€77,519	€48,037	€28,498	€89,914

Note: The costs used in this table as the basis for cost comparison have been calculated using a two-step calculation process. See 'Calculation of Comparator Costs' in Section 5.2.3, Table 5.7 and Table A5.2 in Appendix 5 for further details.

Source: SLA Schedule 3 data (analysis by DoH Information Unit)

For the Intellectual Disability 7-day Residential High Support group, the lowest annual cost per place is in the DML region, at €126,264 per place, followed closely by the Western region at €126,937 (see Figure 5.4). The difference becomes more marked in DNE, at €143,641 (which is 14% higher than in DML), and finally the South at €177,388, which is a substantial 42% higher.

Figure 5.4: 7-day Residential High Support Services– average annual cost per place (including overheads), by HSE region



Note: The costs used in this table as the basis for cost comparison have been calculated using a two-step calculation process. See ‘Calculation of Comparator Costs’ in Section 5.2.3, Table 5.7 and Table A5.2 in Appendix 5 for further details.

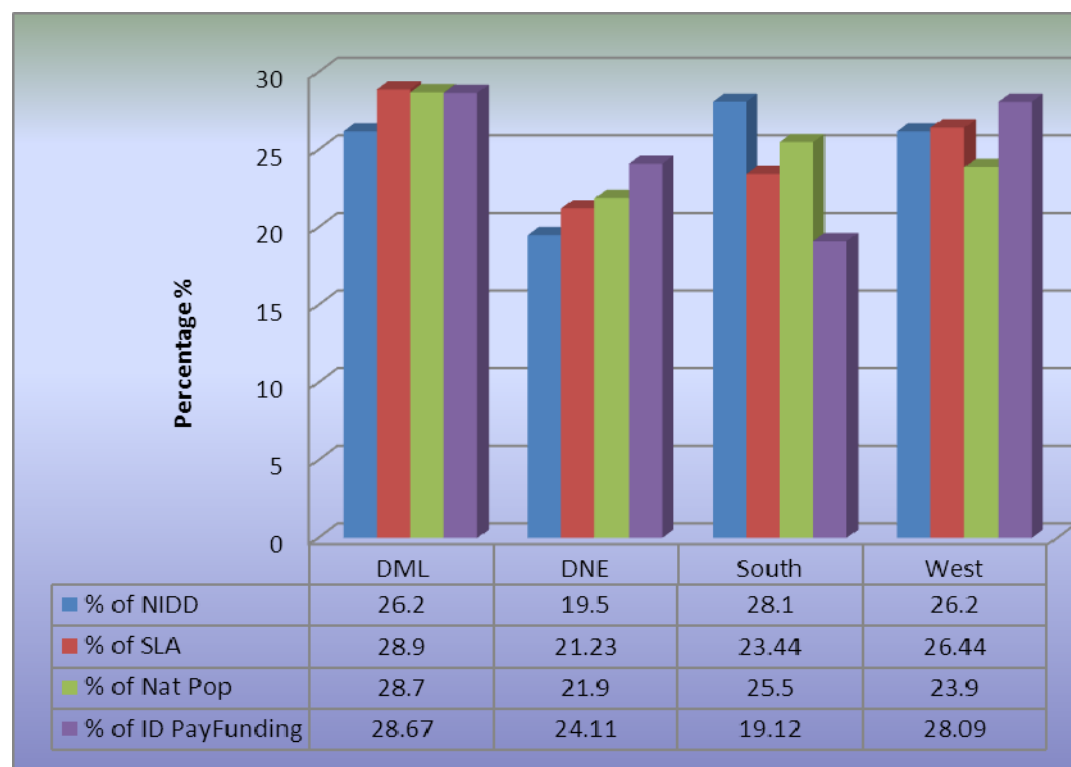
Source: SLA Schedule 3 data (analysis by DoH Information Unit)

There is no obvious reason for the variation of 42% between lowest and highest cost. The client profile (level of intellectual disability) by region was examined to see if it might perhaps explain some or all of the difference, but the profile is similar across the regions. Also, some of the lowest individual agency costs are in the South region, making its position as highest overall for Residential High Support Services more difficult to justify.

On the other hand, while it has the highest costs for High Support Residential Services, the South has lower costs for other residential service types and is substantially lower than the other regions for Intellectual Disability 7-Day Residential Minimum Support, which illustrates the point already made about the absence of any discernible pattern to variations in unit costs.

A comparison between the regional distribution of service user numbers and pay expenditure (intellectual disability services only) shows that funding for the South region is lower than might be expected given its share of service user numbers (see Figure 5.5). Although the pay total and service user numbers have been adjusted to take account of missing SLA returns for the South, the difference is still marked and should be reviewed by the HSE to confirm that the findings are correct and to ascertain whether there are reasons why this should be the case.

Figure 5.5: Regional comparisons of NIDD registrations, service user numbers on SLA returns, national population figures and intellectual disability (ID) pay expenditure*



* In order to perform a fair comparison, the figures used in this graph for SLAs and ID pay funding have been adjusted by inclusion of an estimated amount to reflect the fact that approximately €24m (11%) of SLAs in respect of the HSE South region were not returned in time to be included in the overall analysis.

GEOGRAPHICAL VARIATIONS IN UNIT COSTS

KEY FINDING

- ✓ There are significant regional variations in costs. There are no obvious reasons why this should be the case since the client profile is similar across regions. There is also no clear pattern emerging that pinpoints one region as having higher costs across the board; instead, a region that is highest for one service type is lower or lowest for another. [Finding 5.13](#)

KEY RECOMMENDATION

- ✓ HSE allocations should be adjusted over time to ensure that regional allocations are made on a pro rata basis, based on a combination of service user numbers and types of services provided. In doing this, the HSE should retain the ability to make adjustments to reflect national policies or specific circumstances, once this is done in a transparent manner. [Recommendation 5.21](#)

Unit costs – Agency status

The legal status of agencies in terms of being statutory (i.e. HSE) or non-statutory (i.e. agencies funded under Section 38 or Section 39 of the Health Act 2004) has been explained in Chapter 3. The relative magnitude of the statutory and non-statutory sectors can be seen by comparing numbers of service users and staff, and pay costs (see Table 5.11). It is noteworthy that the HSE itself is a significant service provider, with just over one-third of all service users. This is particularly marked in the area of multidisciplinary supports, where the HSE provides services to about half of all individuals availing of these supports.

STATUTORY/NON-STATUTORY

A summary of total service places, staff numbers and pay cost in the statutory and non-statutory sectors is set out in Table 5.11.

Table 5.11: Total service places, staff and pay costs, by agency status (statutory and non-statutory)

Programme type	HSE	Non-statutory	HSE	Non-statutory	HSE	Non-statutory
	Total service places		Total staff WTE		Total pay cost	
Assisted living/ personal assistance	702	2,561	72	856	€1,425,631	€33,663,091
Day	1,925	17,570	435	4,581	€19,012,507	€213,465,250
Unclassified	2,610	5,954	345	1,550	€16,376,053	€95,362,339
Multidisciplinary supports	29,628	58,001	708	1,375	€38,663,405	€91,319,753
Other	2,150	18,050	188	1,836	€7,509,144	€90,049,222
Residential	1,519	7,271	2,130	8,395	€95,931,206	€452,481,783
Residential centre-based respite	902	7,074	155	863	€8,213,747	€44,147,535
Respite support hours	649	2,384	118	263	€3,934,529	€12,985,662
TOTAL	40,085	118,865	4,151	19,719	€191,066,222	€1,033,474,635

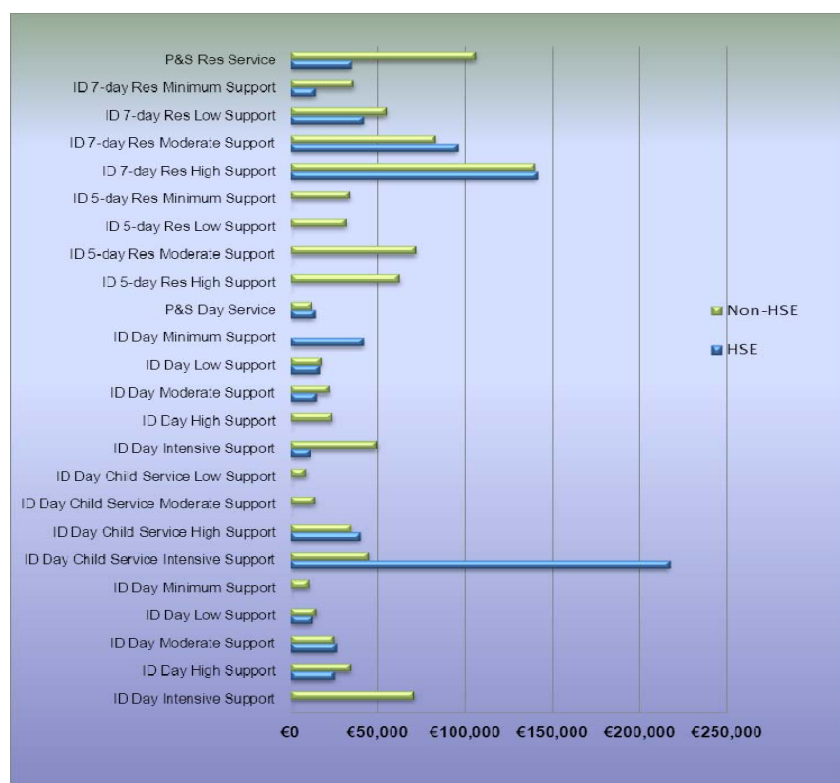
Notes:

- The costs used in this table as the basis for cost comparison have been calculated using a two-step calculation process. See 'Calculation of Comparator Costs' in Section 5.2.3, Table 5.7 and Table A5.2 in Appendix 5 for further details.
- The number of service places in this table does not equate to the total number of service users because many people avail of more than one service type (for example, a standard day service, a multidisciplinary therapeutic input and a respite service).

Source: SLA Schedule 3 data (analysis by DoH Information Unit)

There are significant variations in cost between service programmes in the statutory and non-statutory sectors, but there is no clear pattern of one sector being universally higher or lower in cost across the board. The HSE is a substantial service provider and the single largest direct provider of disability services. Two analyses were done: the first analysis compares the cost in the statutory and non-statutory sectors (see Figure 5.6) and the second separates the non-statutory sector into two groups, depending on whether the agencies are funded under Section 38 or 39, and compares them to the HSE (see Table 5.12).

Figure 5.6: Average annual cost per place – HSE and non-HSE services (statutory and non-statutory)



Note: The costs used in this table as the basis for cost comparison have been calculated using a two-step calculation process. See 'Calculation of Comparator Costs' in Section 5.2.3, Table 5.7 and Table A5.2 in Appendix 5 for further details.

Source: SLA Schedule 3 data (analysis by DoH Information Unit)

Unit costs in this chapter have been based on full costs (direct and indirect pay and non-pay). The feasibility of apportioning some corporate overheads to the Disability Services Programme was discussed with the HSE, but the HSE advised that it was not in a position to come up with a fair apportionment. As a result, in order to test whether the absence of corporate overheads in the HSE's unit costs have distorted the results of the comparison between the statutory and non-statutory sectors, an analysis has been done on the results of pay costs only (see Table 5.12).

Calculating full unit costs by apportioning indirect pay and all non-pay to relevant service units added an average of 31% to the direct pay costs of HSE service units and 39% to the cost of non-HSE service units. A comparison between HSE and non-HSE on the basis of direct pay costs shows the same variability that was found when analysing SLA data using other variables, i.e. HSE costs were lower than non-HSE costs for some service types and higher for others. For Intellectual Disability 7-Day Residential High Support places, the HSE's costs are 5% higher than non-HSE places, although the gap narrows to 1% when indirect pay and non-pay costs are added. In the case of Intellectual Disability Day Activation High Support, the HSE's direct pay costs are substantially lower than non-HSE agencies (32%) and the differential increases to 37% when all costs are added.

Table 5.12: Comparison between average annual cost per place with (i) direct pay costs only and (ii) full cost apportionment

Resource usage groups ID = intellectual disability; P&S = physical and sensory disability		HSE			Non-HSE		
		Average annual cost per place					
		Direct pay only	All pay and non-pay	% increase	Direct pay only	All pay and non-pay	% increase
Day services for adults with ID: Activation and day support	Intensive Support	–	–	–	51,023	69,718	37%
	High Support	18,858	24,892	32%	24,950	33,985	36%
	Moderate Support	19,644	25,886	32%	18,223	25,204	38%
	Low Support	9,121	12,006	32%	10,287	14,817	44%
	Minimum Support	–	–	–	5,465	8,101	48%
Day services for children with ID	Intensive Support	172,351	216,692	26%	29,399	39,429	34%
	High Support	30,048	39,568	32%	24,800	34,476	39%
	Moderate Support	–	–	–	10,345	14,006	35%
	Low Support	–	–	–	6,245	8,681	39%
Day services for adults with ID: Work-like activities	Intensive Support	8,170	10,770	32%	33,075	43,852	33%
	High Support	–	–	–	16,783	23,933	43%
	Moderate Support	11,150	14,642	31%	15,686	21,815	39%
	Low Support	12,095	16,129	33%	12,449	17,457	40%
	Minimum Support	31,489	41,340	31%	2,767	4,414	60%
Day services for people with P&S disabilities only		10,340	13,531	31%	9,090	12,110	33%
5-day residential services for people with ID	High Support	–	–	–	43,537	62,402	43%
	Moderate Support	–	–	–	42,067	69,136	64%
	Low Support	–	–	–	24,138	32,244	34%
	Minimum Support	–	–	–	25,823	33,624	30%
7-day residential services for people with ID	High Support	108,637	141,110	30%	103,410	139,459	35%
	Moderate Support	73,086	95,387	31%	63,175	83,494	32%
	Low Support	31,576	41,280	31%	40,426	54,459	35%
	Minimum Support	10,769	14,046	30%	26,563	36,193	36%
Residential services for people with P&S disabilities only		26,177	34,479	32%	79,176	106,092	34%
		Average increase		31%			39%

Note: The costs used in this table as the basis for cost comparison have been calculated using a two-step calculation process. See 'Calculation of Comparator Costs' in Section 5.2.3, Table 5.7 and Table A5.2 in Appendix 5 for further details.

Source: SLA Schedule 3 data (analysis by DoH Information Unit)

STATUTORY/SECTION 38/SECTION 39

Unit costs were further analysed according to whether the services were provided by the HSE, by Section 38 providers or by agencies funded under Section 39 (see Table 5.13). The figures show that where day services for people with intellectual disability are concerned, unit costs in Section 38 agencies are by and large higher than equivalent costs for the services provided by Section 39 agencies. The cost of day services for people with physical and sensory disabilities differs markedly (€21,000 per person in Section 38 agencies and €12,000 per person in Section 39). These figures should be treated with caution, however, and may not be comparable since Section 38 agencies have much fewer service users in this category and the range of disabilities that are catered for may be diverse.

Table 5.13: Average annual cost per service user, by agency type

Resource usage groups		HSE			Section 38 agencies			Section 39 agencies		
ID = intellectual disability; P&S = physical and sensory disability		No. of service users	No. of service units	Average cost per place	No. of service users	No. of service units	Average cost per place	No. of service users	No. of service units	Average cost per place
Day services for adults with ID: Activation and day support	Intensive Support	–	–	–	299	44	€78,478	183	10	€31,175
	High Support	235	11	€24,892	1,702	111	€34,354	600	45	€33,075
	Moderate Support	595	20	€25,886	1,880	91	€28,980	1,062	43	€17,213
	Low Support	64	3	€12,006	1,028	29	€18,260	815	27	€11,120
	Minimum Support	–	–	–	15	1	€ 5,716	40	1	€10,486
Day services for children with ID	Intensive Support	–	–	–	99	5	€36,978	36	2	€45,557
	High Support	12	1	€39,568	395	24	€41,262	233	11	€19,672
	Moderate Support	–	–	–	561	13	€13,405	27	3	€16,612
	Low Support	–	–	–	197	5	€10,085	54	1	€1,662
Day services for adults with ID: Work-like activities	Intensive Support	40	1	€10,770	10	3	€63,270	41	3	€24,434
	High Support	–	–	–	250	13	€21,290	60	4	€32,523
	Moderate Support	26	1	€14,642	1,270	61	€23,143	344	24	€18,438
	Low Support	531	21	€16,129	2,065	59	€20,386	1,037	41	€13,242
	Minimum Support	6	1	€41,340	19	1	€4,414	–	–	–
Day services for people with P&S disabilities only		60	4	€13,531	41	3	€21,268	2,467	73	€11,734
5-day residential services for people with ID	High Support	–	–	–	59	12	€62,402	–	–	–
	Moderate Support	–	–	–	11	3	€56,000	35	6	€75,704
	Low Support	–	–	–	145	22	€34,757	52	11	€27,218
	Minimum Support	–	–	–	5	2	€45,929	4	1	€9,014
7-day residential services for people with ID	High Support	372	48	€141,110	881	173	€133,592	289	62	€155,832
	Moderate Support	74	15	€95,387	862	166	€85,526	400	70	€78,676
	Low Support	135	28	€41,280	941	175	€54,511	293	56	€54,296
	Minimum Support	19	3	€14,046	184	43	€36,191	34	14	€36,199
Residential services for people with P&S disabilities only		67	2	€34,479	120	5	€126,845	530	44	€103,733

Note: The costs used in this table as the basis for cost comparison have been calculated using a two-step calculation process. See 'Calculation of Comparator Costs' in Section 5.2.3, Table 5.7 and Table A5.2 in Appendix 5 for further details.

Source: SLA Schedule 3 data (analysis by DoH Information Unit)

The position with regard to residential services is interesting – where the Section 38 agencies have lower costs for the most significant grouping (Intellectual Disability 7-day Residential High Support) and virtually identical costs to Section 39 agencies for low and minimum support places. What makes this result particularly interesting is that Section 38 agencies have cited the link to the Department of Health's Consolidated Salary Scales and the associated terms and conditions as being a significant factor in pushing their costs higher than Section 39 agencies. This would suggest that perhaps the obligation on Section 38 agencies to apply the Consolidated Salary Scales is not as significant a factor in explaining cost variations between agencies as might have been expected.

Superannuation

A noteworthy difference in the cost of employing staff by statutory and non-statutory agencies (and cited by several disability providers to the Review's Project Team as explaining some cost differential) is superannuation.

HSE employees are covered by one of the Public Service Pension Schemes (defined benefit schemes under which benefits payable are based on the level of final salary at the date of retirement, with post-retirement increases being awarded in line with pay increases with the consent of the Minister for Finance). Pension payments are met on a pay-as-you-go basis from the HSE Vote and superannuation contributions are credited as Appropriations-in-Aid to the Vote. From the point of view of costing services, this means that the HSE does not pay an employer pension contribution. For historical reasons, some Section 38 agencies are also members of one or other of the Public Service Pension Schemes, such as the LGSS (Local Government Superannuation Scheme) or the NHASS (Nominated Health Agencies Superannuation Scheme) and also do not have the direct overhead of an employer pension contribution.

Section 39 agencies do not have access to the Public Service Pension Schemes and will have their own arrangements in respect of superannuation. The Department of Health has capped the amount of employer contributions to one of these schemes at 7% (of which 5% may be paid into the pension fund and 2% on scheme administration). In the past, the additional funding incurred by some Section 39 agencies that had private pension schemes had this additional funding built into their base allocations, up to a maximum of 7%. Any adjustment to the basis on which these agencies are funded in the future should take this into account.

This Review included a question on pension contributions in the trend and non-pay questionnaires issued to the disability agencies, but did not receive sufficient information from them to draw any conclusions.

AGENCY STATUS AND UNIT COSTS

KEY FINDING

- ✓ It was expected that costs in Section 39 agencies would be lower than in Section 38 agencies because they were not tied to the terms, conditions and rates of pay set by the Department of Health for HSE and Section 38 service providers. This did not turn out to be the case in practice, and while some costs are lower in Section 39 agencies, others are higher. It may be that agencies that pay pension contributions into private pension schemes have a higher cost base, which counter-balances any savings through greater flexibility. By and large, the Review has not found any evidence that the potential flexibility enjoyed by Section 39 agencies resulted in lower costs across the board. [Finding 5.14](#)

KEY RECOMMENDATION

- ✓ Changes to the model of funding for disability agencies should take into account the overhead which will be incurred in agencies that are not members of a public service pension scheme. [Recommendation 5.22](#)

Unit costs – Agency characteristics

Characteristics such as agency size and service unit size were analysed to identify their effect on unit costs.

AGENCY SIZE

An analysis of unit costs based on agency size revealed some unexpected results (see Figure 5.7). Comparing the cost of 7-day Residential High Support places, the smallest agencies (annual expenditure of under €5m) have the highest average cost per place (€175,000), as expected.

Agencies in the next band (€5m-€10m), however, come in at the lowest average cost per place overall, at €96,000. Against this, it should be pointed out that the number of service users and service units in both groupings is very small (90 service users in 20 units in the under €5m group and 50 service users in 7 units in the €5m-€10m group), so any comparisons are probably not tenable – because of smaller numbers, the potentially distorting effects of particularly high or low cost places is increased.

The next grouping is of agencies with an allocation of €10-€50m per year and their average cost for a 7-day Residential High Support place is €139m, which is also the overall national average for this type of residential place. The average cost incurred by agencies in the next size bracket (€50m-€100m) is not surprisingly lower, at €129m. The cost in the largest agencies of all, those with allocations exceeding €100m per annum, which might well have been expected to be lower again, averages out at €139,000 per place. This is the same average cost as agencies that are significantly smaller.

The relative 'rankings' described above change when 7-day Residential Moderate and Low Support places are examined. In both instances, the larger agencies have higher average costs than the smaller agencies, although the variation between the higher and lower costs is not significant. In Table 5.14, the variation in the cost of 7-day residential places in the Minimum Support category is significant, but the overall number of service users and service units in this group is low and hence it is difficult to draw conclusions.

Table 5.14: Average annual cost per place, by size of agency (allocation)

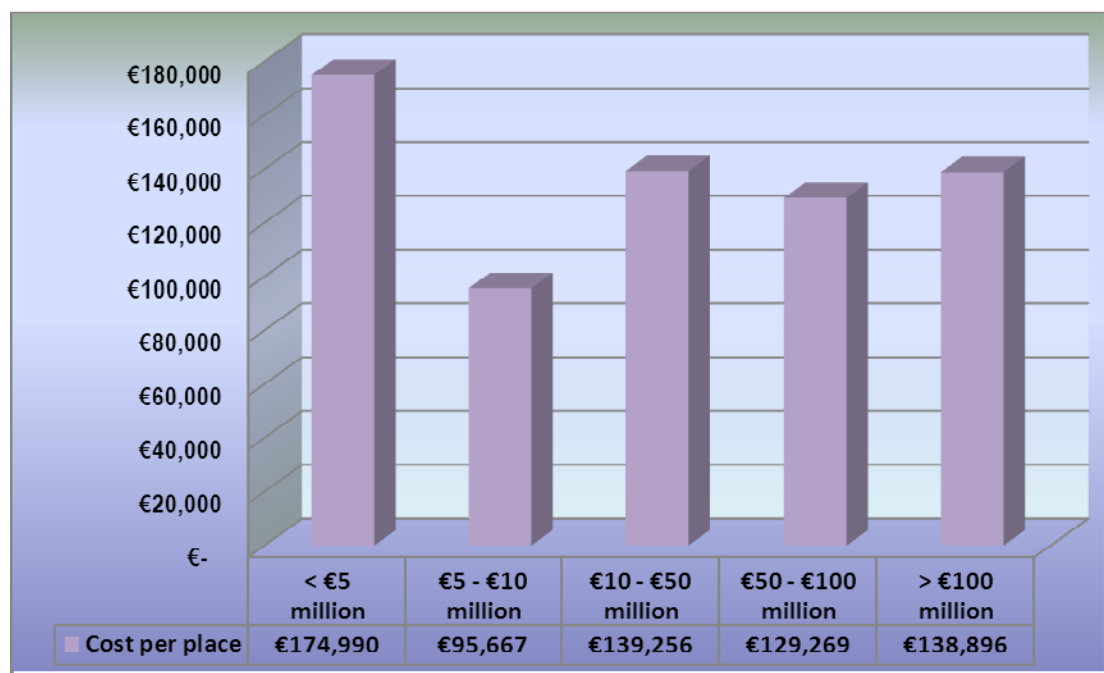
Resource usage groups		Less than €5m	€5-€10m	€10.1-€50m	€50.1-€100m	More than €100m
ID = intellectual disability; P&S = physical and sensory disability						
Day services for adults with ID: Activation and day support	Intensive Support	€21,062	–	€59,675	€59,761	€83,114
	High Support	€37,072	€26,917	€31,500	€36,285	€33,402
	Moderate Support	€16,344	€19,364	€25,156	€26,193	€27,679
	Low Support	€13,836	€12,189	€10,599	€22,014	€19,401
	Minimum Support	–	–	€10,486	–	€5,716
Day services for children with ID	Intensive Support	€9,755	–	€81,358	€14,036	€93,378
	High Support	€13,491	€22,478	€36,830	€33,323	€44,830
	Moderate Support	–	–	€15,160	€10,832	€13,759
	Low Support	–	–	€9,493	€7,057	–
Day services for adults with ID: Work- like activities	Intensive Support	€18,918	–	€27,168	–	€60,570
	High Support	€35,618	–	€24,243	€18,269	€21,793
	Moderate Support	€13,246	€24,125	€31,043	€16,979	€18,803
	Low Support	€13,611	€14,472	€18,050	€15,517	€19,125
	Minimum Support	–	–	–	–	€22,877

Resource usage groups		Less than €5m	€5-€10m	€10.1-€50m	€50.1-€100m	More than €100m
ID = intellectual disability; P&S = physical and sensory disability						
Day services for people with P&S disabilities	P&S Day Service	€10,560	€15,914	€12,260	–	€13,531
5-day residential services for people with ID, including those with a physical, sensory or mental disability	High Support	–	–	€120,404	–	€57,129
	Moderate Support	€79,307	–	€81,006	–	€31,841
	Low Support	€17,165	€46,652	€17,863	–	€47,847
	Minimum Support	€9,014	–	€2,614	–	€89,245
7-day residential services for people with ID, including those with a physical, sensory or mental disability	High Support	€174,990	€95,667	€139,256	€129,269	€138,896
	Moderate Support	€80,301	€67,431	€85,894	€91,500	€84,395
	Low Support	€51,076	€51,002	€55,387	€55,035	€52,137
	Minimum Support	€74,258	€13,690	€50,135	€21,052	€31,519
Residential services for people with P&S disabilities	P&S residential service	€62,026	€142,290	€88,517	–	€34,479

Note: The costs used in this table as the basis for cost comparison have been calculated using a two-step calculation process. See 'Calculation of Comparator Costs' in Section 5.2.3, Table 5.7 and Table A5.2 in Appendix 5 for further details.

Source: SLA Schedule 3 data (analysis by DoH Information Unit)

Figure 5.7: 7-day Residential High Support Services for people with ID – average annual cost per place, by size of agency's annual expenditure



Note: The costs used in this table as the basis for cost comparison have been calculated using a two-step calculation process. See 'Calculation of Comparator Costs' in Section 5.2.3, Table 5.7 and Table A5.2 in Appendix 5 for further details.

Source: SLA Schedule 3 data (analysis by DoH Information Unit)

AGENCY SIZE AND UNIT COSTS

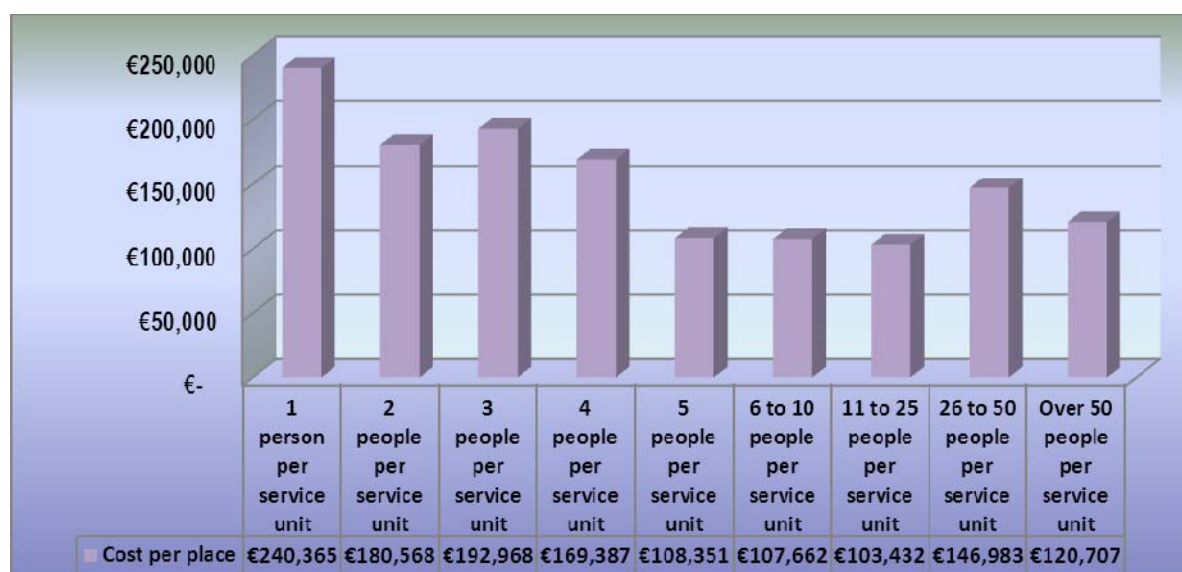
KEY FINDING

- ✓ Agency size has some correlation with costs, but the correlation is not absolute, i.e. costs do not uniformly decrease as agency size increases. [Finding 5.15](#)

SERVICE UNIT SIZE

There is a clear correlation between service unit size and unit costs, with the data indicating that the least costly service unit contains 11-25 residents (see Figure 5.8). Indeed, based on the current model of service provision, service units of 5 residents and over cost less than service units with 4 residents or less. These findings have to be set against the quality of life issues discussed in Chapter 6 of this Review, together with the findings in the HSE's 2011 Report of the Working Group on Congregated Settings and the human rights issues embodied in the UN Convention on the Rights of People with Disabilities.

Figure 5.8: 7-day Residential High Support Services for people with ID – average annual cost per place (including overheads), by size of service unit



Note: The costs used in this table as the basis for cost comparison have been calculated using a two-step calculation process. See 'Calculation of Comparator Costs' in Section 5.2.3, Table 5.7 and Table A5.2 in Appendix 5 for further details.

Source: SLA Schedule 3 data (analysis by DoH Information Unit)

SERVICE UNIT SIZE AND UNIT COSTS

KEY FINDING

- ✓ There is a correlation between service unit size and cost per person, particularly with respect to residential services. This must, however, be viewed in the context of quality of life issues, cost-effectiveness, the recommendations in the 2011 *Report of the Working Group on Congregated Settings* and the UN Convention on the Rights of People with Disabilities. [Finding 5.16](#)

Unit costs – Service user characteristics

Unit costs were analysed by this Review to identify the effects on unit costs of the service user characteristics that could be isolated on the SLA schedules, including age and disability group. An analysis of unit costs allowed the cohort of service users with exceptional needs to be grouped together. Staff/client ratio, which is a characteristic of both staff and clients, is examined under the 'Staff characteristics' section below, but the findings could equally apply under the 'Service user characteristics' section.

AGE

The SLA data available to the Project Team allow for the classification of service users into under 18s and over 18s. There are so few children in residential services that it is not possible to make a fair comparison between costs, although it would be fair to observe that costs are generally higher for children's residential services when compared to adult services (*see Table 5.15*). In respect of day services, costs follow the same pattern as previously observed – children's services have lower unit costs for one service type and higher for another.

Table 5.15: Average annual cost per service user, for under 18s/over 18s

Resource usage groups		Under 18		Over 18		Mixed	
ID = intellectual disability; P&S = physical and sensory disability		No. of service users	Average cost per place	No. of service users	Average cost per place	No. of service users	Average cost per place
Day services for adults with ID: Activation and day support	Intensive Support	0	–	451	70,988	31	€2,392
	High Support	36	€34,922	2,450	33,564	51	€16,020
	Moderate Support	96	€5,809	3,423	25,514	18	€30,912
	Low Support	33	€21,804	1,848	14,220	26	€25,879
	Minimum Support	40	€10,486	15	5,716	0	–
Day services for children with ID	Intensive Support	134	€58,763	0	0	4	€81,358
	High Support	590	€33,012	31	33,841	19	€86,670
	Moderate Support	233	€17,733	0	0	355	€2,825
	Low Support	251	€8,681	0	0	0	–
Day services for adults with ID: Work-like activities	Intensive Support	0	–	91	39,126	0	–
	High Support	0	–	310	23,933	0	–
	Moderate Support	0	–	1,620	21,867	20	€10,202
	Low Support	0	–	3,574	17,227	59	€17,191
	Minimum Support	0	–	35	22,877	0	–
Day services for people with P&S disabilities only		19	€5,107	1,945	12,847	604	€3,736
5-day residential services for people with ID	High Support	30	€64,324	21	61,255	8	€56,610
	Moderate Support	12	€84,971	22	59,301	12	€77,890
	Low Support	0	–	197	32,244	0	–
	Minimum Support	0	–	9	33,624	0	–
7-day residential services for people with ID	High Support	49	€206,659	1,456	135,985	37	€166,626
	Moderate Support	12	€201,278	1,324	82,789	0	–
	Low Support	-	-	-	53,123	55	€9,330
	Minimum Support	0	–	237	35,086	0	–
Residential services for people with P&S disabilities only		0	–	656	104,978	61	€61,763

Note: The costs used in this table as the basis for cost comparison have been calculated using a two-step calculation process. See 'Calculation of Comparator Costs' in Section 5.2.3, Table 5.7 and Table A5.2 in Appendix 5 for further details.

Source: SLA Schedule 3 data (analysis by DoH Information Unit)

AGE OF SERVICE USER AND UNIT COSTS

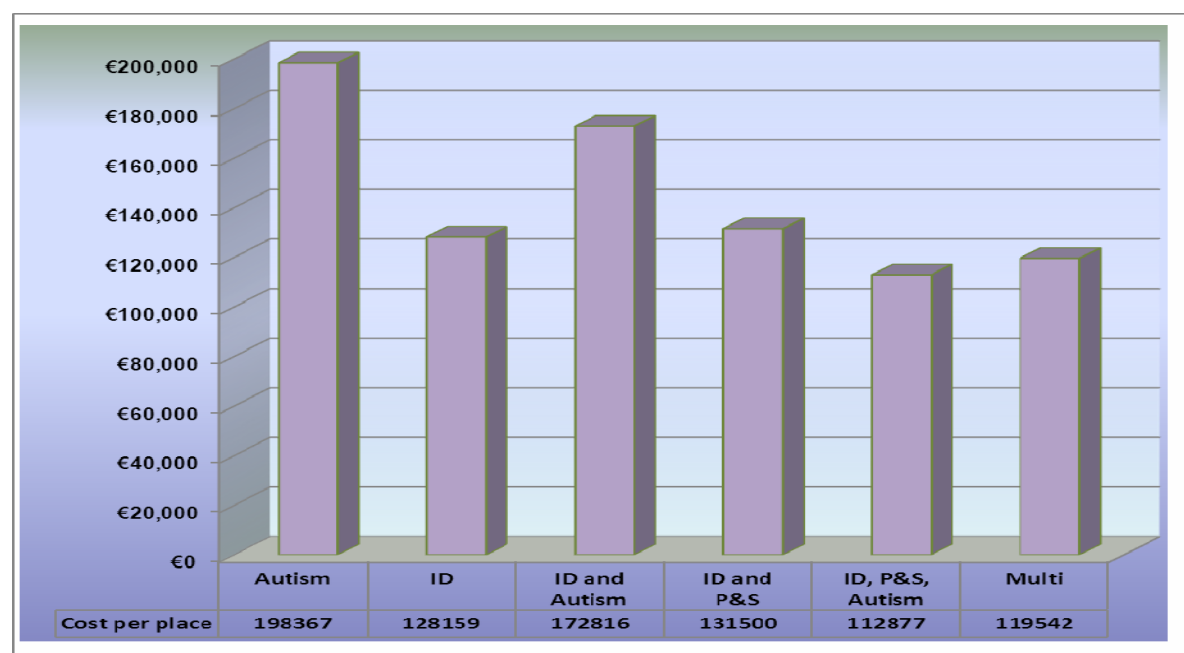
KEY FINDING

- ✓ The cost of residential services for children with ID, and in particular 7-day High Support and Moderate Support services, is higher than for adults. [Finding 5.17](#)

DISABILITY GROUP

The data in Figure 5.9 indicate a correlation between disability group and cost per person. The disability categories used to group service users for the purpose of the SLA Schedule 3 forms are Intellectual Disability (ID); Physical and Sensory (P&S); ID and Autism; ID and P&S; ID, P&S, Autism; and Multiple Disabilities (Multi).

Figure 5.9: 7-day ID Residential High Support Services– average annual cost per place (including overheads), by disability group



Notes:

- The costs used in this table as the basis for cost comparison have been calculated using a two-step calculation process. See 'Calculation of Comparator Costs' in Section 5.2.3, Table 5.7 and Table A5.2 in Appendix 5 for further details.
- Data were not collected on residential services for people in the disability group 'Physical and Sensory Disabilities Only' by degree of support received; they are therefore not included in the above chart.

Source: SLA Schedule 3 data (analysis by DoH Information Unit)

The number of service users and service units in each of the disability groups in Figure 5.9 are now set out in Table 5.16.

Table 5.16: Number of service units and service users in 7-day High Support Units group

Autism		ID		ID and Autism		ID and P&S		ID, P&S, Autism		Multi	
No. of service users	No. of service units	No. of service users	No. of service units	No. of service users	No. of service units	No. of service users	No. of service units	No. of service users	No. of service units	No. of service users	No. of service units
9	2	927	157	325	75	144	22	49	8	89	19

The highest cost per place is for service users who are noted on the SLA forms to be in the 'Autism' only grouping. However, the number (9 service users in 2 units) is too small to allow reliable conclusions to be drawn and other factors aside from disability grouping may apply. The next most expensive cost per place is for service users who have 'ID and Autism'. This is a sizable cohort of people (325 service users in 75 units) and it would be reasonable to infer that the combination of intellectual disability and autism is a contributory factor to the cost per place, which is around 35% higher than the cost of a residential place for someone in the 'ID' only group. The lowest costs overall are for those with 'Multi' disabilities, either a combination of ID, P&S and Autism, or other multiple conditions. An examination of the data shows that a greater percentage of people in these last two disability groupings are in larger residential centres as opposed to smaller community-based units and this may partially explain the difference in cost.

Exceptional need

An analysis of pay costs showed that almost 4% of service users (157) in 7-day Residential High Support settings had a direct pay cost of over €150,000 per annum and accounted for almost 10% of pay expenditure (see Table 5.17). The 40 service users with the highest support needs were housed in a total of 16 residential service units, all of which were in the non-statutory sector.

Table 5.17: Number of service users (cost < > €150,000) in 7-day High Support Service Units

Costs over/under €150,000 per annum	Service users		Total cost	
	No.	%	Cost	%
Service users with a direct pay cost of greater than €150,000	157	4%	€33,724,464	9.55%
Service users with a direct pay cost of €150,000 or less	4,127	96%	€319,320,477	90.45%
Total	4,284	100%	€353,044,941	100%

Source: SLA Schedule 3 data (analysis by DoH Information Unit)

The Review conducted further analysis on the 20 service users with highest costs in order to confirm that the costs were correct and if so, to understand the reasons for the level of costs. With the assistance of the HSE, a short questionnaire was sent to the relevant service providers. An examination of the responses found that these service users had multiple conditions. Levels of intellectual disability were mixed: some fell into the Severe category, but some were designated as having Moderate and even Mild levels of intellectual disability. A small number had brain injuries. The common factor was extremely challenging behaviour (see below), most often in combination with autism and sometimes with mental health issues as well. Physical disabilities and

medical conditions were present in only a very small number of these clients and there was no evidence that these conditions were predictors of exceptional support needs.

CHALLENGING BEHAVIOUR

Reference has already been made to research by St. Michael's House, which found that the most significant cost drivers in its residential service units were challenging behaviour, medical issues (such as epilepsy) and mobility. Other service providers have indicated that the position is similar in their services. Challenging behaviour describes a range of behaviours, which may also be intermittent, and differs from individual to individual.

A research paper by Kissane and Guerin (no date), based on a comprehensive review commissioned and undertaken by the South Eastern Health Board in 2003/2004, defined challenging behaviour as follows: ' "Challenging behaviour" is a global term to describe severe problem behaviour that may include a variety of behaviours, including physical aggression, self-injurious behaviour and property destruction.' The researchers undertook a survey of services in the South Eastern Health Board region and found variable levels of challenging behaviour, from very low levels (0% in sheltered employment and 5% in rehabilitative training) to very high levels in residential settings (31% in community houses and also in life-sharing communities, rising to 55% in residential campus settings and 58% in psychiatric hospitals). The HSE's 2011 *Report of the Working Group on Congregated Settings* also sought to quantify challenging behaviour and found that about half of residents exhibited signs of challenging behaviour, which corroborates the findings in the Kissane and Guerin study.

Most service users with challenging behaviour are supported in residential settings with other service users, with perhaps a higher level of support and more staff time and resources than others living in the same setting. This was seen in Table 5.6 (see above), which set out the actual resource usage in a community-based residential unit. In only a very small number of instances, challenging behaviour may be so severe that it gives rise to exceptional resource requirements, particularly when there are other factors present, such as autism and/or mental health issues.

SERVICE USER CHARACTERISTICS AND UNIT COSTS

KEY FINDINGS

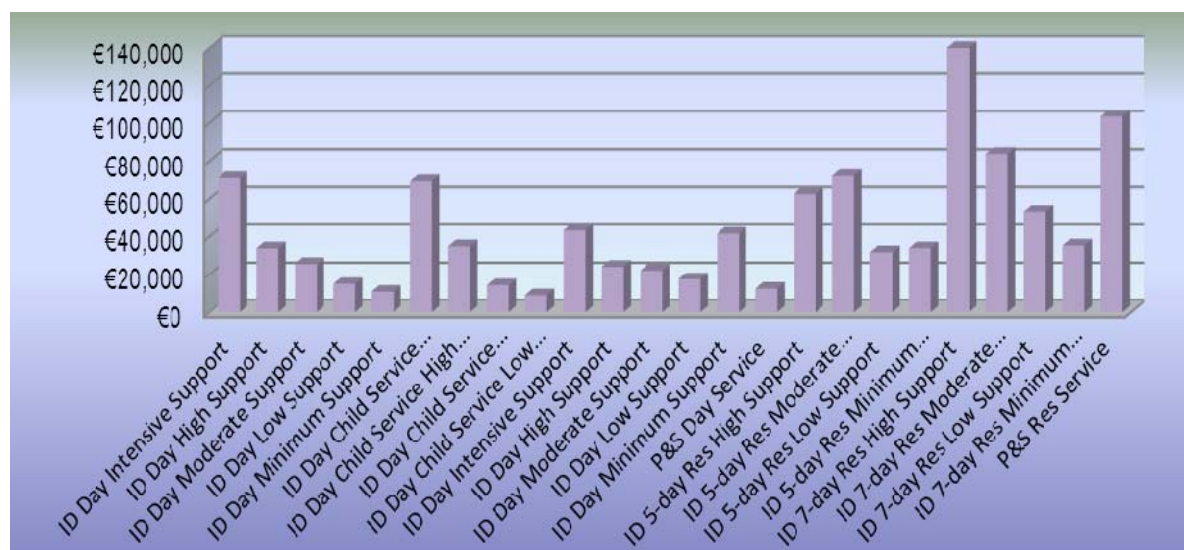
- ✓ There is a correlation between disability group and cost per person. High Support services for persons with autism only, or with autism and intellectual disability, are more costly than services to other disability groupings. [Finding 5.18](#)
- ✓ An examination of clients with the highest support costs found that these clients had complex needs, and in particular a combination of challenging behaviour and autism, sometimes with mental health issues as well. Physical disabilities and medical conditions were present in only a very small number of these clients and there was no evidence that they were predictors of exceptional support needs. This supported the analysis of unit costs by disability group, which found that the presence of autism on its own or in combination with intellectual disability had a greater effect on costs than the presence of physical disabilities. [Finding 5.19](#)

Unit costs – Service characteristics

Programme type is a primary cost driver, but must be considered in conjunction with other factors, such as disability group and service unit size.

One of the evaluation questions that VFM Reviews are typically required to answer is the relative cost-effectiveness of different programmes and whether a less cost-effective programme may be replaced by a more cost-effective one. Programme types in the disability sector include residential, day, respite, multidisciplinary, home support and personal assistance services. These programmes are further divided into sub-types, such as 5-day residential centre or 7-day community residential service, and so on. When details are aggregated on a national level, there is a strong correlation between the programme type and the cost per person (see Figure 5.10). As expected, residential services are, on the whole, more expensive than day services and 7-day residential services are more expensive than 5-day residential services. When the data are broken down into sub-types and client types, the distinction is reduced, so that an Intensive Support day place is more expensive than a 7-day residential Minimum or Low Support place. In the VFM context, this is not a particularly useful finding since an individual may need both services and one programme type is not an alternative or substitute for the other. Some programme sub-types do serve a similar purpose (e.g. personal assistance services and some day services), but these fall into the category of services with undefined outputs and outcomes that could not be costed within the confines of this Review. A standardised assessment of need process which focuses on the individual will identify the best fit between individual need and service type, and assist in the identification of service or support types which are less effective in meeting people's needs. Monitoring of service delivery trends at national level, including the monitoring of outcomes (see Chapter 6) will point the way to service types that are no longer fit for purpose.

Figure 5.10: Average annual cost per place, by programme type



Note: The costs used in this table as the basis for cost comparison have been calculated using a two-step calculation process. See 'Calculation of Comparator Costs' in Section 5.2.3, Table 5.7 and Table A5.2 in Appendix 5 for further details.

Source: SLA Schedule 3 data (analysis by DoH Information Unit)

SERVICE CHARACTERISTICS AND UNIT COSTS

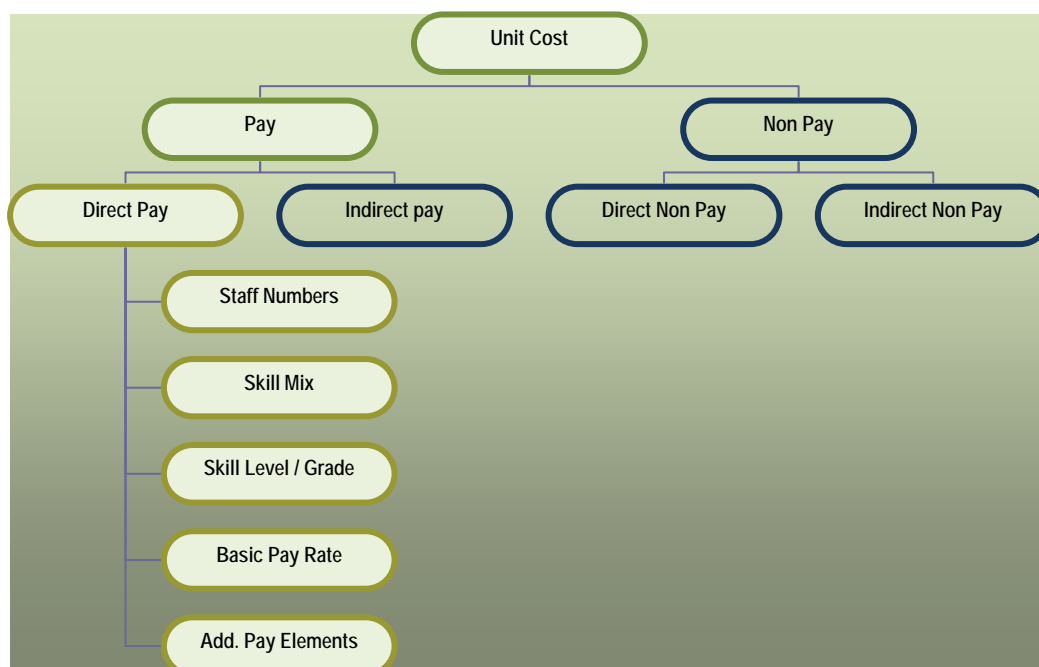
KEY FINDING

- ✓ When details are aggregated on a national level, there is a strong correlation between the programme type or sub-type, and the cost per person. But no useful findings can be drawn from this since many programmes and sub-programmes serve different purposes and different service user groups. The position will need to be kept under review in relation to sub-programmes, which may serve similar purposes but which could not be costed within the confines of this VFM Review. [Finding 5.20](#)

Unit costs – Staff characteristics

Direct pay costs contribute an average of 70% of total unit costs and reflect the combined effects of staff numbers, skill mix, skill level, basic pay and additional pay elements (premium pay). Variations in any of these components will affect the direct pay cost of providing a service. Since total unit costs are also comprised of indirect pay costs (central management costs, for example), which add another 10% on average to total unit costs, staffing factors will also have an effect on this element of overall costs (see [Figure 5.11](#)).

Figure 5.11: Staff characteristics affecting unit costs



ROSTERING

Rostering is the primary mechanism whereby inputs (staff) are deployed so as to create outputs (services or supports). The drawing-up of a roster includes decisions on the numbers, skill levels and skill mix of the staff required to be on duty at any given time and thus is key to the achievement of an efficient service. The optimum position is when sufficient staff of the appropriate skill type and skill level are working the hours and days which best meet the assessed need of the service user.

An important element of rostering is the assessment of the number and type of staff needed for overnight and weekend work, when additional payment rates apply. There are a wide variety of working arrangements that attract payments over and above a staff member's basic salary scale. These can be divided into two main categories: pay for additional hours (overtime) and pay for unsocial hours (premium pay).¹⁴

The standard premium rates used in the disability sector average out at 7% per annum on top of basic pay for people working in 5-day services (regardless of grade or profession) and 6%-17% for staff in 7-day agencies (6% for catering, domestic and care staff, and 17% for nursing and other professional staff). These rates represent the norm, but are not set by any formal agreement or directive, and some agencies pay over and above the norm. In 7-day settings, almost all non-management/administration grades are eligible for premium payments. Some agencies, including the HSE, pay different premium amounts across different locations.

Some professional staff with management responsibilities, such as Clinical Nurse Managers (CNM) or Social Care Leaders, are rostered for overnight and weekend work. There are no national guidelines on rostering and it is not clear whether there are local protocols within agencies determining the skill levels of staff required for out-of-hours work. Anecdotal evidence is that this may be down to local custom and practice, rather than because of an absolute need for management skills at these times of the day or week.

CROKE PARK AGREEMENT

The recommendations on the achievement of greater efficiencies in this Review are in line with the provisions of the Public Service Agreement 2010 to 2014 (the Croke Park Agreement), which says that: *'The parties will work together to implement this Agreement to deliver an ongoing reduction in the cost of delivery of public services along with excellent services to the public'*.

The required re-organisation of health services in the Croke Park Agreement (Part 2: Sectoral Agreements, Section 1, Health Sectoral Agreement) will focus on:

- (a) *providing, across all settings, planned services over an extended (8a.m. to 8p.m.) day on a Monday to Friday basis and/or five over seven day basis, while also providing emergency services on a 24-hour 7-day basis, thereby reducing the staffing and other resources required at nights and weekends;*
- (b) *achieving a more productive match between staffing and service activity levels across the working day/week/ year, while safeguarding quality and clinical performance;*

¹⁴ 'Additional hours' refers to overtime, on-call or stand-by arrangements, planned essential services and sleep-overs (8pm to 8am). 'Unsocial hours' form part of the individual's basic contracted hours, but attract a premium payment. The premium usually applies to work on Saturday, Sunday, Public Holiday, night work, shift work and twilight work. 'Twilight hours' are the hours between 6pm and 8pm, or the hours at the end of a roster. Where an individual regularly receives premium pay, this is included in the calculation of the person's holiday pay entitlement and also pension entitlement.

The Agreement recognises that the scale of organisational and service change envisaged will require robust consultation at national and local levels between management, staff and trade unions.

Among the measures to be implemented with immediate effect is the following:

‘[12.] Reviews by management, including nurse management, of existing rostering arrangements, including skill mix, to incorporate changes to achieve the optimal match between staff levels, service activity levels and patient dependency levels across the working day/week/year’.

These and other provisions of the Agreement echo the recommendations for organisational change reflected in this Review with the aim of achieving greater cost-efficiency, better service user outcomes and improved programme effectiveness.

IMPLEMENTATION OF CROKE PARK AGREEMENT

Disability agencies, in common with other public sector bodies, have been focused on achieving greater efficiencies due to the reduced resources and staffing constraints applied to them since 2009. Some organisations have found that the Croke Park Agreement has given them a framework within which to make the necessary changes. As an example, the Croke Park Agreement Implementation Body website (see <http://implementationbody.gov.ie/>) reports the following:

A number of intellectual disability services in the Dublin area have reported reaching agreements under the Croke Park Agreement which will deliver changed work practices, organisational reform and savings.

At St. Michael’s House, an agreement has been reached with SIPTU, IMPACT and the INMO. The agreement covers 1,542 workers and aims to save over €3m up to 2014. It involves an extended working day from 8am to 8pm, with staff available 5 days over 7, and a redeployment/re-assignment protocol. It also includes the introduction on a pilot basis of an online rostering system. A major part of the savings in the St Michael’s House agreement comes from the integration of the transport department with the day and residential services.

At Cheeverstown House, a cost-saving agreement has been reached which will deliver €435,000 in savings.

STAFF CHARACTERISTICS AND UNIT COSTS

KEY FINDINGS

- ✓ Pay and conditions, staff/client ratio, rostering practices and skill mix contribute significantly to unit costs. [Finding 5.21](#)
- ✓ Rostering practices are a primary determinant of cost-efficiency since they contribute significantly to total pay costs and the unit cost of providing services to specific individuals. There are no national guidelines on determination of staff/client ratios or rostering practices. [Finding 5.22](#)

KEY RECOMMENDATIONS

- ✓ Best practice guidelines should be developed or adopted by the HSE in respect of staff utilisation and deployment practices, with the aim of achieving the most productive match between staffing, service activity levels and client need, while supporting service quality and effectiveness. The guidelines should avoid being over-prescriptive so as to allow service providers to be responsive to new and innovative service arrangements. Indicative benchmarks should be established for staff/client ratios for different models of service and for different support needs, against which performance can be monitored. [Recommendation 5.23](#)
- ✓ In line with international developments, the mainstreaming agenda and the emerging policy proposals developed by this VMF Review's Expert Reference Group, skill mix should be examined by the HSE and by individual agencies to determine the extent to which service provision should be facilitated to move towards the provision of more flexible, person-centred supports. [Recommendation 5.24](#)
- ✓ As a precursor to the implementation of best practice guidelines, all agencies, including direct service units within the HSE, should be required by the HSE, within 6 months after publication of this VFM Review, to audit all rosters by documenting the number of clients and staff in each service unit for each hour of the day and night over a given period (to include a weekend). Each agency should submit details of the audit to the HSE and demonstrate to the HSE, as part of the SLA process, that they have critically reviewed each roster and made any adjustments necessary to rationalise staff deployment patterns across their service units, consistent with client need. [Recommendation 5.25](#)
- ✓ The HSE should, as a result of this exercise, be able to quantify the extent of efficiency improvements attained from this review of rosters (e.g. through reduced premia or overtime). [Recommendation 5.26](#)
- ✓ Agencies should not roster staff unless a service user's assessed support needs require the staff member's specific skill set and grade. For example, if the requirement is for a care assistant, social care worker or a basic nursing grade, then a Social Care Leader or a CNM Grade 1, 2 or 3 should not be rostered (except in exceptional circumstances). This applies to rosters during the standard working week, as well as during periods that attract premium payments. [Recommendation 5.27](#)
- ✓ Common IT solutions for rostering should be investigated by the HSE and initiatives such as the planned Donegal Integrated Service Area eRostering Project kept under review (this is a pilot project and still at an early stage of development). The feasibility of interfacing rostering, HR and payroll administration systems should also be considered within the HSE's overall IT strategy, so as to facilitate the monitoring and control of rostering practices and costs. [Recommendation 5.28](#)

Conclusion on cost drivers

Some cost drivers, such as challenging behaviour, mobility and medical condition, have already been mentioned. Overall, this Review could not test for the effects of these factors individually, but following discussions with service providers formed the view that the staff/client ratio data collected on the SLA schedules were a useful proxy for the combined effects of the most significant client-related drivers. The only drawback was that some of the bands used to categorise staff/client ratio were very wide and not flexible enough to cater for some staffing scenarios. For example, the highest support category in residential services was Intellectual Disability Residential High Support (i.e. two staff on duty plus on-duty night staff), which did not specify the number of night staff on duty and did not capture instances where there were more than two staff members on duty during the day. Also, it did not cater for service units where there were fewer requirements for day support and more for night cover, or vice versa.

Some staff-related cost drivers could be broadly assessed on the basis of SLA data, such as staff mix and staff numbers, but the relative contribution of these factors and the interplay between client-related drivers and staff-related drivers could not be isolated. A bottom-up approach, based on a combination of determining client need and calculating the cost of providing services to that client, would provide greater flexibility in the future to identify the contribution of individual cost drivers to overall costs. Non-pay cost drivers need to be considered separately and are influenced by a range of factors, some of which are national issues (such as pay rates and utility costs) and others local (such as geographical location, size and condition of buildings, transport arrangements, management structures and procurement practices).

Basis for funding decision – New places

While acknowledging the variation in the types of services and supports provided, a very significant body of data has been analysed and the view formed that it is fair to compare the actual average costs of a range of places and the flat costs used to fund day and residential services for over a decade. The average cost of an Intellectual Disability 7-Day Residential place varies from €35,000 for a Minimum Support place to €140,000 for a High Support place. Since service users who receive High Support services form the biggest cohort of those in residential services, it is clear that the flat rate cost (currently €70,000 per residential place per year) does not come close to matching the actual cost of providing many places.

The result has been that the funding for a notional place has sometimes through negotiation between the HSE and service providers provided enough resources for two people, and conversely one person has required to be funded by two notional places (i.e. €140,000 rather than €70,000). In other instances, the cost of a High Support place would have been informally subsidised by the funding received for a place with lower support needs.

A similar pattern is observed in day service provision. Costs for day activation and support range from €8,000 for a Minimum Support place to €70,000 for an Intensive Support place. The largest number of service units fall into the High Support category, at an average cost of €33,000. Since the flat rate fee per place allocated by the HSE was €18,000 in 2009 (and has since fallen to €14,000), it is clear that the notional cost per day place bears little resemblance to the actual cost of a day place. Moreover, there is also the difficulty, mentioned earlier, about the definition of what exactly constitutes a WTE day place since the types of day services provided and the hours/days of attendance per week vary from individual to individual and from service unit to service unit.

This divergence between allocated cost per residential and day place and the actual cost per place widens further over the years, since an individual's service requirements eventually increase rather than decrease over time. Age-related needs, mobility issues and general medical needs are significant cost drivers. But once the funding for an individual is allocated, it is absorbed into an agency's base allocation and not re-assessed to take account of increasing or decreasing needs. The result has been that it is almost impossible to track the number of places created from the amount of new development money expended since the only way the system could continue to operate has been for massive cross-subsidisation of places and services.

While allocations have not been 'index-linked' to changing client needs, it should also be noted that neither have they declined in response to decreasing client numbers. This has not been an issue to date since an examination of the data will show that the overall numbers in receipt of services have not declined over the years, although there may be instances where numbers in individual services or service units have declined. Places vacated when an individual leaves a service are either back-filled from the agency's waiting list or the funding is used to improve the quality of the service provided to the other clients or to offset the deficit caused by changing client needs. However, in the future, places vacated should be monitored on a more formal basis so that the full picture of client movement into and out of services is available to the HSE.

Basis for funding decision – Existing places

The basis of funding the Disability Services Programme has been described in Chapter 3 and the use of notional flat rate costs has been further examined above. As a method of allocating resources, its limitations are obvious, to the extent that it cannot reasonably be described as a 'resource allocation model', which usually refers to a more systematic and evidence-based way of managing a budget and cascading it downwards until the point where the resources allocated fund a single output and outcome.

A recent study by the Expert Group on Resource Allocation and Financing in the Health Sector (2010) described resource allocation as follows:

'Resource allocation (RA) is a procedure for distributing resources between competing claims in order to achieve certain pre-specified goals. RA is an essential function of any government that is providing public services; in particular, it has become a major focus of work in health service planning in many countries. Active RA is driven by the need to achieve efficiency and equity in healthcare provision, regardless of the mechanisms by which these services are provided. The goal is to develop a sustainable and defensible method of distributing resources between areas ... The two central questions to be posed when considering any resource allocation process are: what is to be allocated and what purpose is intended to be achieved as a result of the allocation?'

The study identified three major resource allocation models: models based on individual health utilisation and demographic data (as in the Swedish model), those based primarily on small-area data (as in the English and Scottish models) and those based on direct assessment of health needs (as in the Welsh model). The study concluded that the best option for the Irish health services would be based on the Welsh model, which was described as follows by the Expert Group (*ibid*):

'Resource allocation in Wales was reviewed in 2001. This resulted in the introduction of a model that was based on measures of direct need, and was designed to improve overall health and reduce health inequalities. This novel approach involved an initial budget allocation to the various areas of service provision, followed by distribution within each small health area according to objectively measured levels of need. Estimates of direct health needs were based on a series of health condition indicators, which were developed from epidemiological and service-level data.'

The National Disability Authority (NDA) has conducted extensive research on resource allocation methodologies for disability services and produced a discussion paper on the subject during 2011, entitled *The Introduction of Individual Budgets as a Resource Allocation System for Disability Services in Ireland* (NDA, 2011). It proposes a model of individualised funding, which is defined 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 need’.

Building on its earlier work, the NDA is currently engaged in a feasibility study, which will report in the second half of 2012. During the course of this study, two methodologies for resource allocation – costing and needs assessment (SIS and In Control) – are being tested in parallel across a range of sites. By studying two established tools, the NDA intends to advise Government later in 2012 on the key issues for consideration in the implementation of a resource allocation process in Ireland.

While this VFM Review is not in a position to recommend a particular resource allocation model, the core elements of one are an assessment of individual need and an indication of the resources available to meet that need, calculated by reference to population profile and total budget (this may be full cost of meeting the need or a contribution towards the cost calculated by reference to the total amount available locally, regionally or nationally). Whichever model of resource allocation is adopted for the disability sector should take into account any overarching national decisions by the Minister for Health on resource allocation for the wider primary, community and continuing care sector.

Migration towards an evidence-based resource model will require a disentangling of the cross-subsidisation that exists at present, until the point is reached that the funding provided to an agency for the provision of a specified service or support matches the actual cost of providing that output. In many cases, if not all, the link between costs and services has become so blurred that the process will be gradual and must be carefully planned and monitored so as to avoid destabilising an agency’s financial base.

FUNDING NEW AND EXISTING PLACES

KEY FINDING

- ✓ There is little correlation between the notional cost per place used for planning and funding purposes and the actual cost of providing services. [Finding 5.23](#)

KEY RECOMMENDATIONS

- ✓ The practice of funding places on the basis of a flat rate fee should be discontinued and should be replaced on the basis of standard costs to be calculated by reference to the VFM Review data for a range of service types, set out in Table 5.18, pending the migration to the recommended resource allocation model in due course. [Recommendation 5.29](#)
- ✓ For the purpose of funding new and existing places, the elements that make up a package of services or supports should be capable of being disaggregated, so that the HSE has the flexibility to mix and match elements of services to best meet the needs of the individual. This might mean that funding is provided to purchase the residential element of an individual’s supports from one provider

and the day element (if required) from another, or that a place is funded with or without multidisciplinary care (e.g. where these services are not required, are sourced from a third party or are provided through community mainstream providers). The disaggregation of service costs will also facilitate development of the 'personal budget model' referred to in the current Programme for Government, *Government for National Recovery 2011-2016* (Department of An Taoiseach, 2011). [Recommendation 5.30](#)

RESOURCE ALLOCATION MODEL

KEY RECOMMENDATIONS

- ✓ A standard resource allocation methodology should be developed or adopted by the HSE, starting in 2012, building on the work done by this Review and the NDA. It should also take into account any overarching national decision on a resource allocation model for the wider primary, community and continuing care sector. Full migration to a national resource model will be a medium-term objective, which will require significant effort and strong change management skills. It will also require capacity issues to be addressed. [Recommendation 5.31](#)
- ✓ The methodology should support an equitable allocation of available resources, be transparent and be consistently applied, but also allow for innovation and flexibility on how needs are met and how resources are utilised. The methodology would be linked to the deployment of a standardised assessment method. [Recommendation 5.32](#)
- ✓ A resource allocation methodology should make provision for exceptional or non-standard levels of care, but should equally guard against too many places falling into the 'non-standard' category, and the HSE should develop a mechanism for monitoring this process. [Recommendation 5.33](#)
- ✓ The HSE at national level should engage in negotiation with the larger service providers on funding issues. As part of the implementation of any resource allocation model, there should be provision for the adjustment of funding through the mechanism of the SLA process to take account of increasing service user needs or decreasing service user numbers, wherever this applies. The result will be that the allocation may increase or decrease based on the standardised assessment of actual need, rather than on the basis of an incremental determination. [Recommendation 5.34](#)
- ✓ The migration towards an evidence-based resource allocation model should address the current cross-subsidisation of services and so should be carefully planned and monitored. [Recommendation 5.35](#)

Funding for New and Existing Places: Immediate Actions

The case has been already made in Section 5.2 that funding should be allocated on the basis of a resource allocation model and that work on this model should start immediately. The process of developing or adopting a resource allocation model, testing and refining it, and allocating the totality of specialist disability funding using the model, will take time and its completion will be a medium- rather than a short-term objective. With that in mind, the immediate priorities are to move to a more rational basis for the allocation of funding, to address the variations in unit costs identified in this chapter and to achieve greater efficiencies and make more effective use of scarce resources. Taking these considerations into account, the Review has reached the conclusion that the HSE should work with agencies from 2012 onwards through the mechanism of the SLA process to reduce costs to the average costs identified in this Review and set out in Table 5.18.

The Review is satisfied that these average costs provide a fair and equitable target for funding decisions. The dataset on which the costs were based represents around 95% of all service units in the country. The data was supplied to the HSE directly by the service providers in the context of service level arrangements for 2009.

In calculating the recommended average costs in Table 5.18 below, the spread of unit costs has been examined, and outliers have been removed (*on the basis of two standard deviations from the average*) to take account of exceptional cases and militate against the potential effects of any errors significant enough to distort results. The results have also been adjusted to take account of reductions in direct pay in 2010-2012.

Table 5.18: Recommended target pay cost per place

Programme type ID = intellectual disability P&S = physical and sensory disability	Level of support	Average annual cost per place: direct pay, 2009	Target annual cost per place: direct pay, including 5% reduction on 2009 costs
Day services for adults with ID: Activation and day support	Intensive Support	€39,143	€38,000
	High Support	€23,260	€22,000
	Moderate Support	€15,811	€15,000
	Low Support	€8,787	€8,500
	Minimum Support	€5,465	€5,000
Day services for adults with ID: Work-like activities	Intensive Support	€18,908	€18,000
	High Support	€16,783	€16,000
	Moderate Support	€14,511	€14,000
	Low Support	€10,621	€10,000
	Minimum Support	–	<i>to be decided</i>
Day services for children with ID	Intensive Support	€29,399	€28,000
	High Support	€22,953	€22,000
	Moderate Support	€7,230	€7,000
	Low Support	€6,245	€6,000
Day services for people with P&S disabilities only		€7,579	€7,000

Programme type ID = intellectual disability P&S = physical and sensory disability	Level of support	Average annual cost per place: direct pay, 2009	Target annual cost per place: direct pay, including 5% reduction on 2009 costs
5-day residential services for people with ID	High Support	€43,537	€42,000
	Moderate Support	€42,067	€40,000
	Low Support	€20,822	€20,000
	Minimum Support	–	<i>to be decided</i>
7-day residential services for people with ID	High Support	€92,077	€88,000
	Moderate Support	€57,757	€55,000
	Low Support	€35,059	€33,000
	Minimum Support	€ 21,489	€21,000
Residential services for people with P&S disabilities only		€68,645	€65,000

Note: The costs used in this table as the basis for cost comparison have been calculated using a two-step calculation process. See 'Calculation of Comparator Costs' in Section 5.2.3, Table 5.7 and Table A5.2 in Appendix 5 for further details.

Source: SLA Schedule 3 data (analysis by DoH Information Unit)

The Review has decided that the move towards funding on the basis of average costs should be applied to direct pay costs only, in the first instance, since direct pay costs come to around 70% of total expenditure on relevant day and residential services¹⁵, the data is easily collectible via the SLA process, and is already available, reasonably accurate and complete. Although non-pay costs will not initially be used in the calculation of the average cost per place for funding purposes, the necessity to reduce global non-pay costs by service providers will apply, as recommended in Chapter 4 (*see Recommendations 4.9 to 4.16*).

In making funding allocations, the HSE will need to take into account that the cost of providing multidisciplinary services is not included in the basic direct pay cost and to add an appropriate sum to cover these services, where provided, based on the quantum and type of services to be funded.

The HSE should also decide on a reasonable amount to cover non-pay costs and central administration, taking local factors into account when deciding on the total funding to be made available to an agency. Where an individual is receiving both residential and day services from the same agency, the HSE may consider on a case-by-case basis whether it is reasonable to reduce the total allocation for that person to take account of potential duplications in staffing, non-pay and overheads, and adjust the allocation accordingly. Taking the above factors into account, allocations by the HSE, pending the introduction of a resource allocation methodology, should be comprised of the following elements:

- a basic cost per person per residential and day service, based on the direct pay costs identified by the VFM Review and set out in Table 5.18;
- an additional amount to cover overheads (non-pay and indirect pay) calculated on the basis of a percentage of the basic cost per person;
- an additional amount to cover multidisciplinary services, which is dependent on the quantum and type of services provided to the individual.

¹⁵ This 70% does not include central management and other indirect pay costs. When all pay costs are added in, the total amount spent on pay is approximately 83.5% (*see Chapter 4, Section 4.4.2*).

The percentage to be added to the basic cost per person in respect of overheads (non-pay and indirect pay) costs should be calculated on the basis of actual costs collected through the SLA process. As more accurate data on non-pay costs become available through the SLA process (*see Recommendation 8.1.b*), funding on the basis of an average cost per place should be extended to include direct and indirect non-pay costs, as well as indirect pay costs (i.e. the full cost of providing a place).

Through further refinement and analysis of the SLA data, the HSE may consider adjusting *resource usage groups* and *level of support* to more accurately reflect the distribution of costs by intensity of care category and moving towards the funding of multidisciplinary services, non-pay and overheads according to a set scale of costs, or a percentage of direct pay costs.

FUNDING NEW AND EXISTING PLACES: IMMEDIATE ACTIONS

KEY FINDING

- ✓ An evidence-based method of allocating funding is required in the short to medium term pending the implementation of a resource allocation model. [Finding 5.24](#)

KEY RECOMMENDATION

- ✓ The most immediate priority is to move to funding on the basis of the lower average costs identified by this Review: pending the implementation of a resource allocation model, the HSE should work with agencies from 2012 onwards through the mechanism of the SLA process to reduce current direct pay costs to the levels set out in Table 5.18, based on data given by agencies in respect of staff/client ratios on their 2009 SLA Schedule 3 returns. This should be followed as soon as practicable (based on data availability and quality) by funding the full cost per place, including direct and indirect non-pay costs and indirect pay costs, on the basis of nationally determined average costs. It will be important that the HSE takes steps to ensure that agencies adopt a consistent approach to staff/client ratios, the categorisation of clients and costs by resource usage groups, together with the collection and apportionment of non-pay costs by service unit. This should provide for fairness and equity in the application of average costs for funding allocation purposes (*see Chapter 8 for SLA recommendations*). [Recommendation 5.36](#)

Note: 'Direct pay cost' is the cost of the staff who directly provide a day or residential service to an individual, and is calculated by dividing the total pay cost of a service unit on the SLA Schedule 3 form by the number of service users in that unit.

5.3 CONCLUSION

An objective determination of value for money (VFM) and efficiency is dependent on extensive supporting quality and outcomes data (see *Chapter 6*) and empirically derived costs for a range of standardised service types. The information does not currently exist in the disability sector (and consequently was not available to this VFM Review) to allow such a determination to be made. An examination of the available data shows that in general some agencies or agency types are more cost-efficient at one particular type of service and less cost-efficient at another. Some models of service are extremely cost-efficient, but would score poorly on any 'quality of life' measure. Other types of service are cost-efficient and support the move to social inclusion and mainstreaming. The remaining services should become more cost-efficient during the period of transition from less supportive to more supportive services.

The overall key findings and recommendations on the theme of this chapter, 'How efficient are disability services?', are presented below.

EFFICIENCY

KEY FINDINGS

- ✓ There is a wide variation within agencies, sectors and regions in the cost of providing what may, on the surface, seem to be similar services and there are many contributory factors that explain why services have developed in this way. [Finding 5.25](#)
- ✓ There are interesting disparities in unit cost data across various headings, which suggest the potential for efficiency improvements in comparable categories. While some differences are due to quality considerations or client characteristics, this cannot reasonably explain many areas of difference. The areas where the most variation occurs have been highlighted and areas identified for further examination by the HSE on completion of this Review. [Finding 5.26](#)
- ✓ Some of the variation in costs is due to factors influencing the amount of resources consumed by an individual service user. Some of these factors can be assessed and have been detailed in this chapter. [Finding 5.27](#)
- ✓ The contribution of other factors (such as challenging behaviour, mobility and medical condition) to the cost of providing services and supports to individuals cannot be assessed on the basis of the available evidence. [Finding 5.28](#)
- ✓ There is no evidence of a rational basis for resource allocation, which is based largely on a combination of historical factors and emergency demographic pressures. There is a considerable divergence between the *notional* cost per residential and day place used in the allocation process and the *actual* cost per place. As a result, it is very difficult to track the number of places created from the amount of new development money expended since the only way the system could continue to operate has been through very extensive cross-subsidisation of services and supports. [Finding 5.29](#)

KEY RECOMMENDATIONS

- ✓ Quality service user outcomes that meet the stated objectives of the Disability Services Programme should be of paramount importance. Funding should be allocated on the basis of measurable service user outcomes and this should become part of the resource allocation process. The HSE should be responsible for ensuring that agencies are held accountable for the achievement of these outcomes. [Recommendation 5.37](#)
- ✓ The achievement of measurable outcomes and quality for service users at the most economically viable cost should be an ongoing process and be subject to regular review and audit. Regular review meetings linked to the SLA performance monitoring cycle should be held between the HSE and the service providers to discuss performance in this regard (*see Chapter 3 for details of the HSE's service monitoring procedures*). [Recommendation 5.38](#)
- ✓ There should be a focus in every organisation in receipt of public funding on driving efficiency on an ongoing basis contingent on client need within a value-for-money framework. This should be coupled with a more sophisticated risk assessment and management process. [Recommendation 5.39](#)
- ✓ Driving efficiency within an organisation should be the responsibility of its chief officer, who will report to the HSE on efficiency gains on an ongoing basis as part of the SLA monitoring process. An organisation's achievements or otherwise in respect of efficiency should be taken into account by the HSE when negotiating the organisation's annual funding requirements. [Recommendation 5.40](#)
- ✓ The HSE should maintain a purchaser/provider split between the persons responsible for its commissioning function and the persons responsible for the direct provision of services. The relationship between the HSE's own internal disability service providers and the HSE's commissioning officers (ISA Managers/ Disability Managers) should to all intents and purposes be on the same footing as the relationship between the HSE and any other service provider. SLAs should be signed by the HSE's internal disability service providers and the same monitoring and accountability process should operate. [Recommendation 5.41](#)
- ✓ On completion of this Review, there should be an immediate and robust examination within each agency of the findings and recommendations of the Review and agency-level plans should be drawn up to put relevant recommendations into effect. At a regional and national level, the Consultative Fora will provide a platform through which the stakeholders can engage with the VFM Review and the actions that will emanate from it. [Recommendation 5.42](#)

Chapter 6: How effective are disability services?

The aim of this chapter is to consider the effectiveness of the disability service in terms of the outcomes achieved and the quality of those outcomes. Methods of setting and measuring outcomes are discussed, together with the standards used to assess whether they have been achieved. Service user outcomes are further analysed under a number of headings and the findings of service user consultations are described.

6.1 HOW IS EFFECTIVENESS MEASURED?

6.1.1 WHAT IS QUALITY?

Quality in disability services has been defined as *'meeting the assessed needs and expectations of service users by ensuring the provision of efficient and effective management and processes'*, while a standard is *'a measure by which quality is judged'* (HIQA, 2009).

A quality framework provides an overarching structure by which quality is at the centre of the organisation's focus. An organisation that is focused on quality uses the information gained from measuring progress against standards so as to continuously assess and improve the quality of life and outcomes of the individuals who receive services and supports. A quality assurance system provides a methodology for the practical day-to-day implementation of the quality assessment and improvement cycle (as illustrated here).



6.1.2 HOW IS QUALITY MEASURED?

Outcomes are the results of services and supports on those who avail of them. The outcomes and impacts achieved by disability services are measured by reference to their quality. Standards are used in order to monitor, measure and maintain levels of quality.

There are two questions to be considered in assessing quality: *effectiveness* (meaning whether the right outcome is being achieved) and *efficiency* (whether the outcome is being achieved with least resources). A cost-efficient outcome is not sufficient if the outcome suggests ineffectiveness, and vice versa.

Quality standards tend to focus on service provision and the physical environment, while quality of life measurement focuses on the individual supported by the service. To get a full picture of the effectiveness of a service, it is necessary to take both *quality standards* and *quality of life measures* into account to ensure that basic requirements are met, on the one hand, and to ensure best outcomes are achieved for the individual service user, on the other (see Table 6.1).

Table 6.1: Key concepts

Quality	<ul style="list-style-type: none"> Meeting the assessed needs and expectations of service users by ensuring the provision of efficient and effective management and processes. (HIQA)
Quality Standard	<ul style="list-style-type: none"> A measure by which quality is judged. <i>Standard statements</i> set out what is expected in terms of the service provided to the person receiving the service or support. The <i>standard statement</i> lists the criteria that indicate how a service may be judged to meet the standard.
Quality of Life Indicator	<ul style="list-style-type: none"> Framework for looking at the areas which are of importance to people. May be considered under a number of headings, or domains. A commonly used set of domains is: <i>Physical well-being, Emotional well-being, Interpersonal relations, Social inclusion, Personal development, Material well-being, Self-determination, and Rights.</i> (Schalock and Verdugo, 2002)
Quality Assurance	<ul style="list-style-type: none"> Quality assurance systems measure and improve the processes used to produce quality outcomes and meet quality standards.
Outcomes and Effectiveness	<ul style="list-style-type: none"> Outcomes are the effects on the individual of the services or supports received. Outcomes refer solely to the effects of the services on the individual whereas quality encompasses wider issues and tends to focus on processes, including governance and administration. Outcomes may be influenced by factors other than quality, such as the individual's level of adaptive ability, degree of intellectual disability, personal characteristics, or medical condition.
Outcome Measurement	<ul style="list-style-type: none"> A mechanism for measuring the effects of services or supports on individuals. Some Irish services have voluntarily implemented a quality system which includes outcome measurement. The three main systems used by Irish services – the EFQM, CQL and CARF – are well established and internationally recognised.

6.1.3 QUALITY STANDARDS

There are currently no systems of monitoring or inspection in place for services provided to people with disabilities. While the relevant sections of the Health Act 2007 have not as yet been commenced in respect of the registration and inspection of designated centres for people with disabilities, the Health Information and Quality Authority (HIQA) has prepared and published *draft* standards for this sector, called the *National Quality Standards: Residential Services for People with Disabilities* (HIQA, 2009). These outline what is expected of a provider of services and what a person with a disability, his or her family, and the public can expect to receive from residential care services.

The current Programme for Government includes a commitment to put the residential standards on a statutory footing and to ensure that the services are inspected by HIQA. Discussions have begun between the Department of Health and HIQA to progress this commitment. Given the complex nature of residential service

provision for people with disabilities – ranging from congregated settings to dispersed housing in the community – careful consideration is being given to designing the most appropriate regulatory model.

6.1.4 QUALITY ASSURANCE

Quality assurance systems have been developed to measure and improve the processes used to produce quality outcomes and meet quality standards. A number of quality systems are in operation in the health and personal social care sector. A review of the literature conducted by the HRB (Mongan, 2011) on behalf of this Review found that:

‘In Ireland some services have voluntarily implemented a quality system; and the three systems that are used by some Irish services – the EFQM, CQL and CARF¹⁶ – are well established and internationally recognised systems. There is little evidence in the literature in relation to their effectiveness, but each system contains elements of both quality assurance and quality improvement and all systems would be useful for disability services who wish to assess quality and identify both strengths and areas for improvement.’

HIQA (2009) has defined the dimensions of a person-centred quality service as consisting of the following elements: quality of life; staffing; protection; health and development; rights; the physical environment; and governance/management.

6.1.5 QUALITY DRIVERS

Research to date has indicated the importance of supportive staff and, to an extent, institutional climate as key factors that influence quality. Studies have also repeatedly shown that indicators of basic resources (e.g. costs, staffing ratios, staff qualifications and staff skills) have little or no association with quality (NDA, 2007). A study by Emerson *et al* (1999) on *Quality and Costs of Residential Supports for People with Learning Disabilities* concluded:

‘The existing evidence suggests highly complex relationships between user characteristics, resource and non-resource inputs and outcomes. Thus it appears likely that such factors as: the age, gender, ability and challenging behaviour of users ...; resources available ...; selected structural aspects of the service ...; and aspects of the internal organisation and management of the service ... are all likely to be related to variations in quality.’

A subsequent study by Emerson *et al* (2000) on people with severe and complex disabilities confirmed these findings:

*‘Analysis of the relationship between costs and quality across participants failed to reveal strong associations between costs and quality ... The weak association between costs and quality is consistent with the results obtained in the parent study (Emerson *et al*, 1999). It is also consistent with the results of the existing literature, which has consistently demonstrated an, at best, tenuous relationship between costs and quality in residential supports for people with intellectual disabilities (Emerson and Hatton, 1994, 1996; Stancliffe and Lakin, 1998).’*

¹⁶ These acronyms mean: EFQM = European Foundation for Quality Management; CQL = Council on Quality and Leadership; CARF = Commission on Accreditation of Rehabilitation Facilities.

Thus, the nature of the support provided would appear from the studies to be of more importance in providing a quality service than the number or professional qualifications of the staff.

QUALITY

KEY FINDINGS

- ✓ There is no nationally agreed quality framework in disability service provision. The implementation of HIQA standards in respect of residential services will go much of the way towards setting and monitoring quality standards for residential services. The standards do not address the emerging model of community-based residential supports or other domains of personal outcomes. [Finding 6.1](#)
- ✓ Some service providers have implemented quality assurance and outcome measurement systems, but these are not universally applied. [Finding 6.2](#)
- ✓ The SLAs do not currently provide sufficient information to be useful in national monitoring of quality systems implementation. [Finding 6.3](#)

KEY RECOMMENDATIONS

- ✓ Guidelines for a National Quality Framework should be developed. The framework should:
 - address standards, inspection or audit, monitoring, quality assurance systems, person-centred planning/outcome setting, and outcome measurement;
 - be implemented by each service provider.[Recommendation 6.1](#)
- ✓ In the absence of day service standards being set and monitored by HIQA, the HSE should establish a framework whereby they can satisfy themselves, within the context of the SLA process, of the quality of day services provided and outcomes achieved, through dissemination of quality assurance guidelines, self-evaluation and continuous quality improvement protocols. [Recommendation 6.2](#)
- ✓ Outcomes should be defined at personal, organisational and programme levels. Outcome measurement should be implemented at all three levels. [Recommendation 6.3](#)
- ✓ Agencies should be encouraged to engage in continuous quality assessment and improvement, preferably by the use of an internationally accepted methodology such as EFQM, CQL or CARF. Current work to develop an outcomes-focused performance framework for multidisciplinary therapy services for children and young people with disabilities may be instructive in this context. [Recommendation 6.4](#)

6.2 HOW ARE OUTCOMES MEASURED?

6.2.1 MEASUREMENT OF SERVICE USER OUTCOMES

There is no common national definition of the outcomes expected from the disability services and consequently there is a lack of information on what outcomes are being achieved. The 2005 Report 52 of the C&AG on disability services found that *'the evaluation of outcomes is hampered by a failure to specify desired outcomes in service level agreements'* (C&AG, 2005). The position has not changed materially in the intervening period.

This Review was unable to identify sources of data in the system that would provide evidence on specific outcomes achieved for the expenditure incurred. Instead, for most service areas it has been necessary to consider the available evidence on outcomes generally.

The report of the Expert Reference Group on Disability Policy (2011) states:

'There is a very limited amount of information on the quality of life of people using disability services in Ireland. There is also a very limited amount of information on the outcomes for these individuals, that is, what is the effect of the disability services on those who use them? There is a presumption that provision of services leads to better quality of life, but this is not necessarily the case. In fact, the available information shows that most of those using disability services do not participate in society in any meaningful way; are not given the opportunity to work or contribute to society. A significant proportion live in segregated settings apart from the general community and live with other people, in some cases many other people (over 4,000 people live in settings with more than 10 beds [HSE, 2011]). Overall, people using disability services have little opportunity to self-determine or to live full and independent lives.'

In the case of residential services, the DoH conducted a questionnaire-based survey of residential services and the results informed the work of the VFM Project Team (see Section 6.3.4 below for further details).

Because of the absence of outcome measurement, it has not been possible for the VFM Review to empirically determine whether individual service types are delivering acceptable outcomes or not. However, the evidence from the questionnaires, the Congregated Settings report (HSE, 2011) and the Adult Day Services Review (HSE, 2012a) has provided significant information in this regard. There is no evidence that any major service or support types should be discontinued. However, some rather significant issues have been pinpointed in the way in which services and supports are delivered, funded and evaluated (see also Chapters 5 and 7).

6.2.2 FACTORS INFLUENCING OUTCOMES

Much research has been done in other jurisdictions on aspects of outcome attainment for people with disabilities. Many of these studies have found that differences in outcomes are strongly associated with the personal characteristics of the individual with intellectual disabilities, and in particular with their level of intellectual disability or adaptive behaviour (Walsh *et al*, 2007).

Where the evidence is available on the effects of residential circumstances on outcomes, it generally indicates that outcomes are better in smaller settings. A review of supported living and group homes in the UK by Emerson *et al* (2011) showed that better outcomes are observed for those residing in smaller group homes (1-3 co-residents) compared to those living in larger dwellings (4-6 co-residents). Residents in smaller group homes reported less 'depersonalisation' and larger social networks, and were considered at less risk of abuse from co-residents than their counterparts in larger group homes. This UK study, along with other research reports on outcomes in residential settings, provided an input into the work of the HSE's Congregated Settings Group.

6.2.3 OUTCOME MEASUREMENT SYSTEMS

The National Disability Authority (NDA) conducted extensive research during 2009-2010 on international outcome measures in disability services provision (NDA, 2010c). From this research, the NDA found that while there is a move towards the development of mechanisms to measure outcomes and impacts, none of the jurisdictions have yet completed this process. However, four emerging models of outcomes measurement (England, Scotland, Victoria (Australia) and the USA) were identified and relevant work is also being undertaken by the EU-funded network ANED (see www.disability-europe.net/).

On the basis of its research, the NDA concluded that *'The Victorian model [Australia] seems to merit further consideration when more information is released into the public domain, along with those used in England, Scotland and the USA.'*

6.2.4 CORRELATION BETWEEN OUTCOMES AND EXPENDITURE

The challenge for this VFM Review was to form an assessment of quality of life measures and try to understand the links, if any, between quality of life, service user outcomes and expenditure.

International evidence suggests that quality and costs are not strongly interrelated (Walsh *et al*, 2007). It cannot be assumed, therefore, that an expensive service produces better outcomes and that a less expensive service has less effective outcomes. There have been many studies on the costs of de-institutionalisation and the consensus is that community living, by and large, is more cost-effective than institutional services, although not necessarily cheaper, particularly in Europe (Mansell *et al*, 2007; Mansell and Beadle-Brown, 2009).

In some instances and for some client groups, institutional services may, on the face of it, appear more cost-efficient. However, in a lecture delivered to the NDA's Annual Conference in 2009 by one of the foremost international authorities in this field, Jim Mansell (Emeritus Professor of Learning Disability in the Tizard Centre at the University of Kent, England, and Professor of Disability Studies at La Trobe University, Melbourne, Australia) explained that cost comparisons that appear to make institutional living less expensive than community living cannot be sustained since these comparisons are generally grounded in inadequate staffing and quality of life in the institutions, which, when they are rectified (which almost inevitably they will have to be), will push their costs up (Mansell and Beadle-Brown, 2009).

Professor Mansell also said: *'The main element of cost is staff, so lower costs – or economies of scale – mean less staff support per resident. Congregate care settings – whether they are old long-stay institutions, residential campuses or clusters on one site – might appear to cost less, but if they do it will be because they are providing fewer staff. For people with less severe disabilities, this may not matter so much so long as they*

are free to live the life they choose in decent circumstances in the community. Recent research illustrates this (Stancliffe and Keane, 2000; Felce et al, 2008). For people with severe and profound disabilities, however, less staff support is likely to mean poorer quality of life.'

OUTCOMES

KEY FINDINGS

- ✓ There has been little progress to date in developing national outcome indicators, as recommended in the C&AG's (2005) Report 52 on disability services. [Finding 6.4](#)
- ✓ In the absence of national indicators, other inputs have been taken into account, but have not provided any evidence that any service or support should be discontinued, but rather have highlighted where major changes are required. [Finding 6.5](#)
- ✓ International evidence suggests that quality and costs are not strongly interrelated. It cannot be assumed, therefore, that an expensive service produces better outcomes and that a less expensive service has less effective outcomes. [Finding 6.6](#)

KEY RECOMMENDATIONS

- ✓ A methodology for the measurement of outcomes and impacts should be developed or adopted, with the assistance of the National Disability Authority. In developing or adopting the methodology, the models currently being developed in Victoria (Australia), England, Scotland and the USA may provide useful templates. [Recommendation 6.5](#)
- ✓ Outcomes should be measured in the first instance by service providers as part of the assessment of the individual's person-centred plan. This data should feed into a tiered set of performance indicators at agency level and national level, and feed into resource allocation and performance monitoring processes. [Recommendation 6.6](#)
- ✓ Outcome measurement at national level should feed into a process of continuous assessment on the performance of discrete service and support types, and provide an input into the quality improvement process. Services and supports demonstrated not to be effective should be discontinued. [Recommendation 6.7](#)

6.3 HAVE OUTCOMES MET OBJECTIVES?

As stated in Chapter 2, the high-level objectives of the Disability Service Programme have been derived from the National Health Strategy objectives and the vision and objectives in *Towards 2016*.

Towards 2016 envisaged that, to the greatest extent possible:

- people should be supported, as far as possible to:
 - lead full and independent lives;
 - participate in work and society and to maximise their potential;
 - have access to services as well as wider environmental accessibility; and
- carers should be supported in their caring role.

OBJECTIVE 1: LEAD FULL AND INDEPENDENT LIVES

6.3.1 PERSON-CENTREDNESS

The concept of person-centredness refers to the process of providing the right support at the right time to enable the individual to lead a life of his or her choosing. In its *National Quality Standards for Residential Services for People with Disabilities*, HIQA defines a person-centred approach to service provision as one where ‘services are planned and delivered with the active involvement of the individual and developed around his/her particular characteristics’ (HIQA, 2009). HIQA’s Standard No. 8 states that each individual should have ‘a personal plan to maximise his/her personal development in accordance with his/her wishes’. The preparation of a person-centred plan for people who avail of residential services is one of HIQA’s requirements for a quality service. The development of a person-centred plan should be linked to the standardised assessment process referred to in Chapter 5 (see Section 5.2.2) and its achievement should be monitored on a regular basis.

The capacity of the system to deliver on universal person-centred plans based on the assessment of individual need is constrained by the existing system of service delivery and by the wider position on diminishing resources. This will need to be taken into account in the implementation plan for the recommendations in this Review (see Chapter 7).

There is as yet no information available on the number of residential service users who have their own person-centred plans. However, the HSE’s (2012a) *Report of the National Working Group for the Review of HSE-funded Adult Day Services* gathered data in respect of day service users (including those with mental health issues). The review found that almost 3,000 day service users (12%) did not have access to any form of individual planning. Of those who had an individual plan, over 8,000 (32%) had a nurse-led or clinician-led care plan, almost 6,000 (22%) had an individual programme/training plan and 13,000 had a person-centred plan (51%). Around 4,500 people (18%) had more than one type of plan in place.

6.3.2 HEALTH

Health outcomes may be considered in terms of health status and access to healthcare. Information on health outcomes for people with disabilities is not routinely collected at national level and a literature review was carried out in order to determine whether there was useful information on which to base high-level findings.

Health status

International studies have demonstrated that people with intellectual disability have a greater variety of healthcare needs compared with people of the same age and gender in the wider population, although this is counter-balanced to some extent by a lower incidence of hypertension and certain cancers. Many of those with primary disabilities develop associated secondary conditions as they age. Some also develop other chronic conditions, which might have been mitigated or prevented altogether with early intervention (US Department of Health and Human Services, 2002).

A report by Haveman *et al* (2010) reviewed scientific literature over the previous 15 years on the health risks associated with ageing in people with an intellectual disability. The authors summarised the position as follows:

'Current literature on research in people with Intellectual Disability in developed countries as they age is clear: that as persons with ID survive and live into older age, the combination of life-long disorders and their associated medications use, and the "normal" ageing processes, puts them at a greater risk for ill-health and an earlier burden of disease in terms of neurological decline, but cardiovascular deterioration and some cancers may be less common. Lack of physical activity combined with dental ill-health and inappropriate nutrition resulting in overweight and obesity are the major preventable, and modifiable, risk factors; and these areas need to be addressed in younger age to enable people to develop healthy lifestyle habits that will ensure they continue to mature and age with a sense of well-being.'

The health status of older people with intellectual disability in Ireland has been examined in a paper by McCarron *et al* (2011) under the auspices of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA). A substantial number of people are encompassed by this study: 753 people with intellectual disabilities agreed to take part, representing 8.9% of the cohort of people with intellectual disability who are over the age of 40. Some key findings in the IDS-TILDA study include:

- Many in the IDS-TILDA survey reported that they were in good health, particularly among the younger cohort. There were significant concerns, however, in terms of cardiac conditions, epilepsy, constipation, arthritis, osteoporosis, urinary incontinence, falls, cancer and thyroid disease.
- Younger adults with intellectual disability had a much higher incidence of disease, including cardiac disease, than people of the same age or older in the general population. The rate of falls among younger people with intellectual disability was also a matter of concern.
- Epilepsy was the most common non-cardiac disease among adults with intellectual disability. The incidence was lower in those with Downs Syndrome, but the incidence in the Downs cohort increased with the onset of dementia.
- The prevalence of mental health and emotional problems is greater among people with an intellectual disability than in the general population. 47.5% of the people surveyed reported that they had been diagnosed with an emotional, nervous or psychiatric condition.

- Access to health checks was high overall, but access to cancer screening was of concern, and access to all screenings was lower for people with severe to profound intellectual disability.

Access to healthcare

International research on access to healthcare by people with disabilities pinpoints accessibility as being the core of the problem. A report by the US Surgeon General explained that *'the barriers relate primarily to accessibility. They include such factors as transportation to get to the health care site, access to the building and the necessary health facilities in the building, access to the health care provider and staff for sufficient time and with sufficient supports to promote clear and complete communication'* (US Department of Health and Human Services, 2005).

The National University of Ireland, Galway, was commissioned by the NDA to report on access to healthcare in Ireland by people with disabilities. The report by D'Eath *et al* (2005), entitled *The Experience of People with Disabilities in Accessing Health Services in Ireland: Do inequalities exist?*, consisted of an international literature review and qualitative research exploring the experience of people with disabilities in accessing mainstream health services in Ireland. The report concluded that:

'Key issues highlighted in this study includes the need for synchronised, person-centred health services that incorporate, in practice as well as in theory, the social model of disability; the exclusion of people with disabilities from services such as preventative services; inadequate public provision of certain services including speech therapy and physiotherapy; the inequitable service offered by the mental health services to people with disabilities; and the physical, communication and attitudinal barriers that continue to exist for people with disabilities.'

More recently, the IDS-TILDA report (McCarron *et al*, 2011) also examined this area and stated that *'key determinants of continued good health include healthcare access and healthcare utilisation'*. The report concluded that in general people with an intellectual disability accessed healthcare services on a regular basis and overall the levels of utilisation were similar to the general population, with the exception of higher rates of hospitalisation.

The IDS-TILDA report found that utilisation of health services by people with intellectual disabilities increased with age, with the exception of respite and dental services. Those living in residential centres were more likely to have accessed medical and therapy services than people living in any other kind of living arrangement. Although the report concluded that *'These findings probably relate to the fact that this group are older, with a more severe ID and higher levels of health concerns'*, it raises a question about the boundaries of the State's responsibilities in respect of people with intellectual disability who are living in the community.

The IDS-TILDA report also found that healthcare utilisation was higher in people with more severe and profound levels of intellectual disability, except for optician and auditory services, despite the reported high levels of sensory impairment. While younger people with intellectual disability (particularly in the 40-49 age group) had higher levels of hospitalisation than the wider population, the position reversed in respect of older respondents, so that those who were older, despite having higher levels of chronic illness and disability, had lower rates of hospitalisation than other older adults. Most older adults with intellectual disability live in residential centres and the report indicates that further investigation is needed to determine whether the lower rate of hospital admissions is due to the availability of additional nursing and medical care in these settings.

The report also found that: *'More than half of participants reported they had never received easy-to-read leaflets on keeping healthy and three-quarters said that they had never received information leaflets on healthcare services. This lack of information represents a major barrier to people with an ID engaging in and taking ownership of their own health.'*

In summary, regardless of setting, there were extremely high levels of access overall among people with an intellectual disability to GP services when compared with the wider population, but strikingly lower levels of admission to hospital in the older age group, which will require further investigation by IDS-TILDA. However, the finding that many people had not received information on health promotion/protection and health services points to the need for targeted efforts in this area and is particularly relevant in the light of increasing moves towards community-based residential services.

HEALTH

KEY FINDINGS

- ✓ Life expectancy for people with intellectual disability has increased significantly. Of those with moderate, severe or profound intellectual disability, the proportion who were aged 35 years or over increased from 29% in 1974 to 38% in 1996 and to 49% in 2010, representing an increase in lifespan for this cohort. [Finding 6.7](#)
- ✓ It is reasonable to conclude from this that the health services provided for persons with disabilities, whether under the auspices of the Disability Services Programme or through the generic health services, have been effective at protecting health and prolonging the lives of people with disabilities. [Finding 6.8](#)
- ✓ The changing age profile of people with intellectual disabilities will present its own challenges for service provision in the years to come. [Finding 6.9](#)
- ✓ The NPSDD cannot be used to assess the increased life expectancy or health status of people with physical or sensory disabilities. Since not every individual in Ireland who has a physical or sensory disability is availing of, or requiring, a specialised health and personal social service, the NPSDD cannot provide any definitive epidemiological statement on the number of people with a particular type of disability or diagnosis. [Finding 6.10](#)
- ✓ Access to healthcare is a matter of particular concern to people with disabilities, both in this country and internationally. In general, people with an intellectual disability were found to access health services on a regular basis and have the same levels of utilisation as the wider population, with the exception of higher rates of hospitalisation (except among older adults with intellectual disability where the position is reversed). No similar evidence has been sourced in respect of people with physical or sensory disabilities. [Finding 6.11](#)
- ✓ Key issues highlighted in a study on access by people with disabilities to mainstream health services highlight the difficulties faced, including exclusion from preventative services, inadequate provision of therapy services and physical, communication and attitudinal barriers that continue to exist for people with disabilities. [Finding 6.12](#)

KEY RECOMMENDATIONS

- ✓ Information on health outcomes for all people with disabilities should be collected on a national basis. The dataset to be collected should be identified with the assistance of the NDA and the data should be collated and monitored by the HSE at national level. [Recommendation 6.8](#)
- ✓ Responsibility for the care, safety and general well-being of people who lack full mental capacity should be considered in the context of the increasing move from congregated residential settings to State-supported independent living arrangements. The State's responsibility in respect of the health needs of people with disabilities, and in particular those with intellectual disabilities, should be examined and clearly articulated. [Recommendation 6.9](#)

6.3.3 DAY SUPPORTS, PERSONAL DEVELOPMENT AND PROGRESSION

A review of adult day services conducted by the HSE in 2008 reported that around 25,000 people with disabilities (including 7,000 or so with mental health conditions) avail of day services in over 800 locations (HSE, 2012a). Over 90% of these day services were provided in segregated group settings. There is very little data on the outcomes achieved by these service users in terms of personal development and progression (except for Indecon's 2007 study, referred to below, on those who partook of rehabilitative training courses). The public consultation conducted by the VFM Project Team (*see Section 6.4 below*) did, however, elicit the positive response that most people (85%) felt that services in general were having a significant or partially significant impact on people's lives, while a minority (15%) felt that services were having little or no impact. However, even those who felt that services were providing a positive impact were of the opinion that more person-centred, flexible services were required in order to support greater independence and community inclusion.

A study conducted by Indecon International Economic Consultants (2007) on rehabilitative training courses found that of those who completed their training, almost a quarter (23.9%) continued on to further training, while only 6.6% progressed directly to open employment. Outcomes for the remainder were as follows: supported employment (12.3%); sheltered work services (14.9%); unoccupied/home life (14.9%); illness (11.8%); day activity (6.4%); and education (4.8%).

In respect of day services, the report by the Expert Reference Group (ERG) on Disability Policy (2011) prepared for this Review states that:

'There is little evidence of individualised service provision, with a lack of standardised needs assessment and provision largely based in groups. Even though many services purport to use person-centred planning, the quality of the person-centred plan can be negated if options are framed largely in terms of the current model of provision.'

6.3.4 RESIDENTIAL SERVICES

A range of residential services and supports are made available to people with disabilities, ranging from 5-day or 7-day services in larger residential centres, domestic-style homes in the community or specialist placements for people with specific needs. Domestic-style homes when clustered together, either on a campus or in the community, come within the definition of a ‘congregate setting’ if the total number of residents in the cluster exceeds 10.

Most people with physical disabilities have always lived independently, with family and community support. Almost half of all adults with intellectual disabilities live with their families, with the remainder living in institutional care in congregated settings, community group homes or other settings. However, a small but growing number of people with intellectual disability have already made the transition to independent living (1,076 adults, or 5.9% of the cohort, according to the HRB’s (2010b) *Annual Report of the National Intellectual Disability Database Committee 2009*). Independent living refers to a domestic-style house or apartment in the community, where the number of residents may range from 1 to 4 and the neighbouring houses are occupied by members of the wider community. Independent living does not necessarily mean living alone or without support. A minority of people in independent living settings may require overnight residential support, but the individual is in control of their own living arrangements and daily life, and is not the passive recipient of care. Where there is more than one resident in an independent setting, the residents will have chosen to live together and they may or may not each have a disability – some home-sharing schemes popular in the USA, for example, facilitate a person with a disability to share a home with an able-bodied person.

Details on the number of people availing of residential services and the cost of those services are given in Chapter 5.

Assessment of outcomes for those availing of residential services

Expenditure on residential care services accounts for around 45% of total expenditure on specialist health services for people with intellectual and physical disabilities (see Chapter 5). In this context, the Office for Disability and Mental Health (ODMH) undertook a focused examination of programme outcomes for the residential services element of the Disability Services Programme. This work was resourced separately by ODMH in view of its importance to the VFM Review and also because it will have added value for other areas of work, including work to progress the Government commitment to put HIQA’s (2009) *National Quality Standards for Residential Services for People with Disabilities* on a statutory footing.

The ODMH’s examination of programme outcomes had two elements:

- an online questionnaire to explore issues around service quality for residential services for people with disabilities (a summary of the development of the questionnaire, together with its findings, are described below);
- a literature review, conducted by the HRB (Mongan, 2011) on behalf of the VFM Review, of quality assurance and quality improvement systems in use in the disability sector (described above).

The purpose of the research was to support commentary on the responses to the questions on quality improvement systems and also to support work to develop future performance indicators (see Chapter 8).

Report on Congregated Settings

It is now generally accepted that large residential institutions are no longer appropriate for the provision of accommodation for people with disabilities, as found in the various research studies examined by the Working Group on Congregated Settings for the HSE's 2011 report *Time to Move on from Congregated Settings: A Strategy for Community Inclusion* (see References in that report for further details). Congregated settings are defined as living arrangements for people with intellectual, physical or sensory disabilities where 10 or more people share a single living unit or where the living arrangements are campus-based. The Congregated Settings report recommends a move away from congregated/institutional-type settings for the 4,000 people who resided in such settings in 2008 to community-based settings over a 7-year timeframe.

Key findings in the Congregated Settings report (HSE, 2011) include:

- Over 4,000 people with disabilities were living in congregated settings in the period under review (2005-2009), 93% of whom have intellectual disability as their primary disability and 7% have physical or sensory disability as their primary disability.
- People in congregated settings live isolated lives, set apart from any community and from families. Many experience institutional living conditions where they lack basic privacy and dignity. Most have multiple disabilities and complex needs.
- The model of service is highly medical – almost 40% of staff are nurses – while many residents do not have access to basic therapies or activities. Just over a quarter of residents had no day programme (or a very limited one) in their wards.

The Congregated Settings report makes **31 recommendations**, focusing on the following topics:

- policy – no new congregated settings should be built;
- cessation of admissions;
- links with local authorities;
- implementation-change model;
- leadership;
- new community models – dispersed housing in the community;
- funding – individualised budgets;
- bridging funding;
- evaluation;
- reviewing residential services for people with a disability residing in nursing homes and mental health institutions.

The thrust of the Congregated Settings report is for a new model of support in the community and envisages a 7-year phased closure of congregated settings, with people moving to dispersed forms of housing in ordinary communities, provided mainly by local housing authorities, and actively supported to live full inclusive lives at the heart of the family, community and society. This entails access to mainstream facilities (such as housing, social, education and work), with specialist support as required. They will have the same entitlement to mainstream community health and social services as any other citizen, such as GP services, home help and public health nursing services, and access to primary care teams. They will also have access to specialised services and hospital services based on an individual assessment. People will get the supports they need to help them to live independently and to be part of their local community.

The HSE is engaging with the relevant stakeholders to ensure that an action plan is developed and implemented to address the recommendations of the Congregated Settings report. The HSE's draft Corporate Plan 2011-2014 identifies the implementation of the report over a 7-year period. In response to public policy and investment, the numbers in congregated settings have been declining and most centres have made arrangements to enable a number of residents to move to the community. Since 2008 the number of people living in congregated settings has reduced from around 4,000 to 3,600; however, admissions have continued.

The report recommends that there should be a number of Accelerated Learning Sites, which will demonstrate effective and efficient service provisions for the new model of service delivery. The HSE is working with Genio (a non-profit organisation that works with the public, private and non-profit sectors to stimulate and support social innovation in Ireland that has lasting impact) on foot of €2m funding to *'move people from institutions to the community, or to become more independent in the community where they belong, [enabling] an institution or hospital to close in its entirety. The funding will also be directed towards increasing the provision of cost-effective, family and community-based respite care, as an alternative to traditional institutional models'*.

The HSE's Congregated Settings report does not identify costs associated with the transition between the current congregated provision and the new service model in the community (*see Chapter 7 for consideration of capacity issues and costs generally*). There is little international research available on transition costs associated with de-institutionalisation (studies focus on comparing costs between institutional and community settings). However, there may be an element of double running costs, with the need to resource both the old and the new services in parallel for a period until an institution has fully closed down. The cost of community living after the transition period is also more complex to compute – while costs for individuals in congregated institutions is already known, and may be calculated with reasonable justification by dividing the total cost of the institution by the number of residents, when these individuals move to the community they will each have individual support requirements that will be influenced by a myriad of factors, including functional ability, health status, geographical location and availability of social and family support. The projects currently being supported by Genio will identify costs and change management processes associated with the move from congregated settings to community settings, which will inform the implementation of the Congregated Settings report. The findings and recommendations of this VFM Review will also provide an input.

The Department of Health has engaged with the Department of the Environment, Community and Local Government in relation to the development of a housing strategy for people with disabilities, which has taken account of the findings of the Congregated Settings report. The HSE and a National Advisory Group comprised of relevant stakeholders also assisted with the development of the strategy, which was published in October 2011. On launching the strategy, the Department of the Environment explained that:

'The strategy sets out a framework for the delivery of housing for people with a disability through mainstream housing policy by directing the efforts of housing authorities and the HSE to support people with a disability to live independently in their own homes rather than having to move into residential care settings.'

Residential services – Irish research

There is little detailed information available on people in Ireland in receipt of disability services with which to judge their overall quality of life or the extent to which they are leading a 'full life'. Some research has, however, been undertaken with specific cohorts of people. A study by Walsh *et al* (2000) of 125 Irish adults living in both group homes and congregated settings indicated that people living in group homes had greater choice about their everyday activities, such as mealtimes, bedtimes and holidays; they also had larger social networks and more scheduled activities than people living in campus settings.

A 2007 survey of a representative sample of 300 service users with a mix of disabilities gives some insight into the quality of their lives (Outcomes Network of Ireland, 2007). The study used Personal Outcome Measures (POMs) as its assessment tool. Participants in the survey were asked about 23 personal outcomes in their lives. On average, participants reported about 10 out of the 23 outcomes were fully present for them. Individual scores varied greatly: 2 participants had none of the outcomes present, while one participant had all 23 present. Some outcomes were present for most of the sample; for example, 66% felt that they were 'connected to family'. However, the majority of service users had limited opportunities to exercise choice or control over their lives: only 17% chose with whom they lived, 22% with whom they worked, 22% chose their services, and 18% reported that they could exercise their rights. There was no significant difference in scores between men and women, or between younger and older participants. Size of the agency was not found to be associated with a significant difference in average outcomes or supports achieved. With regard to residential circumstances, those living independently scored highest (average of 15 outcomes), while those in campus settings scored lowest (average of 7 outcomes). Participants who lived at home had, on average, 10 personal outcomes fully present.

Generally the number of personal outcomes present varied with the type and severity of the disability. Participants with physical disabilities averaged higher (13 outcomes) than those on the autistic spectrum (11) or with a mild/moderate (10) or severe/profound (7) intellectual disability.

Residential services – International experience

As part of its 2009-2010 research on international outcome measures in disability services provision, the NDA (2010c) identified and examined 4 major international reviews of the outcomes knowledge base on independent living services. The consensus in the 6 jurisdictions which were the focus of the NDA investigation, and also in the 30 jurisdictions considered in the overviews, was that *'The international knowledge base available (albeit limited) indicates that independent living is at the core of the range of changes required in order to ensure better lives and full participation by people with disabilities in society. However, it is also clear, that a "one size fits all" approach to health and personal care services for independent living will not produce the desired results. Therefore, it will be important to develop a nuanced approach to reconfiguring services, one which takes into account the differences between groups of people with disabilities (such as those based on age or type of disability) with regard to independent living systems and practice'*.

The NDA, in its Advice Paper to this Review, confirmed that there is strong evidence from many international studies and many jurisdictions that supports community-based, supported living arrangements (NDA, 2010a). A recent European Commission Report (2009) concluded that *'available studies confirm that if high quality community services are provided, most formerly institutionalised users have a clear preference for community living and display higher level of personal satisfaction and social inclusion'*. The evidence from a recent European study (Mansell *et al*, 2007) also shows that the overall costs for community-based living

arrangements are generally the same as institutional residential settings, i.e. community-based living is not a lower cost option. However, the *cost-effectiveness* of community-based arrangements is at least the same, and usually better, because the outcomes for the person are superior to those achieved in institutional settings. It must be noted, however, that there is as yet no comparable information available in Ireland and although it might be expected that the results would be comparable with the European study, this is by no means guaranteed. The research being undertaken by Genio in conjunction with the individualised living projects they are supporting (on foot of a €2m grant from the Department of Health) will provide a body of information on the cost of independent living during 2012 (*see above, under 'Report on Congregated Settings'*).

The NDA concluded that *'there is as yet no robust outcomes knowledge base on which to base an evaluation of the different configurations of health and social care services which underpin the independent living policies and programmes of different jurisdictions'*.

RESIDENTIAL SERVICES

KEY FINDINGS

- ✓ There are no indicators to objectively measure the effectiveness of residential services and supports on a national basis. The implementation of HIQA standards in respect of residential services will go much of the way with regard to quality measurement, but a separate, though related, piece of work will still be required in respect of effectiveness indicators. [Finding 6.13](#)
- ✓ Some service providers have implemented quality assurance and outcome measurement systems in residential services, but these are not universally applied. [Finding 6.14](#)
- ✓ The recommendations of the Report of the Working Group on Congregated Settings are that no new congregated settings should be built, no new admissions should be made to existing settings and a new model of support in dispersed community housing should be implemented. The report did not cost the transition from congregated services to community living (*see Chapter 7 for further discussion on capacity issues in relation to the implementation of these recommendations*). [Finding 6.15](#)
- ✓ The Department of the Environment, Community and Local Government (2011) Housing Strategy for people with disabilities sets out a framework for the delivery of housing through mainstream housing policy. [Finding 6.16](#)
- ✓ International research demonstrates that in the jurisdictions studied the cost-effectiveness of community living is at least the same as, and usually better than, congregated living. [Finding 6.17](#)

KEY RECOMMENDATIONS

- ✓ The following recommendations of the Congregated Settings report should be prioritised within the implementation process for the report:
 - no new congregated settings to be opened;
 - no new admissions to be made to existing congregated settings;
 - a new model of community-based supports to be put in place for persons moving from congregated settings.

Recommendation 6.10
- ✓ It will be the responsibility of the HSE to monitor the results of the HIQA inspections of residential centres in due course and, where relevant, an agency's progress on meeting the action plans specified by HIQA. Adherence to HIQA standards should be incorporated into the SLA funding and monitoring processes.

Recommendation 6.11

OBJECTIVE 2: PARTICIPATE IN WORK, SOCIETY AND MAXIMISE POTENTIAL

6.3.5 EDUCATION

Education of children, including those with a disability, is the responsibility of the Department of Education and Skills, while the provision of health and personal social supports that facilitate access to mainstream education (such as speech and language therapy) is the responsibility of the Department of Health. Government policy is to encourage the maximum possible level of inclusion for special educational needs students in mainstream schools and to establish the necessary supports to facilitate this development (Ware *et al*, 2009).

Almost 7,000 children receive their education in special schools and around 2,600 pupils with special education needs attend mainstream primary schools (see *Table 6.2*). The number of children who attend mainstream schools is increasing, particularly at primary level. There is a trend for greater integration at post-primary level too, but this is counter-balanced by evidence of a growing number of students at post-primary level moving back from mainstream educational settings to special schools, according to Kelly and Devitt (2010). A variety of reasons have been cited by the authors for this, including the lack of an appropriate curriculum in mainstream educational settings and the availability of a greater level of supports in special schools.

Table 6.2: No. of pupils by type of primary school setting

Pupils in ordinary classes in mainstream schools	Pupils with special needs in mainstream schools*	Pupils in special schools	Total
490,010	2,635	6,905	505,998

Note : *This excludes 6,458 traveller pupils who were taught by a designated Resource Teacher for Travellers. The special posts were withdrawn in Budget 2011 and traveller children are now integrated with supports from the General Allocation Model for all children with special educational needs.

Source: Department of Education and Skills (available at: www.education.ie)

The length of time the young person remains in education is crucial. The ERG Report (2011) has concluded that people with disabilities do not stay in education as long as the wider population and states that:

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

The role of the health sector in supporting continued access to post-primary and third-level education by people with disabilities has not been examined by this VFM Review.

6.3.6 EMPLOYMENT

The ERG Report (2011) considered the degree to which the employment situation of those using disability services was in keeping with the overarching objective that people with a disability would be supported to live full and independent lives, and to participate in work. Based on the HSE’s Adult Day Services Review (2012a), the report concluded that:

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

The ERG Report also examined the position regarding the wider cohort of people with disabilities (regardless of whether or not they were accessing disability services) and highlighted the following statistics:

- In 2004, 37% of people of working age with a disability or long-standing health problem were in work, compared to 67% of other adults of working age.
- Between 2002 and 2004, the employment rate for people with disabilities fell from 40.1% to 37.1%, despite an overall employment growth of 5.6% over that period (Central Statistics Office, 2006).
- The employment rate of people with disabilities in Ireland is one of the lowest in the OECD at 32% in 2005, compared to an OECD average of 43% (OECD, 2009).
- People with a disability work fewer hours on average than the overall population, as well as being more likely to work part-time. Both of these factors affect earnings (Gannon and Nolan, 2006).
- The onset of disability for adults led to a decline in 20 percentage points in the probability of being in employment (*ibid*).
- Persistent disability is strongly associated with unemployment, lower income (largely because of unemployment) and a significant reduction in social participation compared to the non-disabled population (*ibid*).

The ERG Report (2011) concluded that people with disabilities have much less participation in the workforce than do people without disabilities. There is nothing to suggest that the position of those accessing services is any different from the findings outlined above in respect of the full cohort of people with disabilities, and it would be reasonable to expect that the position would be the same or worse. Not everyone who avails of disability services has the capability to engage in work in the open labour force. But if participation in employment is deemed to be a positive outcome, then it should be concluded that this outcome is not present for most people with disabilities who access disability services. Apart from the effects on their personal outcomes, the barriers to the participation of people with disabilities in employment commensurate with their abilities have an obvious economic consequence for the individuals themselves, for service providers and for the State.

PERSONAL PROGRESSION, EDUCATION AND EMPLOYMENT

KEY FINDINGS

- ✓ There are no indicators to objectively measure the effectiveness of the Disability Services Programme in promoting personal progression through access to day services and supports. [Finding 6.18](#)
- ✓ The provision of health supports plays a vital part in enabling a person with disabilities to access education and employment. [Finding 6.19](#)
- ✓ With the appropriate health supports, over half of all children with disabilities attend mainstream schools at primary level and this number is increasing. Overall, however, children with disabilities do not stay in education as long as the wider population. [Finding 6.20](#)
- ✓ Most people accessing specialist disability services are not in employment in the open labour market. [Finding 6.21](#)
- ✓ Some service providers have implemented quality assurance and outcome measurement systems in respect of day services and supports, but these are not universally applied. [Finding 6.22](#)

KEY RECOMMENDATIONS

- ✓ Indicators should be developed to measure the effectiveness of the disability services in promoting personal progress through access to day services and supports. [Recommendation 6.12](#)
- ✓ The health sector should continue to be responsible for providing health-related supports to facilitate access to mainstream services in the following areas: education, employment, housing, transport, healthcare and community inclusion. The provision of personal assistance supports for adults who live in the community or therapy supports for children attending school are examples of the type of support in question. [Recommendation 6.13](#)

- ✓ In the absence of day service standards being set and monitored by HIQA, the HSE should establish a framework whereby they can satisfy themselves, within the context of the SLA process, of the outcomes and quality of day services through dissemination of quality assurance guidelines, self-evaluation and continuous quality improvement protocols. [Recommendation 6.14](#)

6.3.7 COMMUNITY PARTICIPATION

Community outcomes encompass the effects on the individual in terms of community inclusion, participation, accessibility and equality. Although wider issues of community inclusion are outside the ambit of this VFM Review, the supports provided by the health service to enable an individual to access the community are essential. The public consultation undertaken by the Project Team (*see below*) found that community inclusion was of great importance to people with disabilities, as it is for the wider population, but that in general it was not being achieved.

OBJECTIVE 3: ACCESS TO SERVICES, AS WELL AS WIDER ENVIRONMENTAL ACCESSIBILITY

6.3.8 ACCESS TO SERVICES AND WIDER ENVIRONMENTAL ACCESSIBILITY

Access is generally understood to mean the physical accessibility of the built environment. Other factors that facilitate accessibility include disability awareness (among health and public sector officials, employers and the general public), as well as information, communications and transport. While these are largely outside the remit of the Disability Services Programme, service providers have a role to play in supporting people with disabilities to participate in the community and in mainstream activities.

Wider environmental accessibility is the responsibility of the Department of the Environment, Community and Local Government. The NDA also has a specific role in the promotion of ‘universal design’ and has produced best practice guidelines on how to design, build and manage buildings and spaces so that they can be readily accessed and used by everyone, regardless of age, size, ability or disability. A *Code of Practice on Accessibility of Public Services and Information Provided by Public Bodies* has also been produced by the NDA (2006).

OBJECTIVE 4: SUPPORT FOR CARERS IN THEIR CARING ROLE

6.3.9 SUPPORT FOR CARERS

Carers are supported by the health services through a variety of means, including the provision of advocacy services, advice and support, respite services and home support. (Financial supports to carers come under the remit of the Department of Social Protection.) Results from this Review’s public consultation (*see below*)

showed that 11% of respondents believed that this objective had been met, one-third (34%) reported that it had not been met and 49% reported that it had been partially met.

One of the priority actions in respect of support for carers in *Towards 2016* was envisaged to be the development of a National Carers' Strategy; this is also a key commitment in the current Programme for Government. Responsibility for the preparation of this strategy has been allocated to the Minister of State with responsibility for Disability, Equality, Mental Health and Older People (Ms Kathleen Lynch, TD), with the support of the Minister for Social Protection. Minister Lynch has recently said that the National Carer's Strategy:

'will address the needs of informal and family carers ... The Strategy will not be an operational plan, but will set the strategic direction for future services and supports for carers in recognition of their role and contribution to maintaining children, adults and older people with physical or mental health difficulties in their own homes.'

6.4 OUTCOMES: WHAT DO STAKEHOLDERS THINK?

6.4.1 MEASUREMENT OF SERVICE USER OUTCOMES

A public consultation on 'The Efficiency and Effectiveness of Disability Services in Ireland' was undertaken by the VFM Project Team. The consultation was initiated by an invitation for submissions on 13th November 2009. Replies to an online questionnaire were received from 191 bodies and individuals: 61.2% replied in a personal capacity and 38.8% on behalf of an organisation. The submissions varied greatly in length and complexity, ranging from a couple of short responses on specific points to more detailed responses addressing a number of issues. Most respondents answered most questions: over 90% of the responses addressed half or more of the questions posed in the consultation document.

6.4.2 KEY THEMES

The key themes that emerged from the consultation were clustered around two strands: quality of life issues and the organisation and delivery of the Disability Services Programme.

Quality of life was perceived as being determined by the exercise of choice and control, achieving and maintaining independence and participating in one's community. Choice, control, independence and community inclusion were seen as being inextricably linked. Respondents stressed the importance of consultation, individualised funding, control over one's own money, flexible and person-centred services, and access to healthcare, transport, housing, education and employment.

The views expressed on the organisation and delivery of the Disability Services Programme were wide-ranging, covering areas such as policy, strategy and funding, the most effective ways to organise and manage services, and the most efficient use of resources in order to support service objectives. The full report on the findings is available on the Department of Health's website (see www.dohc.ie/publications/).

6.4.3 CONSULTATION WITH STAKEHOLDERS UNDERTAKEN BY THE NDA

Consultation was undertaken by the NDA on attitudes of people with disabilities and other stakeholders to draft policy proposals by the Department of Health and Children in relation to individualised supports and mainstream services.¹⁷ The consultation was carried out by Weafer Research Associates on behalf of the NDA in March 2010 among 15 focus groups with a broad range of stakeholders, including service users, parents of children with disabilities, advocates and front-line staff.

Views were sought on two interrelated policy ideas: a movement away from segregated disability services towards the provision of individualised supports and a move to mainstream services. For the most part, the participants in the 15 focus groups were in favour of the proposals and would welcome their implementation. Many of the participants responded positively to the greater choice and control over funding, which they associated with an individual funding mechanism, although some people queried the capacity and willingness of the Government to deliver effectively on this policy. They were also in favour of mainstreaming in principle, provided appropriate supports are made available to enable people with disabilities access the services they need.

Because of the composition of the focus groups and the broad nature of the topics put to them, the results of the focus group consultation cannot be claimed to be conclusive, but are nevertheless a useful confirmation of the results achieved from the online questionnaire used in the public consultation (see Section 6.4.1 above).

6.4.4 OUTCOMES QUESTIONNAIRE

Since the HSE does not currently collect data on the outcomes of its residential services programme, it was accepted that any data used to analyse outcomes would have to be collected at source. To this end, an Outcomes questionnaire was designed for dissemination to disability service providers at service unit level. The questionnaire aimed to explore issues around both service quality and the impact of services on service users' lives and well-being.

Development of the Outcomes questionnaire

The Outcomes questionnaire was grounded in the *National Quality Standards: Residential Services for People with Disabilities* (HIQA, 2009). These standards were designed to assist service providers, in advance of inspection, to assess the quality of the service they provide and it is anticipated that the standards will, in time, play a key role both in the assessment of quality and in driving improvements in quality across residential services for people with disabilities. The standards were examined in detail and tangible criteria extracted that were quantitative or around which questions could be crafted where a closed response could be given. To avoid duplication, the selected criteria were cross-referenced against data currently being collated by the HSE as part of its work in formalising service arrangements with the non-statutory disability service providers. No significant cross-match was found.

¹⁷ See [www.nda.ie/cntmgmtnew.nsf/0/E093380FB2F9DD5580257775003E0E6B/\\$File/AttitudesofpeoplewithdisabilitiesandotherstakeholderstopolicyproposalsbytheDoHC.doc](http://www.nda.ie/cntmgmtnew.nsf/0/E093380FB2F9DD5580257775003E0E6B/$File/AttitudesofpeoplewithdisabilitiesandotherstakeholderstopolicyproposalsbytheDoHC.doc)

The domains incorporated into the questionnaire from the standards included autonomy and participation; privacy and dignity; daily life; personal relationships and social contacts; decision-making and consent; complaints; accessing information; staffing; physical environment; health and safety; safeguarding and protection; governance; and record-keeping. Due consideration was given to the issue of mental capacity, which is of particular relevance in the context of interventions provided to persons with intellectual disabilities. Reference was also made to a survey instrument developed and validated as part of a research study by Murphy *et al* (2006) commissioned by the National Council on Ageing and Older People, comprising a questionnaire that explored the likely impact on the quality of life of older people in residential settings of physical, environmental and staffing issues. An explanatory note was developed to supplement the questionnaire, outlining the rationale for the questions on a section-by-section basis. The questionnaire also provided for some 'free text' responses.

Results of the Outcomes questionnaire

In total, 263 responses were received for the Outcomes questionnaire from about 70 service providers, in respect of 4,534 permanent residents, 1,604 short-term respite users and 379 in other types of residential placement at over 250 separate locations. Completed questionnaires were returned by a cross-section of intellectual disability and physical/sensory disability service providers, including some of the largest service providers in the State. It should be borne in mind that because it is a self-reported questionnaire, there is no guarantee against bias.

Returns were requested on a service unit level, but composite returns were accepted where a manager had operational responsibility for a number of group homes and could confirm that these were being operated according to the same procedures/standards. Accordingly, the number of service units for which a return was made exceeds the number of responses received.

The age profile of residents ranged from under 18 to over 75, but most were in the 25-64 age bracket, with the highest concentration being between 45-54 years of age.

The 4,534 permanent residents who were encompassed by the responses represented almost 53% of all permanent residents in disability services nationwide. The number of residents in each centre ranged from 1-242, of which 3,847 were in single bedrooms. There were also 446 double bedrooms and 237 bedrooms for 3 or more. This gives a capacity of over 5,450. This indicates that most people are in single rooms and that overcrowding is not a feature of living in a residential institution, for those services that responded to the questionnaire.

Quality of life outcomes

The responses to selected questions that tell us about the quality of life for residents in these settings are presented in Tables 6.3-6.7.

Table 6.3 shows that in the majority of cases, residents either decide exclusively or are consulted about decisions that affect their daily life. However, it is worth noting that in all areas of daily life, some service users have no choice in even the most basic of decisions.

Table 6.3: Exercise of personal choice by people in residential settings

For each of the following areas, please indicate the option that most accurately reflects your facility's approach to personal choice:	Determined exclusively by the residents	Formal consultation with the residents and/or their guardians	Independent advocacy for residents who cannot independently indicate their personal choice	Determined exclusively by nursing/care staff
Personal appearance of resident, including clothes they wear	40.4%	31.9%	25%	2.7%
Participation of residents in organised leisure activities	37.1%	38.6%	22%	2.3%
Participation of residents in organised programmes of activity/work	30.7%	41.6%	22.6%	5.1%
Times of meals	40.4%	26.5%	20.4%	12.7%
Food and drink menus	40.5%	32.8%	21.6%	5%
The time at which residents get up	43.3%	31.4%	17.6%	7.7%
The time at which residents go to bed	51.8%	25.7%	16.7%	5.8%

Table 6.4 indicates that almost all service users have control over their immediate living space and possessions.

Table 6.4: Exercise of control over living environment by people in residential settings

	Yes	No
Are residents in your facility allowed to decorate their own bedrooms?	97.7%	2.3%
Are residents in your facility provided with their own cupboard /wardrobe /storage space to store personal clothing/possessions?	100%	0
If yes, do these residents have the facility to lock away their personal clothing/possessions?	87.6%	12.4%

Table 6.5 indicates that most service providers who responded have written policies in a range of vital areas and keep relevant records, but it is surprising that there are some services where certain written protocols and records are not maintained.

Table 6.5: Administration of residential service

Administration	Yes	No
Does your service have a mission statement?	99.6%	0.4%
Does your facility have a written statement of purpose and function?	79.2%	20.8%
Does your facility have a written risk management policy?	81.3%	18.7%
Does your facility have a written policy and/or procedures for dealing with problematic behaviour?	88.2%	11.8%
Does your facility have a written policy and/or procedures for safeguarding and protecting residents from abuse?	99.2%	0.8%
Does your facility have a written policy on the assistance provided to residents in relation to the management of their financial affairs?	74.4%	25.6%
Does your facility have its own written code of conduct for all staff?	98.5%	1.5%
Do staff at your facility have written job descriptions?	93.4%	6.6%
Does your facility develop written personal development plans for each of your members of staff?	42.1%	57.9%
Does your facility maintain a register of all residents in its care?	96.5%	3.5%
Does your facility maintain an individual file on each resident in its care?	99.6%	0.4%
Does your facility have a written policy for the retention and destruction of records?	83.4%	16.6%

Table 6.6 indicates that 60% of residents avail of many services in the community. This is in line with mainstreaming policy. However, it is notable that a significant number of people access health therapies, social work and psychology services in their place of residence (in-house).

Table 6.6: Use of community services or specialist services

To which of following services do the residents in your facility have access? <i>In each case please indicate whether the service accessed is in-house, in the community or both.</i>	In-house service No.	In-house service %	Community service No.	Community service %
General practice	70	6.8%	219	14.5%
Physiotherapy	129	12.6%	110	7.3%
Occupational therapy	138	13.5%	97	6.4%
Speech therapy	125	12.2%	80	5.3%
Social work	179	17.5%	55	3.6%
Psychology	198	19.4%	47	3.1%
Dentistry	60	5.9%	226	15.0%
Optometry	16	1.6%	223	14.8%
Chiropody	62	6.1%	215	14.2%
Hairdressing	45	4.4%	239	15.8%
Total	1,022	100%	1,511	100%

As seen in Table 6.7, almost half of respondents report that there are circumstances where residents may be unable to remain in the residential setting or may be asked to leave. The most commonly cited reason (64%) is due to a permanent deterioration of the service user's medical condition. However, there were substantial numbers where residents might be asked to leave due to severe behavioural problems (37.6%) or physical aggression (28%).

Table 6.7: Circumstances where residents can no longer reside in their current residential service

Are there particular circumstances where residents can no longer reside in your facility?	No.	Valid %
Yes	124	48.8%
No	130	51.2%
If yes, please indicate the circumstances that apply:		
Severe behavioural problems	47	37.6%
Physical aggression	35	28.0%
Permanent deterioration of medical condition	80	64.0%
Other	49	39.2%
Where residents are asked to leave the residential service, does your facility assist in the process of making alternative arrangements?		
Yes	127	95.5%
No	6	4.5%

Among the 'Other' reasons given in response to the question in Table 6.7 were:

- alcohol drug abuse;
- risk to self, staff or other service users;
- funding does not meet the need;
- over 18% no longer attending school;
- anti-social behaviour/contravention of lease;
- service provider unable to meet needs.

Analysis of the returns indicates that a number of circumstances give rise to service users being asked to leave the service or facility. This raises questions about the ability of some service providers to deal with issues of challenging behaviour. It is also a concern that 6 service providers indicated that no assistance is provided to the service user who is asked to leave in accessing alternative accommodation.

OUTCOMES – STAKEHOLDER CONSULTATIONS

KEY FINDINGS

- ✓ Quality of life was perceived by respondents to the public consultation as being determined by choice, control, independence and community inclusion. [Finding 6.23](#)
- ✓ The recurring themes in the consultation centred on the importance of access to healthcare, transport, housing, education and employment. [Finding 6.24](#)
- ✓ In the majority of cases, residents either decide exclusively or are consulted about decisions that affect their daily lives. However, there are some service users who have no choice in even the most basic of decisions. [Finding 6.25](#)
- ✓ Almost all service users have control over their immediate living space and possessions. [Finding 6.26](#)
- ✓ Most respondents have written policies in a range of vital areas and keep relevant records, but there are some services where certain written protocols and records are not maintained. [Finding 6.27](#)
- ✓ Many service users avail of many services in the community, but health therapies, social work and psychology services are mainly delivered in-house. This suggests that such services are not available to people with disabilities in mainstream settings. [Finding 6.28](#)
- ✓ A number of circumstances can give rise to service users being asked to leave the service or facility, such as behavioural issues or a deteriorating medical condition. [Finding 6.29](#)

KEY RECOMMENDATION

- ✓ The future delivery of services and supports to people with disabilities should acknowledge the views of stakeholders – that choice, control, independence and community inclusion are the keys to an effective, person-centred service. [Recommendation 6.15](#)

6.5 NATIONAL AND INTERNATIONAL RESEARCH

6.5.1 INTERNATIONAL EXPERIENCE

In order to inform this VFM Review, research was commissioned from the National Disability Authority (NDA) on specialist disability services in 6 jurisdictions – England, Scotland, the Netherlands, Norway, New Zealand and the State of Victoria (Australia) – which were regarded as models of innovation and of good practice. This research informed the Advice Paper provided by the NDA to the VFM Steering Group in July 2010 (NDA, 2010a) and is detailed in a Synthesis Paper (NDA, 2010b), as well as in individual reports on 5 of the 6 jurisdictions.¹⁸

The NDA research found that the international experience is mixed and no one jurisdiction has been empirically demonstrated to have achieved the ideal model across all services and service user groups: *'It has not been possible to identify a full configuration of services in a single jurisdiction which has been proven by robust data collection, evaluation and/or research to significantly improve outcomes for people with disabilities.'*

Most countries, like Ireland, are at varying stages along the path to a more equal and inclusive model of service and some of the jurisdictions reviewed by the NDA had made significant strides towards that goal. The provision of more effective services, which contain costs and are sustainable into the future, was observed to be a common aim across all public services. The NDA's Synthesis Paper provides a very useful summary of the key learning points in the development of optimal person-centred services and supports.

6.5.2 RESEARCH – IRELAND

A 2009 report by Genio (formerly The Person Centre) on *Disability and Mental Health in Ireland: Searching out good practice* documented a strategy designed to address the perceived gap between the supports desired by people with disabilities and mental health difficulties and those currently provided in some parts of the country. The strategy set out to identify, develop and extend good practice, supported by advocacy and research, in order that they can be offered to more people with disabilities and mental health difficulties. Overall, the findings demonstrated that there are strong examples of person-centred work in Ireland and that it is possible to discriminate between strong and not-so-strong examples using identified criteria as an assessment tool. These criteria were person-centeredness (involvement in design; implementation and review; individualised supports and services; dignity and respect); engagement (collaboration; advocacy; inclusion); leadership (vision; sharing the learning; evaluation and research); efficiency and effectiveness (meeting needs; flexibility); and growth (growing to scale/reaching more people). The criteria proved to be effective in differentiating between various projects on each of five domains used for assessment purposes. Further details of the individual projects are given in the report (Genio, 2009).

¹⁸ See www.nda.ie/website/nda/cntmgmtnew.nsf/0/083EC79FA6AAF18280257877004DE7DD?OpenDocument

INTERNATIONAL AND NATIONAL RESEARCH

KEY FINDINGS

- ✓ No one international jurisdiction has arrived at the ideal model of disability services, but many are far advanced along the path towards more equal and inclusive services. The lessons learnt by these jurisdictions have been synthesised by the NDA. [Finding 6.30](#)
- ✓ Criteria for the assessment of good practice have been identified and documented by Genio (2009). Using these criteria, many examples of innovative developments and practice in the field of person-centred services can be found in Ireland. [Finding 6.31](#)

Chapter 7: How should supports and services be delivered in the future?

The aim of this chapter is to consider whether the objectives of the Disability Services Programme have been achieved and whether the strategies used to achieve them have been effective. The validity and continued sustainability of the objectives and strategies are then discussed. The chapter proposes defining the vision and goals that pertain to the Disability Services Programme and develops a more focused and explicit implementation strategy by which they may be achieved more effectively. The steps necessary for a planned migration towards the vision and goals are then considered.

7.1 HOW VALID ARE CURRENT OBJECTIVES?

As described in Chapter 2, current national objectives for the provision of services to people with disabilities were set out in *Towards 2016* (Department of An Taoiseach, 2006). These objectives set out a ‘whole of Government’ approach and were not confined to the delivery of health services alone. Chapter 6 then examined the degree to which outcomes have met these objectives.

7.1.1 HOW DO CURRENT SERVICE DELIVERY STRATEGIES CONTRIBUTE TO MEETING THESE OBJECTIVES?

In order to inform the work of the VFM Review, an Expert Reference Group (ERG) was established to review current policy in relation to disability services. The report from the ERG, entitled *Report of Disability Policy Review*, was published in 2011. Among other things, the ERG was asked to examine the achievement and sustainability of programme objectives and the continued effectiveness of the current policy approach. The ERG concluded that the general approach, particularly in respect of people with intellectual disability, was to provide services in institutionalised settings, which were by and large segregated from the rest of society. Individuals generally received all their services from the same agency and in many cases had little choice in the types of services they received or where they received them, but rather had to accept what was on offer.

Service provision was also geared towards meeting the needs of the *group* rather than the *individual*. The ERG Report (2011) says:

‘There is little evidence of individualised service provision, with a lack of standardised needs assessment and provision largely based in groups. Even though many services purport to use person-centred planning, the quality of the person-centred plan can be negated if options are framed largely in terms of the current model of provision. For example, some day services may be described as supporting “community participation”, although this often involves service users attending a community setting as a group, on a special bus, often in a segregated manner (for example, a special hour for swimming or bowling). Those attending in the group usually have not selected that activity themselves.’

The points made by the ERG are valid, but do not reflect the reality that current services are the product of decades of historical and social development, and that these services have provided extensive and valued supports for people with disabilities over the years. Although there is little argument that the time has come for change, it should be acknowledged that the service provided to very many services users has generally reflected prevailing expectations and norms. The disability agencies should also be credited with having developed considerably over the years, such that the services provided by them are considerably more advanced compared to their original state. However, advancements in national and international recognition of the rights of people with disabilities, a shift from the medical to the social model of disability, and general social and cultural developments have all contributed to a different vision of what people with disability require – a vision based on social inclusion, full citizenship and the realisation of individual potential.

7.1.2 HAVE THE OBJECTIVES BEEN ACHIEVED?

Most people who have a substantial reduction in capacity due to enduring physical or intellectual impairments do not lead full and independent lives, are not supported to participate in work and society on the same basis as the wider population, and do not have the personal supports necessary to enable them to maximise their potential (*as demonstrated in Chapter 6*). Section 5.5.1 of the ERG Report (2011) states that:

'The available information shows that disability services as currently organised and structured are not meeting stated policy objectives. Contrary to the T2016 [Towards 2016] objectives, many of those using disability services do not participate in society in any meaningful way and many are not given the opportunity to work or contribute to society. A significant proportion of people live and spend their days in segregated settings apart from the general community. Overall, people using disability services have little opportunity to self-determine or to live full and independent lives. The objectives are, nonetheless, still relevant and reflect the thinking in national and international policy documents. However, the realisation of these objectives has not been evident for most people with disabilities.'

It should, however, be noted that the policy objectives in *Towards 2016* extend beyond the remit of the health sector, making it difficult to isolate the effects of the HSE-funded Disability Services Programme from the effects of other governmental and social developments.

Notwithstanding the perception that the *Towards 2016*'s objectives may have only been partially achieved, it is clear that many people's lives have been enhanced by the services provided to them by the health sector, even where these services may not now be considered in line with current best practice. The public consultation conducted by the VFM Project Team for this Review (*see Chapter 6*) found that once the initial hurdle of accessing services had been overcome, the services received were considered by respondents to have a beneficial effect. In response to the question '*Do you feel that the range of services available is having a positive impact on the lives of the people who use them?*', 82% of respondents replied that services were having a significantly positive or partially positive impact on people's lives. Despite this, just one in 10 respondents reported that each of the four *Towards 2016*'s objectives was being met. Dissatisfaction levels with the extent to which objectives have been met ranged from 53%-68%. Respondents were least satisfied with '*the amount of control people with disabilities have over their lives*' and none reported being very satisfied with this objective.

Taking all the responses to the consultation into consideration, it may be concluded that the services provided are valued and are having a generally positive impact, but, in the light of new emerging models of service delivery, disability stakeholders are strongly of the view that the objectives are not being met in the most efficient and effective manner possible. The time has come to re-focus the way in which services are delivered so as to better meet the stated objectives of *Towards 2016*, reframed in the context of the current Programme for Government (Department of An Taoiseach, 2011) and current Government policies.

7.1.3 ARE THE OBJECTIVES STILL VALID?

The ERG Report (2011) pointed out that the policy goals in *Towards 2016* closely reflect the views of people with disabilities and their families, but that there is a gap between the policy objectives and what is provided by many disability services:

‘While current policy objectives emphasise “full and independent lives”, the available information shows that many disability services are not organised or provided in a way that supports this goal. The objectives are, nonetheless, still relevant and reflect the thinking in national and international policy documents. However, the realisation of these objectives has not been evident for many people with disabilities.’

The ERG’s view was supported by the results of the public consultation conducted by the VFM Project Team on the efficiency and effectiveness of current services (see www.dohc.ie/publications/). The responses to the consultation strongly supported the validity of the current objectives, but, as indicated above, questioned whether they had been met. Virtually all respondents (96%) agreed that the objectives of the disability services remain significantly or partially valid. Respondents who supported the stated objectives qualified their answers by commenting that more emphasis is needed on independence, safety and quality of life, with greater flexibility and choice.

Current objectives are high level and have not been translated into operational objectives. Their continued validity has been supported by the public consultation, but they require to be underpinned by meaningful, detailed and measurable operational objectives, and a more explicitly defined service delivery framework.

7.1.4 CAN THE OBJECTIVES BE SUSTAINED INTO THE FUTURE?

The ERG Report (2011) considered the sustainability of current policies and investment, and concluded the following: *‘This model of provision must also be considered in light of the current environment with regard to the economic climate, changing demographics and changing expectations. Information on demographics show that there will be increasing demand for disability services into the future (Doyle et al, 2009).’*

In considering the sustainability of current policies, the ERG Report addressed the implications of demographic changes on service provision:

‘The greater numbers of people overall with intellectual disability [see Chapter 2 data from the NIDD] and physical/sensory disabilities will place increasing demands on disability services. In addition, the improved life expectancy of older adults with more severe intellectual disability will place an increased demand on health services. Fewer places (both day and residential) are becoming free over time, resulting in increased pressure on the current service model ... The majority of adults with intellectual disability and physical/sensory disabilities live at home with their families. As these caregivers age beyond their care-giving capacity, further supports will be required.’

The ERG Report also considered the changing expectations of service users and families and concluded that people with disabilities and their families now have higher expectations and expect to live a more normal and inclusive life in the community, with their services and supports delivered in a new and more flexible way. The report also noted that:

'The National Disability Authority has advised [NDA, 2010a] that better outcomes for people with disabilities can be achieved through aligning services with the policy goals of promoting community integration, independent living, choice and participation'.

The views of the ERG and the NDA are consistent with the general view that the objectives of the Disability Services Programme are mostly being pursued through a resource-intensive approach, based on a medical model of disability, delivered in segregated settings with high staff/client ratios and skills mix designed for *group* rather than *individual* need. While the objectives remain valid, they are not sustainable if delivered through the current approach, for the following reasons:

- the cost of delivering services is high and even if more efficiently delivered, will remain high (see Chapters 4 and 5 of this Review);
- expenditure cannot be maintained at current levels (see Chapters 4 and 5);
- there are increasing demographic pressures that will put further strain on reducing resources (see Chapter 2);
- resources are not allocated according to assessed need nor is funding linked to outcomes achieved (see Chapters 3, 4 and 5);
- the achievement of personal outcomes is generally not compatible with a service delivered in a group setting (see Chapter 6).

The current approach has not been successful in meeting objectives despite the significant resources invested in it in recent years and there is no evidence that a more cost-efficient version of the same policy approach would be any more effective. Since, however, there is a broad level of agreement with the objectives, it follows that the approach used to achieve them should change.

OBJECTIVES – ACHIEVEMENT, VALIDITY AND SUSTAINABILITY

KEY FINDINGS

- ✓ The operational approach used to achieve current objectives has not been as effective as it should be. [Finding 7.1](#)
- ✓ Demographic pressures and changing expectations will place increasing demands on services. [Finding 7.2](#)
- ✓ The high-level objectives of the Disability Services Programme remain valid, but the current policy approach is not sustainable for reasons of cost, accountability and effectiveness. [Finding 7.3](#)

KEY RECOMMENDATIONS

- ✓ A more sustainable approach should be adopted to support the realisation of the vision, goals and objectives of the Disability Services Programme at service user level. [Recommendation 7.1](#)
- ✓ Greater transparency and accountability should become an integral part of the delivery and funding of services and supports. [Recommendation 7.2](#)
- ✓ Migration toward a more effective policy approach should take place within the constraint of reducing expenditure ceilings for the health sector and within the context of the prevailing national economic climate. [Recommendation 7.3](#)
- ✓ A comprehensive set of operational objectives should be developed that are specific to individual services and supports. The objectives should be realistic, meaningful and quantifiable. [Recommendation 7.4](#)
- ✓ Resource allocation should be linked to operational objectives and take account of the considerable logistical challenges involved. [Recommendation 7.5](#)

7.2 HOW SHOULD SERVICES BE DELIVERED IN THE FUTURE?

The findings detailed in Chapter 6 (on ‘How effective are disability services?’) and the 2011 report of the ERG (*see above*) have demonstrated that current objectives are relevant and continue to be valid, but that the strategies developed to implement these objectives served their purpose at the time but are not sustainable in the future. A new vision and goals are proposed for the disability services, which provide an overarching framework for the objectives set out in *Towards 2016* and the health reform programme envisaged in the Programme for Government over the period 2011-2016.

7.2.1 VISION AND GOALS OF THE PROPOSED NEW DISABILITY POLICY FRAMEWORK

Based on its analysis of current disability service provision and the wider context, the Expert Reference Group (ERG) proposed a policy framework to articulate policy objectives for people with disabilities and for disability services, and to support the achievement of those objectives. The vision proposed for this policy is *‘To realise a society where people with disabilities are supported to participate fully in economic and social life, and have access to a range of quality supports and services to enhance their quality of life and well-being’*.

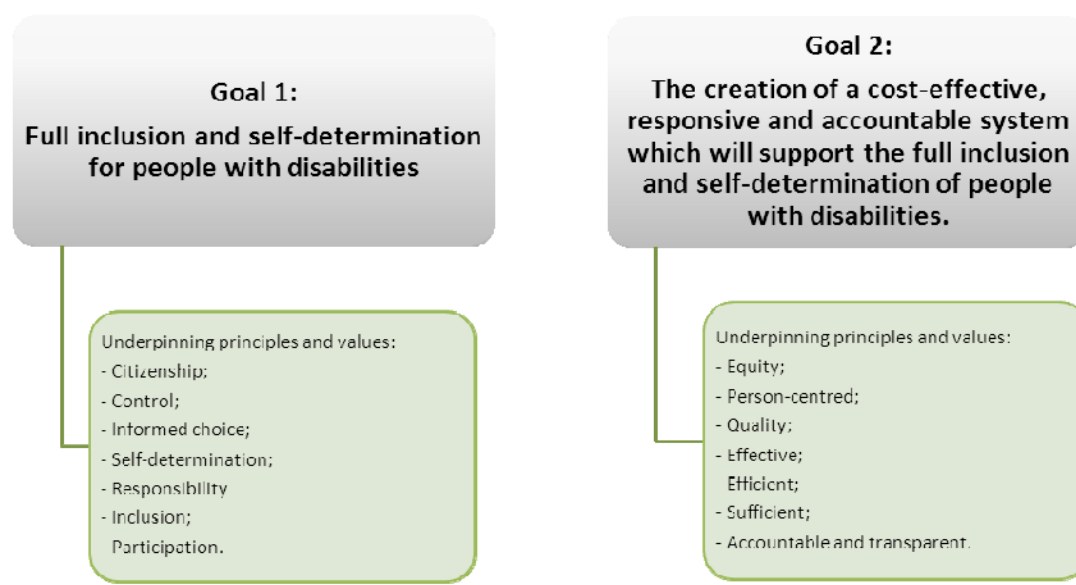
This vision takes a ‘whole of society’ view and is wider than the remit of the Disability Services Programme funded from the Health Vote. In view of the Terms of Reference of this VFM Review, it seems appropriate to adapt the vision somewhat and express it specifically in terms of the health sector (changes are indicated in **bold type**):

‘To contribute to the realisation of a society where people with disabilities are supported, as far as possible, to participate to their full potential in economic and social life, and have access to a range of quality personal social supports and services to enhance their quality of life and well-being.’

In this context, ‘personal social supports’ refer to any non-clinical supports provided by the health service, such as the provision of care, therapeutic supports, training, early childhood intervention, assistance with daily living, aids and appliances, welfare and protection, communication and advocacy support.

The ERG’s revised policy proposals are rooted in key principles and values, and have two overarching goals (see Figure 7.1): *‘The first goal captures the objectives in T2016 [Towards 2016] and spells out the ultimate desired outcomes for people with disabilities. The second goal expresses characteristics of the disability service system which are required to support the achievement of the full inclusion and self-determination of people with disabilities.’*

Figure 7.1: Goals proposed by the Expert Reference Group (ERG)



Central to Goal 1 – of full inclusion and self-determination for people with disabilities – is the reframing of current disability service provision *from* services that, as reported by the ERG, act to keep the person as passive and dependent *towards* a system of individualised supports that enable active citizenship and independence. The ERG defines individualised supports as:

‘a personal social service which includes a range of assistance and interventions required to enable the individual to live a fully included life in the community. Individualised supports require the provision of a flexible range of supports and services that are tailored to the needs of the individual, and are primarily determined by the person. This provision enables people with disabilities to live as full citizens instead of having to fit into standardised models and structures ... Supports include assistance provided by others, whether in the form of personal care, communication or advocacy support, learning support, therapeutic interventions, aids and equipment, adaptations to the physical environment, and so on’.

Goal 2 acknowledges the importance of cost-effectiveness and accountability. The ERG recognises that a strong governance framework is needed to underpin the provision of supports and services for people with disabilities, covering such elements as assessment of need, resource allocation, procurement and commissioning, quality assurance, performance management, information systems and management structure. Supports in this context would refer primarily to those provided by the health and other mainstream services, consistent with the needs of daily living, separate to any social welfare payments that a person with a disability might be entitled to. However, clearly the capacity of any person to live a normal life in the community is dependent on having sufficient income to live on, preferably earned through paid employment but where this is not possible, through receipt of statutory entitlements.

In the new framework, the vision and goals would be supported by operational objectives, which would form a set of practical targets that are specific, measurable, attainable, realistic and time-bound. The objectives would cascade down into lower levels of detail as appropriate (see Figure 7.2).

Figure 7.2: Example of vision, goals and programme-level objectives



PROPOSED NEW DISABILITY VISION AND GOALS

KEY RECOMMENDATIONS

- ✓ The following vision statement should be adopted as an expression of a revitalised and re-orientated Disability Services Programme:

To contribute to the realisation of a society where people with disabilities are supported, as far as possible, to participate to their full potential in economic and social life and have access to a range of quality personal social supports and services to enhance their quality of life and well-being.

Recommendation 7.6

- ✓ The vision should be underpinned by the following goals:
 1. Full inclusion and self-determination through access to the individualised personal social supports and services needed to live a fully included life in the community.
 2. The creation of a cost-effective, responsive and accountable system which will support the full inclusion and self-determination of people with disabilities.

Recommendation 7.7

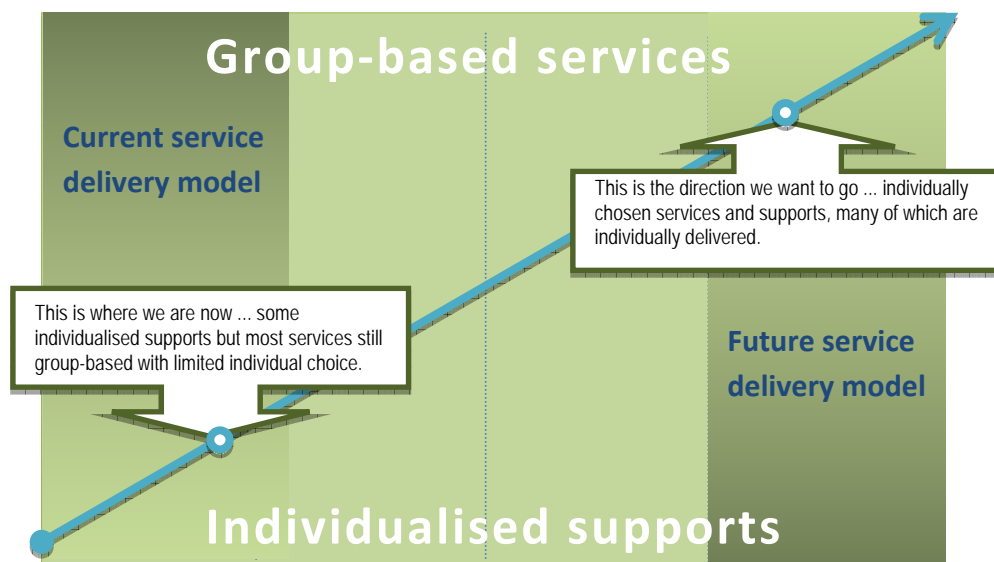
7.3 DESCRIBING THE SHAPE OF FUTURE SERVICE DELIVERY

7.3.1 SHIFT OF EMPHASIS IN THE WAY SERVICES ARE DELIVERED

Much of what has been proposed by the ERG (*described in greater detail below*) is already evident in current provision. Developments in the delivery of services and supports have been evolving, albeit slowly, towards a more person-centred approach. More changes have been made in some areas than others; for example, the move to community-based residential settings has been marked, although it should be noted that this, of itself, does not provide an indicator of full community participation.

The demand for change will accelerate with the implementation of the Congregated Settings report (HSE, 2011) and the Adult Day Services Review (HSE, 2012a), and it is clear that current and future capacity and resource constraints, including reducing expenditure ceilings and increasing pressure to achieve 'more with less', can be a driver for the kind of strategic change envisaged in the ERG Report. Instances of service provision that is aligned more closely to the ERG's re-articulated vision are described below. If service provision is considered as a continuum, the Disability Services Programme has already started on the path to a more individualised service (*see Figure 7.3*), although with the preponderance of services still provided in group-based settings.

Figure 7.3: Pathway to a more individualised service delivery model



While many elements of the ERG proposals represent a progression based on current developments, some elements are more radical, such as the change to individualised payments, which echoes the commitment in the Programme for Government to *'move a proportion of public spending to a personal budget model so that people with disabilities or their families have the flexibility to make choices that suit their needs best'*. Other aspects of the ERG's proposals, particularly in relation to governance and administration, corroborate the findings and recommendations outlined throughout this Review.

7.3.2 REFRAMING SERVICES TOWARDS A MODEL OF INDIVIDUALISED SUPPORTS

The ERG Report (2011) proposes a reframing of disability services towards a model of individualised supports, underpinned by mainstreaming of all public services. State funding would be allocated based on a standardised independent assessment of individual needs. Following the needs assessments, individual support plans would be drawn up and individualised budgets allocated, from which the supports and services needed would be purchased. A number of mechanisms are proposed to achieve this, including direct payments (where the person manages the budget and purchases the supports themselves) or a broker system (where the person has the choice and control, but the broker administers the budget and commissions supports and services on their behalf).

The proposals envisage:

- Reframing of current disability service provision – *from* services that act to keep the person as passive and dependent *towards* a system of supports that enable active citizenship and independence.
- Provision of individualised supports, including a range of assistance and interventions required to enable the individual to live a fully included life in the community.

The supports would be:

- primarily determined by the person;
 - directed by the person (with their family/advocate as required);
 - provided on a one-to-one basis to the person and not in group settings (unless that is the specific choice of the person or a 'natural' group activity, such as group therapy or team sports);
 - flexible and responsive, adapting to the person's changing needs and wishes;
 - encompassing a wide range of sources and types of support, so that very specific needs and wishes can be met;
 - not limited by what a single service provider can provide;
 - having a high degree of specificity ('provision' expressed in terms of residential, day or respite does not capture the specific nature of an individual's support needs).
- Adoption of individualised budgeting approaches, which would put a monetary value on the supports required by the individual to live a fully included life in the community.
 - Mainstreaming as the central mechanism to realise the proposed policy vision. A 'whole of Government' approach can ensure people with disabilities will have access to the universal services they need.
 - A strong governance framework to underpin the provision of the recommended supports and services.
 - Provision based on need, using an approach to needs assessment that is driven by the person and family/advocate (as appropriate), who are centrally involved in the entire process; covering the important domains in a person's life; using a standardised reliable process; and is independent of those providing supports and services.

As well as articulating the proposed policy framework, goals, principles and values, the ERG also made a number of specific recommendations in respect of the Department of Health, including recommendations on cross-sectoral working (see *Appendix 7*). It should be noted that cross-sectoral working is already a feature of how the Department works, particularly since the establishment of the Office for Disability and Mental Health and the substantial input that the Office makes towards advancing mainstreaming of policies across Government departments encompassed by the National Disability Strategy.

The conclusions of the ERG Report (2011) were informed by growing evidence from international practice. A detailed assessment of the transferability of the international experience to Ireland was not made, although the ERG was influenced by examples of innovative practice throughout the country that demonstrate elements of the proposed approach in specific instances (see *Appendix 8*).

Since the remit of the ERG Report did not extend to exploring the effects of the policy approach for service users in any detail or the implications for current services and service providers, this work should form part of the detailed appraisal of the proposed policy approach, in line with the overall thrust of the recommendations of this VFM Review. The ramifications of the policy approach for service providers will require developing and shaping the market – responsibility for shaping the market has already been identified as one of the core functions of the National Disability Lead (see *Figures 3.1 and 3.2 in Chapter 3*).

7.3.3 ADVICE PAPER FROM NATIONAL DISABILITY AUTHORITY

The National Disability Authority (NDA), which is an independent statutory advisory body on disability, shares a similar vision to the Expert Reference Group. The NDA (2010a), in its *Advice Paper to the Value for Money and Policy Review of Disability Services*, summarised its vision for the future as follows:

'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.'

On the subject of outcomes and effectiveness, the NDA recommends that:

'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.'

The NDA's Advice Paper gives practical guidance on better use of existing resources:

'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.'

A full list of the NDA's recommendations is given in Appendix 9.

7.3.4 CONCLUSIONS

It is proposed by this VFM Review that instead of a slow and tentative drift towards individualised services, the policy approach would be recalibrated to focus more closely on the proposed vision and goals, and that all future developments would be planned and evaluated in terms of their progress towards the vision and goals. This progress should be advanced in parallel with the recommendations around reframing existing services (*as outlined in Chapter 5*) so that the development of new resource allocation models and units of cost can provide a basis upon which the transition from traditional programme type to more individual costing approaches can take place.

7.4 STAKEHOLDERS' VIEWS

Stakeholders were consulted at various stages of this VFM Review, including two public consultations, both advertised widely in the national media. At the outset, a public consultation was held on the objectives, efficiency, effectiveness and funding of the disability services (*see Chapter 6*). The emerging proposals from the Expert Reference Group (ERG) were published in summary form in December 2010, with the final ERG Report being published in October 2011 and public submissions were sought on its proposals. The views of the various stakeholders are summarised below.

7.4.1 VIEWS ON CURRENT SERVICES

As outlined in Section 7.1.2 above, virtually all respondents to the public consultation on services agreed that the objectives of the disability services remain significantly or partially valid, but questioned whether they had been met. Dissatisfaction levels with the extent to which objectives have been met ranged from 53%-68%. Respondents were least satisfied with *'the amount of control people with disabilities have over their lives'* and none reported being very satisfied with this objective. Respondents cited a variety of reasons to explain their answers, the common theme being a failure to provide the supports needed in order for people with disabilities to live independent lives. In relation to carers, many respondents felt that despite support for carers being one of the four primary objectives of the disability services, there is a lack of acknowledgement for carers and a lack of support for them.

Although some ambivalence was apparent in respondents' answers and significant concerns were voiced on certain issues like access to services, the majority (82%) reported that the disability services were having a significantly positive or partially positive impact on people's lives. This supports the Review's contention that the Disability Services Programme has been relatively successful in meeting the needs of people with disabilities in the past, but should now adjust to a changing social environment which places a greater emphasis on outcomes, choice and control, participation and active citizenship.

7.4.2 VIEWS ON EMERGING POLICY PROPOSALS

The ERG Report (2011) was released for the public and interested parties to have their say on the future direction of disability policy in Ireland. In total, 94 submissions were received (64 from disability service organisations and 30 from individuals). In all cases, the organisations strongly supported the proposed policy vision and goals, and were keen to see the service focus more directly on the individual needs of people with disabilities.

Organisations agreed that the current service and financial models were no longer efficient or capable of providing services appropriate to the individual. They were of the view that the model needs to be changed to allow for greater flexibility and to distribute funding in a fair and equitable manner.

Organisations also agreed that the proposed new funding model has a great deal of merit, although some remained cautious since there is no clear picture yet of what it will look like and how exactly it will change the way services are delivered.

A large number of the submissions were concerned with the challenges that implementation of any revised policy would present. The need for a comprehensive plan, further consultation, reform of staffing, timeframes, costs, transition, dual systems running at the same time were all mentioned in some detail as needing careful consideration.

7.4.3 VIEWS OF OTHER DEPARTMENT OF HEALTH DIVISIONS

The National Disability Unit consulted with other Divisions across the Department on the ERG Report (2011). There was broad agreement across these Divisions on the direction of proposed policy as set out by the ERG, i.e. to move more fully to mainstreaming, separate health from personal social services and introduce individualised budgeting for people with disabilities. The proposed policy was also seen to be consistent with

the development of primary care policy and Government policy on the move to Universal Health Insurance, which places a strong emphasis on a patient-centred care model.

While being supportive of the policy shift, it is clear from the Divisions' responses that the move to individualised budgeting will pose challenges and that further clarity on how this would be implemented in a fair and equitable manner will be required before they can assess the full impact on their areas of responsibility.

7.4.4 VIEWS OF OTHER GOVERNMENT DEPARTMENTS

All Government departments were consulted to ascertain their views on the proposed policy. Generally, they all saw the ERG Report (2011) as a positive input for the future development of disability policy, but felt unable to comment any further until more details were available, with the Department of Public Expenditure and Reform identifying a number of critical implementation issues which require further development and validation. There was, however, general agreement by Government departments that the proposals would allow for a more customer-focused, integrated and efficient service for people with disabilities.

While the ambition behind the proposals was welcomed, the fact that the ERG Report contains high-level objectives with no detailed costing was identified as an important issue that would need to be examined at an early stage. Overall, Government departments stated that they would like to see more detail before commenting further on how implementation might impact on policies or services that come within their control.

Several concerns were expressed by the Department of Public Expenditure and Reform (D/PER). It pointed out that the ERG policy has not been appraised from a cost or feasibility perspective. It also raised issues about the transferability of evidence from international experience and the lack of 'a bridge' between the vision portrayed and realistic implementation steps. In addition, it made a number of points on the ERG Report itself, commenting that, as well as the policy not being costed, the implications for current organisational structures for disability service providers and the HSE were not explored. It also stated that any proposal to put in place a system of individualised funding for people with disabilities would have to be achieved not only within existing resources, but also within the resources available up to 2014 in the National Recovery Programme. It cited a lack of evidence in the ERG Report to support the view that the new way of delivering services could be provided at the same cost as the current model of service delivery. Finally, it expressed the view that the ERG Report was not specific on action points for named Government departments or agencies under a number of headings, including assignment of responsibilities, identification of costs, timelines, implementation actions and performance measurement indicators.

7.4.5 EXAMPLES OF PROPOSED APPROACH IN ACTION

There are many examples of projects that are already delivering better outcomes to service users, often at the same or lower cost to the organisation (*see Appendix 8*). Many of these projects are in the area of service provision and focus on ways to deliver a more effective service to the individual. Other innovations are testing administrative ways to improve service delivery, while at the same time cutting costs.

Among the areas where the proposed approach is already in action are:

- support for independent living;
- alternative ways of providing respite support, including respite for people with High Support needs;
- innovation in service delivery and administration, such as a team approach to the delivery of services to children.

7.5 ISSUES AND CHALLENGES IN MOVING FORWARD

The practical and logistical task involved in advancing these proposals should not be underestimated. Also, establishing the necessary structures for the new models of service outlined in this chapter (e.g. advocacy, procurement, brokerage, family supports, and administration of funding models) will pose a considerable challenge, given the scale of the transition now proposed.

7.5.1 HOW TO INCREASE THE EFFICIENCY OF THE CURRENT SYSTEM

Ensuring the efficiency of the current system will prepare the groundwork for the migration to the more person-centred model of service delivery. Not to do so would result in carrying forward inefficiencies into the new approach. An analysis of outputs in Chapter 5 found that there is a requirement to put a framework in place to assess need, identify outputs and outcomes, and plan and monitor resource usage. At the moment, the Review found that there is no national standard methodology for assessing clients' needs or for linking those needs with target outcomes. Equally, there is no nationally agreed means of predicting the amount of resources which an individual is likely to require and no common method of calculating the amount of resources which an individual actually consumes and the cost of those resources.

Calculating the amount of resources used and their cost at individual service user level was identified as being the key building block to a more cost-efficient service, regardless of the model of service. Key contributors to unit costs were identified as being pay and conditions, staff/client ratio, rostering practices and skill mix. Of these, rostering is a primary determinant of cost-efficiency since it is the means by which the needs of the individual are matched on a 24-hour, 365-day basis with the appropriate staff numbers, skills and grades. At client level, contributors to unit costs were found to be level of functional ability, challenging behaviour and co-morbidity (particularly mental health conditions and autism).

Chapter 5 addressed these findings by way of appropriate recommendations on the development or adoption of standard client assessment and resource allocation tools. While work on these tools should start immediately, they will take time to complete and will require pilot implementation before being rolled out nationally. Other recommendations (e.g. an audit of rosters and examination of skill mix) can be put into practice at agency level without delay and do not need to await a national response. As a first step, therefore, it is recommended that an immediate and robust examination should take place within each agency of the Review's findings and recommendations (*see Chapter 9*) and agency-level plans should be drawn up to put relevant recommendations into effect.

The most basic requirement for national management of the disability function was identified as being accurate and timely information at national, regional and local level on funding allocated and expended, at a reasonable level of detail. That being the case, an immediate action required at national level is the adoption

of a common coding scheme (or a reliable means for matching disparate coding schemes) and maintenance of central records on allocations and expenditure, to include the HSE's own services and the For Profit sector, as well as Section 38 and Section 39 agencies. This should be supported by a revised SLA Schedule 3 dataset, consolidated at regional and national level, which will collect information on key cost drivers identified by the VFM process and will build on the dataset collected by the HSE for the purpose of this VFM Review. Access to this information will allow the national disability function to monitor unit costs and to identify, understand and address cost disparities. Information availability will also be the key to supporting the HSE in developing commissioning, market-shaping and capacity-building expertise, which it can use as tools for ensuring efficient and effective service delivery in the future.

7.5.2 HOW TO ENSURE THAT RESOURCES ARE FAIRLY DISTRIBUTED

A national resource allocation methodology is fundamental to the equitable distribution of resources and is another key recommendation in Chapter 5. A national resource allocation model takes into account service user needs (determined through a standardised assessment process), on the one hand, and the amount of resources available at national level, on the other. A national model should be predicated on finite resources and should provide a framework for the distribution of available resources to meet assessed need in as fair and transparent a way as possible. It should also include protocols for determining eligibility and prioritisation. Chapter 4 (*Section 4.7*) examined the current geographical distribution of resources and found that there were variations in resource distribution that warrant further investigation. A similar finding was made in Chapter 5 (*Section 5.2.3 under 'Unit costs – Geographical variations'*). The recommendations made to address this issue were that resource allocation should be matched to the location of clients so that a proper assessment of geographical resource allocation can be made (*see Chapter 4*) and that funding should be adjusted over time to better reflect the actual position on service user numbers and service delivery (*see Chapter 5*).

7.5.3 HOW TO MOVE TOWARDS THE PERSON-CENTRED MODEL

The groundwork for the move towards a more person-centred service will be achieved in the first instance through the implementation of the efficiency and effectiveness measures recommended in Chapters 5 and 6. The shift in *funding people rather than places* is one of the core elements of the required changes and will be supported by implementation of the recommendations on standardised needs assessment and unit costing. This transition has the potential to support greater efficiency and effectiveness by matching individual needs to resources, allowing resource usage to be tracked and eliminating any mismatch between need and provision by tailoring supports to meet identified needs. Also following on from the recommendations in Chapter 5, the rationalisation of funding and expenditure by means of a national resource allocation model (*see above*) will support the move to more person-centred services and provide information on which fair and transparent decisions can be made. Similarly, the recommendations in Chapter 6 on effectiveness will provide the foundation for a quality framework and link the allocation of funding to the achievement of measurable service user outcomes.

While unit costing is seen as key to the achievement of efficiencies, regardless of the model of service, it also has the capability to support the move to 'individualised budgeting'.

Individualised budgeting is an umbrella term that may take many forms, ranging from a method of determining resource allocation to agencies based on assessed client need and actual costs, to a 'money follows the client' model, a brokerage system or a personal budget model administered by the individual service user. With individualised budgeting, the main transfer to the service user is the transfer of choice and control over funding decisions. This might or might not involve the transfer of actual funds to the individual.

The priority should be to further improve current services while expediting the analysis of the benefits to be gained from newer models of individualised supports currently being tested (*see Section 6.3.4 in Chapter 6*). Pending the introduction of the improvements and reforms outlined in Chapters 5 and 6 (and paraphrased above), it would not be advisable to move to a fully individualised budgeting system until the necessary availability of alternative service options had been properly piloted, tested and sufficiently established so as to avoid the creation of a vacuum in service quality. However, the balance and emphasis needs to shift firmly and comprehensively towards these new models of individualised supports once (i) sufficient analysis of the benefits is carried out in the Irish context and (ii) adequate financial management, resource allocation and governance structures are in place to ensure their long-term viability. In parallel, every encouragement should be given to further pilots and initiatives as long as their inputs are clearly ring-fenced and fundable into the medium term, and adequate monitoring structures are put in place in the HSE, pending the wider reforms being recommended. As part of the preparation for migration towards a person-centred approach, a unique identifier should be put in place for those seeking or receiving services, consistent with plans for a wider health sector identifier, to facilitate individual needs assessment, person-centred planning and individualised budgeting.

It is clear that a significant challenge lies ahead in making the current system as efficient as possible in the short to medium term. However, it is also apparent that many voluntary agencies are already introducing more individualised person-centred approaches into their programmes and these initiatives need to be encouraged and accelerated, so that they gradually become the norm for service delivery, particularly for new entrants to services. This approach, as much as the newly piloted small initiatives, when evaluated for wider application, will provide a strong basis for establishing the new policy approach proposed by this Review, both within the existing agencies and in new independent entities.

It is accepted that it will be necessary to improve the efficient use of the existing resources in the system, while encouraging the development and expansion of the newly piloted initiatives in parallel. This process should be driven and directed by the national disability function to avoid the risk that some agencies might choose to focus on the more easily implementable community-based client options, while risking a prolongation of less effective and poorer quality residential-type delivery, particularly for service users who have lower levels of functional ability or exceptional resource needs. However, there should be no ambiguity about the necessity for a change in the way in which services are currently organised and delivered, as the current model of predominantly group-based institutional service delivery (in the intellectual disability sector in particular) is not financially sustainable in the medium to long term.

7.5.4 CONSTRAINTS ON PROPOSED APPROACH TO SERVICE DELIVERY

Migration toward a more effective policy approach should take place within the constraints of reducing expenditure ceilings for the health sector and within the context of the prevailing national economic climate. Operating within a reduced budget has been a feature of disability services for the past 3 years, and this position will continue for the foreseeable future, making the achievement of operational efficiencies a continual priority. Moreover, freeing up resources through greater efficiency is the only realistic way in which a move to more individualised services can be financed. While some proponents of individualised services argue that the move will be cost-neutral or result in savings, this has not been definitively proven.

This VFM Review has been mindful of questions and concerns raised about the refocused service delivery approach, including the contention that the refocused model of service delivery has yet to be tried, tested and costed in the Irish context as a mainstream approach.

Set against these concerns, however, is the fact that the current system is not sustainable in terms of cost, accountability or effectiveness, so fundamental changes have to be made. Not alone is the current system unsustainable, but it does not meet its objectives and no longer meets the changing aspirations and needs of people with disabilities. In addition, the degree of fit between the delivery of services and support and the UN Convention on the Rights of People with Disabilities should be improved.

It is not accepted that the refocused model of service delivery is entirely untried and untested in the Irish context. Service providers have been moving along the road to a more individualised service, although developments have been uneven and without strong national focus. The physical disability representative organisations have argued strongly that services for the people they represent are already provided in the community and that they can provide a roadmap for how services and supports should be delivered. It should also be noted that many of these supports, where required, are not provided through specialist disability providers, but rather through the mainstream health services or through agencies that support people to access mainstream services and opportunities. The personal assistance service, which is largely confined at the moment to people with physical disabilities, supports choice, independence and control, and is highly valued by those who avail of it; the case for its extension to those with intellectual disabilities was highlighted in the public consultation for this Review. Both the HSE and disability agencies are also engaged in projects to move people into community settings and relevant case studies have been mentioned earlier in this chapter, and are also detailed in Appendix 8. It is acknowledged that the pace of change in the intellectual disability sector has been slow, but nevertheless services are already working towards a more individualised and community-based approach.

The case for some of the fundamental elements of the new framework has already been made, independently of any policy considerations, during the course of this Review. Chapter 3 has recommended that administrative and governance procedures be strengthened and a commissioning and procurement environment be developed. Chapters 4 and 5 have described the need for a radical overhaul of the way in which services are funded and expenditure recorded; recommendations included the development of a national resource allocation model, based on a standardised assessment of need, a methodology for costing assessed needs and protocols for determining the basis for allocation of resources. Chapter 6 has concluded that outcome measures and quality assurance systems need to be put in place.

The cost of the newer way of delivering services has not been analysed in an Irish context, but the development and application of a national resource allocation model, coupled with the efficiencies identified in this Review, should support the evidence-based use of resources towards the achievement of programme

objectives. Moreover, some of the costs of the movement to the newer model of services will arise because of the transition from one model to another – both service users and staff who have spent their adult lives in institutional settings will require targeted resources to facilitate their transition to a different way of living and working. Younger people, on the other hand, will not be removed from their natural family and community supports, will be better educated than previous generations and will have received more therapeutic supports from an earlier age. Just as the expectations of young people and their families are different, the nature of the supports this cohort will require from the health services will also be different. The cost of the transition to community-based support is difficult to predict and will require to be addressed in incremental stages through the implementation planning process, which is one of the recommendations in this Review.

The capacity issues in the current system are acknowledged, but, as indicated above in Section 7.3.1, the capacity constraints currently being experienced by the system can be a driver for strategic changes in service delivery envisaged by the ERG. In addition, the degree of support and goodwill for the refocused proposals among service users, their families and service providers can be harnessed so that, with effective leadership the changes envisaged can be delivered over time within the constraints which currently prevail with the health sector and the public service as a whole (*see also Section 3.1 in Chapter 3*).

7.5.5 CONCLUSIONS

This VFM Review has taken all relevant factors into account in its deliberations and has agreed that the movement towards individualised services and supports should necessarily adopt a common-sense incremental approach, which acknowledges capacity issues and financial constraints, but which is nevertheless purposefully and centrally directed towards the achievement of the vision, goals and objectives outlined in this chapter.

7.6 MOVING TOWARDS A BETTER WAY OF DELIVERING SERVICES

7.6.1 RECOMMENDATIONS ON FUTURE DIRECTION OF THE DISABILITY SERVICES PROGRAMME

This VFM Review considers that the person-centred model described in this report would form the basis of the future direction of disability policy. The policy will be grounded in the vision:

‘To contribute to the realisation of a society where people with disabilities are supported, as far as possible, to participate to their full potential in economic and social life, and have access to a range of quality personal social supports and services to enhance their quality of life and well-being’

and supported by the twin goals of:

1. Full inclusion and self-determination through access to the individualised personal social supports and services needed to live a fully included life in the community.
2. The creation of a cost-effective, responsive and accountable system that will support the full inclusion and self-determination of people with disabilities.

The Review proposes that the HSE should drive migration towards the new policy approach through the mechanism of the SLA process from 2013 onwards by requiring agencies to identify relevant demonstration or pilot projects and prepare plans for their implementation. Inputs should be clearly ring-fenced and fundable into the medium term within ongoing funding limits. Adequate monitoring structures should be put in place in the HSE and costs and benefits evaluated. Agencies should be required to report to the HSE at predetermined intervals on progress in implementing these initiatives as an integral part of the SLA monitoring process. The HSE should identify an evaluation framework for these projects so that they are evaluated for their suitability for mainstream application.

Migration towards the future policy direction will encompass the following:

- establishment of the financial viability of an individualised supports model, through a detailed appraisal process, as a precursor to final decisions on discrete elements of the policy;
- all aspects of a revised policy approach to be demonstrated to be both cost-efficient and effective, having regard to all the findings in this Review;
- acknowledgement of the challenges that will be faced in fully implementing the recommended approach, including the capacity of the system to respond to major changes at a time of funding and staffing constraints;
- recognition that all decisions on implementation steps should be taken in the light of current and future expenditure, employment ceilings and the likelihood of funding restrictions over the coming years.

FUTURE DIRECTION OF THE DISABILITY SERVICES PROGRAMME

KEY RECOMMENDATIONS

- ✓ The person-centred model described in this Review should form the basis of the future direction of disability policy. [Recommendation 7.8](#)
- ✓ Pilot projects should be developed as proof of concept and run in parallel with current services as part of the migration towards person-centred services and supports, and their suitability for wider application subsequently evaluated. [Recommendation 7.9](#)
- ✓ The HSE should drive migration towards the new policy approach from 2013 onwards by requiring agencies to identify demonstration projects as part of their SLA negotiations and to commit to their implementation. Inputs should be clearly ring-fenced and fundable into the medium term. Adequate monitoring structures should be put in place in the HSE to follow up on progress as an integral part of the SLA monitoring process. [Recommendation 7.10](#)
- ✓ An individualised supports model has many facets and may be implemented in a number of ways. Further work should be undertaken by the HSE and the Department of Health to identify the precise features of the model proposed, taking into account that the model will be multi-form and multi-faceted, in order that it may be fully appraised and costed. [Recommendation 7.11](#)

- ✓ Where appropriate, clinical and therapy supports should be provided in a mainstream setting, i.e. provided by non-disability-specific providers. The precursor to this should be the establishment of the primary care network. [Recommendation 7.12](#)
- ✓ The HSE should further develop its business coding systems and structures so that it is capable of identifying allocations to, and expenditure by, its own directly provided services and voluntary disability agencies on supports and services for people with disabilities, at national, regional and local levels. [Recommendation 7.13](#)
- ✓ All funding should be allocated on the basis of a standardised assessment of individual need, which should be linked to the resource allocation methodology. [Recommendation 7.14](#)
- ✓ A unique identifier should be put in place for those seeking or receiving services, consistent with plans for a wider health sector identifier and a national health information strategy, to facilitate individual needs assessment, person-centred planning and individualised budgeting. [Recommendation 7.15](#)
- ✓ Since it will not be feasible for all assessed needs to be met in full by the HSE in the context of competing resources, the protocols for prioritising need, and deciding which needs are met and which are not, should be transparent, fair and equitable. [Recommendation 7.16](#)
- ✓ Cross-sectoral working will be crucial to the implementation of the revised model and will be an integral part of the planning process. The Department of Health and the health sector should continue to liaise with their colleagues in other Government departments and agencies to ensure that cross-sectoral working arrangements are prioritised and maintained. [Recommendation 7.17](#)

7.6.2 PLAN FOR MIGRATION TOWARDS VISION AND GOALS

An extensive amount of detailed analysis will be required to develop a migration plan from the current way of delivering disability services to the point where service provision, administrative structures and governance procedures all support the achievement of the proposed vision and goals. Other matters to be taken into account in conducting the analysis will be the Government's reform plans for the health sector and the implementation of current and planned reforms in primary care. Other matters such as the pace of reform will also provide an input into the practical assessment of the policy proposals. For example, the full implementation of the primary care network will be a significant influencing factor in the assessment of proposals to 'unbundle' primary care and therapy services, and provide these in the mainstream.

Organisational change

Progress towards the new way of delivering services and supports will depend on fundamental organisational changes. A number of organisational changes have been identified as necessary following an examination of systems efficiency and these approaches have been incorporated into the recommendations in Chapters 3, 4 and 5 of this Review. The Programme for Government is also committed to reforming the delivery of services and enhancing the effectiveness of those services. Recommendations on a quality framework and an outcomes-based approach have been addressed in Chapter 6.

The organisational changes recommended necessitate the development of systems for governance, quality assurance and information management, together with appropriate management structures and operational processes, to support the delivery of optimum outcomes through individualised funding and supports. Good governance – which has been defined in the ERG Report (quoting from Australia’s Department of the Prime Minister and Cabinet, 2006) as *‘the set of responsibilities and practices, policies and procedures, exercised by an agency’s executive, to provide strategic direction, ensure objectives are achieved, manage risks and use resources responsibly and with accountability’* – is central to the realisation of the revised policy proposals.

The proposals that have implications for administration, governance, management and organisation include the following:

- The processes for assessing the support needs of people with disabilities should be reviewed, taking into account the requirements for a standardised needs assessment process.
- The necessary actions should be taken to put in place a system of individualised funding for people with disabilities. A comprehensive commissioning framework for disability services should be developed so that a range of service and support options will be available to people with disabilities. This should include, at least on a pilot basis, the sourcing of services through a procurement process (*see also Chapter 3 for recommendations on commissioning and procurement*).

Many of these proposals have already been addressed in Chapters 3, 4 and 5 because they will provide the building blocks for a more efficiently operated and financed service, regardless of the policy approach adopted. In conjunction with the proposed policy approach, they will have an integral role in the migration towards a re-engineered disability service.

Implementation priorities

Recommended implementation priorities are detailed below. Some actions are prioritised because they provide the necessary infrastructure to support other key recommendations, others because they have the potential to result in immediate efficiency savings.

Administration and governance

1. The national disability function within the HSE should be strengthened and given a central directional role in funding, shaping and driving the Disability Services Programme. The implementation of the recommendations in this Review should be the responsibility of a Director of Disability Services who would have the qualifications, skills and experience necessary at senior management level to drive the change management process.

Person-centred services and supports

2. The HSE should drive migration towards a person-centred model of services and supports through the SLA process. Demonstration projects should be initiated by service providers as proof of concept and run in parallel with current services, and their suitability for wider application subsequently evaluated.

Commissioning and procurement

3. The HSE should, in consultation with the disability sector, work towards the directional re-shaping of certain services and models of service delivery based on a new commissioning and procurement framework.

Resource allocation

4. A national resource allocation model should be developed, based on a standardised and appropriate assessment of need process, a methodology for associating standard costs with assessed needs and transparent protocols for determining the basis for allocating finite resources.

Information infrastructure

5. The strategic information requirements needed for the effective management of the Disability Services Programme should be established, having regard to existing information sources and datasets, and an implementation plan put in place.

Immediate actions

Immediate actions should focus on making the current system as efficient as possible as a necessary precursor to freeing resources to support a more comprehensive migration towards the new policy approach. The most immediate actions to be taken are:

- | | |
|----------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Streamline SLA process | 1. Make the recommended adjustments to the SLA process to facilitate immediate improvements to basic information gathering and performance monitoring. |
| Standardise financial reporting | 2. Immediate action should be taken to arrive at a system where allocations and expenditure can be tracked, analysed and compared at national, regional and local levels. The basis of this will be the development of a common coding system and work on this should commence as a matter of urgency. |
| Prepare groundwork for individualised service provision | 3. A unique identifier should be put in place for those seeking or receiving services, consistent with plans for a wider health sector identifier, to facilitate individual needs assessment, person-centred planning and individualised budgeting. |
| Examine VFM findings | 4. Each agency should undertake an immediate and robust examination of the findings and key recommendations of the VFM Review, and draw up an implementation plan to give effect to the recommendations. The following recommendations should be advanced as a priority: |
| Audit of rosters | a. Agencies should immediately audit and critically review their rosters, and make necessary adjustments to rationalise staff deployment patterns across service units, consistent with client need and cost-effectiveness. |
| Skill mix | b. The appropriate mix of professional and non-professional staff needed to deliver services and supports should be determined through an examination of skills, functions and grades. Agreed national guidelines should be determined. |
| Unit cost base | c. The HSE and disability service providers should critically examine their existing cost base in the light of the findings and recommendations in Chapter 5 of the VFM Review. The HSE should also engage with disability agencies to establish the reasons for costs that remain higher than the average costs detailed in the Review. |
| Average costs | d. Pending the implementation of a resource allocation model, the HSE should work with agencies from 2012 onwards through the mechanism of the SLA process to reduce current direct pay costs to the levels set out in Table 5.18 (based on data given by agencies in respect of staff/client ratios on their 2009 SLA Schedule 3 returns). |
| Policy appraisal | 5. Appraisal of the new policy approach endorsed in Chapter 7 of this Review should be conducted according to Government guidelines on policy appraisal, i.e. the VFM Code. |
| Implementation plan | 6. Develop an implementation plan, taking into account the outcome of the policy appraisal, the scale of the organisational change required and the capacity constraints already referred to. |

IMPLEMENTATION GUIDELINES

KEY RECOMMENDATIONS

- ✓ A plan for migration towards revised policy objectives should be drawn up, with milestones, dependencies and critical path identified and a feasibility analysis and appraisal carried out. [Recommendation 7.18](#)
- ✓ Migration toward an alternative policy approach should take place within a value-for-money framework and within the context of the prevailing national economic climate. [Recommendation 7.19](#)
- ✓ Based on the high-level migration plan, a more detailed plan should be drawn up to implement any revised policy. [Recommendation 7.20](#)
- ✓ Further work is required to cost, prioritise and plan for the implementation of a revised policy approach. Work should commence on this without delay. [Recommendation 7.21](#)
- ✓ A full costings plan for the revised model of service should be produced. [Recommendation 7.22](#)

Chapter 8: Performance indicators

8.1 INTRODUCTION

This chapter aims to achieve the following objectives:

- describe and assess the Disability Services Programme's current suite of performance indicators;
- outline and evaluate the current data collections systems to support performance measurement for disability services;
- recommend new performance indicators.

In reaching these objectives, the chapter also aims to address two of the Terms of Reference of the Review. Firstly, it brings together and summarises material regarding the availability of information concerning outputs and outcomes (ToR 4), some of which has already been alluded to in previous chapters, notably Chapters 4, 5 and 6. Secondly, it specifies potential future performance indicators (ToR 9) that could be used to better monitor the performance of the disability services. The chapter draws on the HSE service planning and reporting documentation, HRB annual reports on disability databases and the range of performance data produced for the purposes of the VFM. The discussion focuses on the current configuration of services and does not include a comprehensive formulation of performance indicators for the revised model of service provision.

8.2 PERFORMANCE INDICATORS FOR DISABILITY SERVICES

8.2.1 DESCRIPTION OF INDICATORS

The performance measures in the National Service Plan for Disability Services have been developed and improved over the last number of years. Initially, the measures were focused on the implementation of Part 2 of the Disability Act. In 2009, new measures were introduced to the National Service Plan to monitor day, residential, respite and personal assistant/home support services. The full set of performance indicators from the 2011 National Service Plan is set out below.

Day Services

- Number of work/work-like activity WTE places provided for persons with intellectual disability and/or autism.
- Number of persons with intellectual disability and/or autism benefiting from work/work-like activity services.
- Number of work/work-like activity WTE places provided for persons with physical and/or sensory disability.
- Number of persons with physical and/or sensory disability benefiting from work/work-like activity services.
- Number of Rehabilitative Training places provided (all disabilities).

- Number of persons (all disabilities) benefiting from Rehabilitative Training (RT).
- Number of persons with intellectual disability and/or autism benefiting from Other Day Services (excluding RT and work/work-like activities).
- Number of persons with physical and/or sensory disability benefiting from Other Day Services (excluding RT and work/work-like activities).

Residential Services

- Number of persons with intellectual disability and/or autism benefiting from residential services.
- Number of persons with physical and/or sensory disability benefiting from residential services.

Respite Services

- Number of bed nights in residential centre-based respite services used by persons with intellectual disability and/or autism.
- Number of persons with intellectual disability and/or autism benefiting from residential centre-based respite services.
- Number of bed nights in residential centre-based respite services used by persons with physical and/or sensory disability.
- Number of persons with physical and/or sensory disability benefiting from residential centre-based respite services.

Personal Assistant/Home Support

- Number of Personal Assistant/Home Support hours used by persons with physical and/or sensory disability.
- Number of persons with physical and/or sensory disability benefiting from Personal Assistant/Home Support hours.

Implementation, Part 2 Disability Act

- Number of requests for assessments received.
- Number of assessments commenced as provided for in the regulations.
- Number of assessments commenced within the timelines as provided for in the regulations.
- Number of assessments completed as provided for in the regulations.
- Number of assessments completed within the timelines as provided for in the regulations.
- Number of service statements completed.
- Number of service statements completed within the timelines as provided for in the regulations.

8.2.2 ASSESSMENT OF INDICATORS

Comprehensiveness

The set of national indicators are not sufficiently comprehensive across the different services. They do not cover aids and appliances or multidisciplinary services. For individual services, there are also gaps.

It is also evident from the above that the indicators currently in use are focused on measuring outputs and activities in relation to disability services and do not measure outcomes. The current set of indicators does not

help to inform a view on the impact of services for people with disabilities or whether the objectives of disability policy are being achieved. A detailed discussion about outcomes measurement in general and factors influencing outcomes is contained in Chapter 6, which also recommends that outcomes should be defined at personal, organisational and programme levels. Chapter 6 also noted that indicators should be developed to measure the effectiveness of the disability services in promoting personal progress through access to day services and supports.

The national set of indicators also does not address the general direction of Government policy in recent years. There are no indicators measuring the implementation of new organisational/reconfiguration policies, such as reconfiguration of residential services, the introduction of early intervention services and the focus on community living. There are also no indicators that relate service provision to demand and the relative level of unmet demand for different services.

Quality of data

It is noted that some of the indicators are based on incomplete data. For example, the quantum of personal assistant hours is an extrapolation and is not based on an accurate measurement of actual client-facing personal assistant hours. Clarification is also required as to whether the data provided relating to places reflect actual WTE places consumed or notional capacity levels.

Baselines and targets

The 2011 National Service Plan for Disability Services shows that the baselines and the targets for certain services are precisely the same (number of persons with physical and/or sensory disability benefiting from residential services). The disability-related material in the body of the 2011 service plan similarly contains targets and baselines for the regions, which reflect no change in service levels. While these figures may indicate the plan to maintain services at a constant level given funding reductions, there is no explanation or commentary to contextualise the data or to explain why some services will be increased (e.g. personal assistant hours) while others remain constant.

Reporting

Reporting on the disability performance indicators has proven to be problematic. The majority of the indicators are reported as incomplete according to the 2011 Metadata report. No full set of data has been received in relation to 15 of the 23 indicators listed. The frequency of reporting is also inadequate. In 2010, the monthly performance reports were limited to reporting on the Emergency Placements and the Disability Act indicators. Most other indicators were due to be reported bi-annually. Data availability (lack of a complete dataset) was identified as the main barrier to reporting on the other indicators. Significant work will be required in relation to the remaining unreported performance indicators.

The majority of indicators are intended to be reported by HSE Area Business Managers via Local Health Offices to the Business Intelligence Unit in the Corporate Planning and Corporate Performance Division. To date, the indicators are not underpinned by data sourced from the SLAs.

The HSE has now scheduled a comprehensive review of performance indicators to be completed by the 4th Quarter of 2012. It is important that this review is prioritised by the HSE and finished as soon as possible. The results of the review should inform the service planning and reporting process for 2013 so that improved performance indicators are reported during 2013.

8.2.3 GAPS IN PERFORMANCE INFORMATION EMERGING FROM THE VFM REVIEW

The Terms of Reference for the VFM Review require the identification of gaps in the available datasets regarding outputs and outcomes. Some of these gaps have previously been identified in C&AG reports and NDA publications. Gaps were also identified by the Project Team as it attempted to source data to address the Terms of Reference. Although some work has been carried out to develop information on inputs and outputs through the SLA process, many significant data gaps remain and many of the same management information deficits identified in 2006 by the C&AG have not been addressed.

The main gaps are summarised below:

- Poor availability of aggregated data on personal outcomes at client, service provider or system level (*see Chapter 6*).
- Little, if any, useable data on intensity of care requirements or functional abilities of clients which can be linked to cost and resource data.
- Data deficit in relation to Section 39 agencies generally, regarding staff (not part of HR Staff Census) and outputs (although the SLA process should address this).
- Insufficient data on the outputs for key services, such as multidisciplinary services, personal assistant services, day services and aids/appliances, as well as for other diverse services provided by smaller providers (e.g. peer support, early intervention).
- Underdeveloped management information on the unit costs for different services incorporating overheads apportionment at service provider level.
- No data on HSE overhead apportionment to the disability care group.
- Lack of an integrated dataset regarding rostering arrangements.

It is worth highlighting that one of the Terms of Reference (ToR 5) required an identification of the trend in output delivery in recent years. This information is currently not available in a comprehensive form and although a pilot data questionnaire to collate output information was developed and tested, it was decided that the degree of data validation and checking work required would be too resource-intensive to warrant collecting questionnaire data from a large number of voluntary and statutory providers. There was also a risk that this data collection exercise might not have yielded sufficient output data to extrapolate output levels for the entire disability services. However, this meant that the VFM Review could not directly link the substantial expenditure increases in recent years to changes in output levels – a critical data gap that prevented the Project Team and Steering Group from assessing services over the last 5 years.

8.2.4 MAIN DATA SOURCES FOR POPULATING PERFORMANCE INDICATORS

The main data sources that can be used to develop performance indicators regarding disability services are:

- Service Level Arrangement (SLA) data provided by disability service providers and monitored by the HSE;
- the national disability databases maintained by the HRB – the NIDD and the NSPDD;
- HSE National Service Plan performance reports;
- returns provided by Local Health Offices to HSE Corporate on national indicators.

Service Level Arrangements

Background

The HSE introduced the Service Level Arrangement (SLA) framework in 2009 to link funding and the quantum of service provided in response to the C&AG's 2005 Report 52 on the *Provision of Disability Services by Non-Profit Organisations*. Section 3.2.2 of Chapter 3 of this VFM Review outlines the contents of the service level arrangements and the types of data collected, e.g. service levels, quality, staffing, costs. The arrangements have been in place for 3 years. There is no data repository at national level that collates the service levels, outcomes and performance indicators defined at individual SLA level.

The following discussion examines the quality of SLA data in populating performance indicators. This is based on an analysis of the SLA data and the practical issues faced by the HSE in collecting and processing data on the Disability Services Programme. Table 8.1 summarises the main deficiencies in SLA data for performance measurement purposes.

Table 8.1: Deficiencies in Service Level Arrangement data for performance measurement purposes

Data types

- The units of measurement for key outputs are inappropriate for services such as multidisciplinary services and personal assistant hours, where output is measured as the numbers of persons receiving the service instead of front-line hours of service delivered to clients. For example, 15 clients could receive personal assistant services, but the quantity or number of hours per person could vary substantially. Similarly, the unit of measurement for respite nights is the number of people in receipt of respite, which does not reflect the actual quantity of respite nights availed of by clients.
- The quantum of resource use and cost for disability services depends on the intensity of care requirements for clients. These care requirements are influenced by factors such as age, type of disability, incidence of challenging behaviour (CB), mobility and medical condition. The current SLA does not capture enough of these cost drivers or does so in a way that is not amenable to measurement, e.g. using 'free text' information for CB which prevents analysis¹⁹. This makes analysis

¹⁹ As noted in Chapter 5, this is in part due to the lack of a common assessment methodology or classification of functional ability to collect data on an individual's current service requirements.

of the efficiency of resource allocation difficult because the resource requirement cannot be determined. In short, there is no objective and independent common assessment methodology to allow a nationally consistent dataset to be collected regarding an individual's current service requirements.

- The SLA contains a field requiring agencies to specify the staff/client ratio for clients according to set categories, mainly for intellectual disability clients. However, it is not known whether the data reported record the targeted staff/client ratio per the client's needs or the actual staff/client ratio pertaining, which may or may not be an over/under allocation of staffing resources based on the client's needs and taking into account that services may comprise a mix of clients with very different staffing requirements (e.g. day services). Although it can be argued that there should be more clarity around the staff/client ratio data, detailed audits of SLA data and on-site visits would be required to validate the data.
- The SLA contains fields to allow for the comparison of capacity and actual service delivery for particular services. However, for some services the unit of measurement for capacity and actual is different, which makes the comparison impossible (e.g. personal assistant services – staff hours (capacity) and clients in receipt of service (actual)).
- The SLA currently measures the output for HSE-contracted services. It does not measure the output for all funded services, regardless of source of funding. This has the potential to skew the comparison of costs and services.
- There is insufficient breakdown of the headline staffing categories (nursing, support care, medical and dental, etc) by sub-category of staffing resource. As a result, for categories that contain a mix of front-line and administrative staff types (i.e. support services), it can be difficult to reach conclusions about the optimal staffing mix and the ratio of front-line to administrative staff.
- The current SLA does not collect any information on non-pay costs (requiring the VFM Project Team to source such costs through a non-pay questionnaire), which, although a low proportion of total service costs, are significant at a macro level for services and may form a high proportion of costs depending on the model of service delivery.
- There is no common method of uniquely identifying service locations for costing purposes.
- There is no disaggregation of baseline levels of service provision and development/investment in new services. As a result, it is not possible to assess the impact of investments on capacity levels.

Scope

The SLA process is intended to apply to all Section 38, Section 39 and HSE statutory agencies. Data were, however, incomplete for some of the HSE service locations. This impedes the development of a comprehensive analysis of service delivery.

Data collection, validation and quality standards

It has taken significant HSE resources to collect, validate and report on SLA data. In particular, there have been problems in categorising services. In addition, HSE staff have carried out extensive checking of staff numbers and grade types to assess pay costs by service unit. The data collection process has highlighted the variety of service delivery configurations and the extent of different staffing type and grades across different providers.

A key determinant of the accuracy of a dataset is completeness and validation. This requires a clear explanation of the data requirements to the staff in service providers completing the schedules. The current validation procedures are summarised below:

- check of SLA data against management accounts for service providers to validate payroll figures;
- check of client numbers for selected services against HRB database data and information in the *Report of the National Working Group for the Review of HSE-funded Adult Day Services* (HSE, 2012a);
- check of staffing data against the HSE HR Staff Census.

Significant improvements could be made to enhance the validation of SLA data, focusing in particular on the investigation of outliers and extreme values by reference to benchmark values for comparable groups of providers and service units. In his 2009 Annual Report, the C&AG noted that data quality standards need to be enforced to ensure that the information base is fully reliable. These standards have not yet been developed. Such standards should be clearly specified on the HSE website.

Monitoring and review

The HSE, through the Service Level Arrangement framework, requires agencies to participate in a monitoring and review process, through submission of information to the HSE and attendance at review meetings. At each review meeting, consideration is given to various issues specified in the SLA, including financial, staffing, administrative and activity issues. There is no available information from the HSE regarding the number of review meetings held to date, if any, or the outcomes of those meetings.

The aggregation and management of SLA data does not support accountability. SLA agreements are not aggregated into a consolidated form to reflect the services of national organisations that operate in many different parts of the country. This prevents a coherent approach to performance management, particularly in relation to some of the larger organisations.

As part of its monitoring arrangement with an agency, if the HSE considers that the provision of the services by the provider is not in accordance with the SLA, the agency may be issued with a First Performance Notice, which will require them to take whatever steps are necessary to ensure compliance with the SLA. This may be followed by a Second Performance Notice. The effects of non-compliance may include a decision by the HSE that:

'The Executive itself will provide or procure the provision of one or more of the Services at the expense of the Provider until the Provider has shown to the reasonable satisfaction of the Executive that the relevant Services will in future be provided by the Provider in accordance with the terms of this Arrangement'

or withhold a proportionate amount of the agency's funding until matters have been resolved. In exceptional circumstances, the HSE may, without terminating the SLA in its entirety,

‘appoint a manager, whether in a caretaker basis or otherwise, to undertake managerial responsibility for the Services (or part thereof) who will report directly to the Executive’.

No First Performance Notices or Second Performance Notices have been issued by the HSE in respect of disability service providers.

The SLA also contains a termination clause, which, in the event of a serious breach of its obligations by the agency, allows the HSE to terminate the SLA with immediate effect. This clause has not yet been invoked in respect of any disability service provider.

There has been no formal review of the operation of the SLA process, its effectiveness for resource allocation purposes or the methodological adequacy of the data requirements. A review was carried out by the HSE’s internal audit unit, but this mainly related to governance issues rather than resource allocation. The principal objective of the audit was to assess the current governance structures within the larger funded agencies and their compliance with good governance principles and the requirements of their service level arrangements with the HSE. The audit review found that there was a high level of compliance with the HSE’s requirements. The audit made 20 recommendations covering governance issues, such as public information, procurement, complaints and information. The audit review also made some recommendations which coincide with recommendations made in this VFM Review. These are repeated below.

- The HSE should consider designating a single service manager for national and regional agencies with multiple service arrangements to coordinate overlapping funding and monitoring arrangements.
- HSE Finance should designate responsibility for review of annual accounts to a lead manager in the case of agencies with multiple service arrangements. The finance lead manager should liaise with the service lead manager for such agencies.
- HSE Finance should issue guidance to agencies on its preferred presentation of certain information in annual accounts, and/or disclosures which it requires to supplement the annual accounts.
- HSE Procurement should investigate the feasibility of assisting agencies to reduce insurance costs by a combined tendering process.
- The service arrangements should specify the requirement for agencies to advertise contracts on eTenders, as per the Department of Finance’s public procurement Guidelines and Circular 10/10.
- The HSE should as part of the SLA process ask agencies to provide details of the assets held by them or affiliates in which the HSE has an interest.

The SLA process has not been updated since its introduction in 2009, 3 years ago. It is also not clear how the SLA data supports resource allocation decisions at LHO level – one of the principal aims of the original data collection process.

However, it should be noted that while some aspects of the SLA are deficient, it is the first attempt at matching funding with services and it has been carried out in the absence of a standardised needs classification model.

HRB disability databases

There are two disability databases maintained by the Health Research Board (HRB), namely the NPSDD and the NIDD. The databases are intended to be used to inform regional and national planning by providing information on the demographic profile of persons with disabilities, current service provision and future service needs. It is not clear how these databases are used to support local resource allocation. The C&AG has previously commented on these databases, noting the following points: since participation is voluntary, there will always be some element of under-reporting; the NSPDD is incomplete, covering about 60% of physical and/or sensory disability clients; and the assessment process is not independent. Table 8.2 outlines some of the ongoing areas of improvement for the HRB disability databases.

Table 8.2: Issues regarding HRB disability databases

NIDD

- The database records the number of clients receiving multidisciplinary services, but there is no measurement of the quantity of multidisciplinary services delivered.
- The database collection form measures the number of days received for each service, but this data is not analysed in the main body of the report or used to show how different day services have different profiles of service provision (e.g. 5-day, 4-day, 3-day services).
- There is no analysis of the progression in service provision for cohorts of clients. For example, it would be useful to know whether there was any progression in services provided for similar groups of clients for whom such progress would be expected (e.g. moving from support employment to open employment). This type of longitudinal work would require tracking clients using the unique database identifier.
- The HRB records second and third day-services received, but does not outline the number of clients receiving second or third services and whether or not there are any demographic characteristics associated with these clients.
- The database records future service requirements, but this reflects the views of service providers and lacks independence.
- The database does not capture the types of non-standard services that may be supplied by smaller providers.
- The database does not collect detailed diagnostic/functional ability data for clients.
- The database classifies clients as borderline, mild, moderate, severe or profound based on IQ, but this categorisation does not correlate well to an individual's level of functional ability.

NSPDD

- The database has been historically incomplete, with 67% coverage of relevant clients.
- The data on current services does not sufficiently capture the quantity of output (e.g. personal assistant hours).
- The data on aids and appliances does not reflect the number of aids and appliances issued during the year.
- The database cannot be used to assess the increased life expectancy or health status of people with physical or sensory disabilities.

There will be an overlap in the future for the HRB disability databases and the SLA process since these datasets collect data relating to service provision. At present, HRB data are used to validate SLA data, but it is possible that HRB data are simply re-entered for SLA templates, rendering the validation less than useful. Although both data collection mechanisms have different objectives, some coordination is required to ensure that data matching between both sets of data can be carried out, if required. In the medium term, this could involve use of common identifiers across both types of dataset. It will also be important to rationalise data collection across the HRB databases and that of the SLA to avoid unnecessary duplication. This should be informed by a consideration of the specific objectives for HRB and SLA datasets.

8.3 NEW PERFORMANCE INDICATORS FOR DISABILITY SERVICES

The following additional high-level performance indicators are recommended and their capacity for collection assessed (*see Table 8.3*). This list is indicative only and not intended to be a comprehensive list of all new performance indicators required to address the current deficiencies. It is intended to illustrate the type of additional indicators required to monitor performance effectively. The list should be further disaggregated by service, disability type and organisation. It does not include detailed information on health outcomes, which are context indicators for the disability services. Chapter 6 recommends that these outcomes be separately specified and collated by the HSE. Further work is required to assess the extent to which those indicators with 'low feasibility' ratings could be developed in a cost-effective way.

Table 8.3: Proposed new performance indicators for the disability services

Indicator	Data collection source	Collected & reported by	Feasibility
INPUTS			
Percentage of total front-line staff who are non-medical/social care professionals by service type and sector	SLA/HR Staff Census	HSE	High
Administration (pay and non-pay) costs as a percentage of total services costs	SLA	HSE	Medium
Senior management pay as a percentage of total pay costs	SLA/Accounts	HSE	High
OUTPUTS			
Number of client-facing multidisciplinary support hours by type of multidisciplinary support	SLA	HSE	Low
Number of client-facing personal assistant hours	SLA	HSE	Low
Number of days of day services delivered by category of day service (education, training, excursions, etc.)	SLA	HSE	Medium
Number of aids/appliances issued to clients, by type and region	SLA	HSE	Medium
Number of adaptive technology solutions funded	SLA	HSE	Medium
Number of clients in receipt of services by type of disability, grouped by intensity of care bands	SLA	HSE	Medium
Number of personal needs assessments carried out	SLA	HSE	High
Number of clients for whom a person-centred plan has not been developed	SLA/Personal outcome questionnaires	HSE	Low

Indicator	Data collection source	Collected & reported by	Feasibility
OUTCOMES			
Number of disabled clients accessing specified health and social services delivered in mainstreams settings	Questionnaires	HSE LHOs/ agencies	Low
Number of clients who have transitioned from congregated settings to community settings by level of disability	SLA	HSE	Medium
Number of disabled clients in employment settings by type of setting (open, supported, etc)	Personal outcomes questionnaires/ SLA	HSE/ agencies	High
Percentage of clients spending time engaging in social activities of client's choice at least once a week	Personal outcomes questionnaires/ SLA	HSE	Low
Number of clients for whom the staff/client ratio has decreased due to improvements in behavioural problems	Case studies/ Aggregated person plans	HSE	Low
Number of targeted* clients who have progressed through identified pathways of day services (including employment and training)	Personal outcomes questionnaires/ SLA	HSE	Low
Number of clients showing an improvement in functional abilities/health outcomes due to specific therapy services (e.g. rehabilitation therapy)	Case studies/ Personal outcomes questionnaires/ SLA	HSE	Low

* This relates to the cohort of clients for whom it may be reasonably expected that they could progress through a pathway of services based on intensity of care requirements and abilities..

It is important to note that reporting on output and outcome indicators should be accompanied not only by targets and baselines, but also by contextual commentary that explains the context for performance. This should include the related trends in input. For example, an increase in the number of multidisciplinary support hours could be due to additional staff, greater productivity or changes in rostering arrangements.

Some indicators may be more difficult than others to attribute to service interventions. Some of the programme indicators are context indicators, such as disabled persons in education or employment (participation rates, etc), which, while useful, may reflect a number of contributory factors, such as the economic environment. Outcome indicators that are directly attributable to service interventions should be separately identified.

PERFORMANCE INDICATORS

KEY FINDINGS

- ✓ The current set of performance indicators for the disability services are not comprehensive since they focus on a subset of the key services and do not cover outcomes. [Finding 8.1](#)
- ✓ There are quality problems with some of the indicators, with inappropriate units of measurement used for some of the services. [Finding 8.2](#)
- ✓ There are deficiencies in the quality of performance information collected through the SLAs. Similarly, there are many areas for improvement in the dataset collected by the HRB. [Finding 8.3](#)
- ✓ Many of the deficiencies identified by the C&AG in 2005 in relation to performance data remain unaddressed. [Finding 8.4](#)
- ✓ In his 2009 Annual Report, the C&AG noted that data quality standards need to be enforced to ensure that the information base is fully reliable. These standards have not yet been developed. [Finding 8.5](#)
- ✓ Significant work is required to ensure data collection mechanisms match data requirements to assess performance across the different disability services. In this context, there is an overlap in the role of the HRB and the National Disability Unit in collecting and aggregating disability services data. [Finding 8.6](#)

KEY RECOMMENDATIONS

- ✓ The Department of Health and the HSE should agree on a revised SLA Schedule 3 for 2013 data collection. [Recommendation 8.1](#).
As part of the revision process, the following measures are recommended:
 - Data should be collected for all directly provided HSE services on the same basis as for non-statutory agencies. This change should be implemented for the 2013 round of SLA data collection. [Recommendation 8.1a](#)
 - The SLA should be amended by the HSE, in consultation with the ODMH, to take account of the deficiencies highlighted in this chapter (unit of measurement, capacity *versus* actual comparisons, breakdown of staffing categories by the relevant sub-categories and inclusion of intensity of care-related cost drivers, such as mobility, challenging behaviour and medical condition) for the 2013 round of data collection. Data on non-pay and overheads should also be collected so as to facilitate the calculation of service user and service unit costs. Costing and output data should be

based on all funding sources and not just HSE funding. The SLAs should continue to be managed in an Excel-based mechanism. [Recommendation 8.1b](#)

- The revised SLA schedules should be presented by the HSE to service providers at seminars to support completion of the SLA templates, prior to launch of the new SLAs (i.e. Quarter 4, 2012). [Recommendation 8.1c](#)
 - Data quality standards need to be developed and enforced by the HSE to ensure that the information base is fully reliable and validated. These standards should be developed by end Quarter 4, 2012. The standards should be clearly specified on the HSE website. [Recommendation 8.1d](#)
 - The amended schedules should be accompanied by a document or detailed guide setting out the data quality standards and data definitions, including worked examples to ensure accurate completion of schedules. This suite of documentation should be finalised by the HSE by Quarter 4, 2012. [Recommendation 8.1e](#)
 - There should be independent periodic spot checks of SLA data at service provider level. These should be carried out by the National Disability Unit in the HSE. [Recommendation 8.1f](#)
 - The HSE's Internal Audit Unit should also carry out independent audits of the accuracy of SLA performance data. It would be helpful if an audit was carried out in 2015, once the revised agreements had been fully implemented and in operation for a year or two. [Recommendation 8.1g](#)
 - Data on outcomes and performance indicators (*as indicatively outlined in Table 8.3*) should form part of the data collection process and be aggregated by the National Disability Unit (by end Quarter 4, 2012) at agency (i.e. consolidated across all regional branches), regional and national level to allow effective monitoring of performance. [Recommendation 8.1h](#)
 - Any future development funding should be coded separately on SLA agreements to allow for an assessment of the impact of development funding relative to baseline levels of output. [Recommendation 8.1i](#)
- ✓ As a general principle, data gathering (both once-off and recurring) should be rationalised across the HRB disability databases, the SLAs and any other HSE data collection tools, to avoid unnecessary duplication of effort and the creation of multiple potentially inconsistent or incompatible datasets. This principle should also apply to the DoH, NDA or any other bodies seeking to collect data relating to the Disability Services Programme. As a general rule, any data which is not required should no longer be collected to avoid administrative overhead for providers. In particular, given the central role of the SLA in performance data collection, unnecessary disability-related data collection by the HRB and the NDA should be curtailed where this arises. This raises into question the continued need for the HRB disability databases in their current form in the medium term. To address this issue, there should be a review of the resources currently engaged in data collection, the overall information requirements necessary to support monitoring and review of the disability services, the optimal contribution

that SLA agreements can make to data collection and the remaining contribution, if any, that can be made by the HRB disability databases. The review should be led by the ODMH and completed by end Quarter 4, 2012. [Recommendation 8.2](#)

- ✓ New performance indicators are required to better assess the performance of the disability services and address the gaps in outcomes and outputs measurement. The indicators described in Table 8.3 should be piloted by the HSE for a large disability service provider by end Quarter 3, 2012, with a view to early implementation in 2013. [Recommendation 8.3](#)
- ✓ The HSE should prioritise the comprehensive review of performance indicators scheduled for completion by the 4th Quarter of 2012. It is important that this review is advanced to completion by the HSE as soon as possible. The results of the review should inform the service planning process for 2013 so that improved performance indicators are reported during 2013. [Recommendation 8.4](#)
- ✓ The HSE should publish a summary report presenting aggregated performance analysis of the annual SLA data. This should be carried out in Quarter 1 of the year following the SLA reference period. The first report should be published in 2013. The report should incorporate:
 - geographic profiling of services;
 - trend information relating to key outputs and costs;
 - commentary about completeness and accuracy issues regarding performance information.[Recommendation 8.5](#)
- ✓ The ODMH should also publish a short annual report on disability services, drawing on all the various data sources available to it and reporting specifically on performance, i.e. linking objectives and funding, outputs, efficiency, outcomes and progress in developing datasets. The first report should be scheduled for completion in 2013. [Recommendation 8.6](#)

Chapter 9: Conclusions and Recommendations

9.1 CONCLUSIONS

9.1.1 RATIONALE

The VFM Review has been conducted in the context of the current economic climate and the prospect of continuing resource constraints into the foreseeable future. The rationale for the provision of publicly funded services and supports for people with disabilities – that it serves the needs of those who could not otherwise afford to provide basic social and personal supports for themselves – remains valid. On the one hand, information on demographics shows that there will be increasing demand for disability services in the future. On the other hand, the current model of service delivery is not providing a sufficient quality and quantity of services at an affordable price. The thrust of the recommendations in this report are aimed at resolving this dichotomy and pointing the way to a more affordable service, which is fit for purpose and better meets the needs of those who avail of it.

9.1.2 RELEVANCE

In the context of the current social, cultural and economic climate, many of the services being provided to people with disabilities are not considered as relevant to people's lives as they would once have been. The findings from the public consultation conducted as part of the VFM Review clearly show that people are now looking for more choice in disability services and control over how they access them. They are looking for flexible services that meet their individual needs and systems that vest more control with the service user and, where appropriate, their families. These features are not generally available in the existing system, particularly to people with intellectual disabilities. It is worth noting, however, that some agencies, particularly those serving people with physical disabilities, have developed from a community base with the aim of promoting and protecting client choice, control and independence. These agencies already operate a client-focused model of service and they provide examples of good practice, which can be used to inform decision-making in the wider disability sector.

9.1.3 EFFICIENCY

An objective determination of value for money and efficiency is dependent on extensive supporting quality and outcomes data and empirically derived costs for a range of standardised service types. The information does not currently exist in the disability sector (and consequently was not available to this VFM Review) to allow this finding to be made. The results of the data analysis conducted as part of this Review reflect the complexities of disability service provision, which is not a single, homogeneous and easily measured programme, but rather a multiplicity of service types and agency types serving a varied client population with widely differing needs.

An examination of the available data shows that in general some agencies or agency types are more efficient at one particular type of service and less efficient at another. Some models of service are extremely cost-efficient, but would score poorly on any 'quality of life' scale. Other types of service are cost-efficient and support the move to social inclusion and mainstreaming. The remaining services should become more cost-efficient during the period of transition from less supportive to more supportive services.

9.1.4 EFFECTIVENESS

There are no indicators to objectively measure the effectiveness of the Disability Services Programme in promoting personal progression, community inclusion and the application of choice, control and independence. However, many people's lives have been enhanced by the services provided to them by disability service providers, even where these services may not now fully accord with our current understanding of best practice. The public consultation conducted by the Project Team found that once the initial hurdle of accessing services had been overcome, the services received were considered by respondents to have a beneficial effect.

The health services provided for persons with disabilities, whether under the auspices of the Disability Services Programme or through the generic health services, have been very effective at protecting health and prolonging the lives of people with disabilities.

9.2 PRIORITY RECOMMENDATIONS

9.2.1 OVERARCHING CONSIDERATIONS

- Agencies that receive funding from the State for the delivery of services and supports to people with disabilities are accountable for that funding and the necessary systems and protocols should be put in place to ensure full accountability and transparency on a standardised basis.
- The achievement of measurable outcomes and quality for service users at the most economically viable cost underpins the recommendations.
- All recommendations should be considered in the light of the national financial position and the funding available to the health sector during the period of the National Recovery Programme, 2012-2014.
- Implementation of the recommendations should be driven at national level by a strong, standard and consistent approach if they are to be effective.

IMPLEMENTATION PRIORITIES

- | | |
|---------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Administration and governance | 1. The national disability function within the HSE should be strengthened and given a central directional role in funding, shaping and driving the Disability Services Programme. The implementation of the recommendations in this Review should be the responsibility of a Director of Disability Services who would have the qualifications, skills and experience necessary at senior management level to drive the change management process. |
| Person-centred services and supports | 2. The HSE should drive migration towards a person-centred model of services and supports through the SLA process. Demonstration projects should be initiated by service providers as proof of concept and run in parallel with current services, and their suitability for wider application subsequently evaluated. |
| Commissioning and procurement | 3. The HSE should, in consultation with the disability sector, work towards the directional re-shaping of certain services and models of service delivery based on a new commissioning and procurement framework. |
| Resource allocation | 4. A national resource allocation model should be developed, based on a standardised and appropriate assessment of need process, a methodology for associating standard costs with assessed needs and transparent protocols for determining the basis for allocating finite resources. |
| Information infrastructure | 5. The strategic information requirements needed for the effective management of the Disability Services Programme should be established, having regard to existing information sources and datasets, and an implementation plan put in place. |

IMMEDIATE ACTIONS

- | | |
|----------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Streamline SLA process | 1. Make the recommended adjustments to the SLA process to facilitate immediate improvements to basic information gathering and performance monitoring. |
| Standardise financial reporting | 2. Immediate action should be taken to arrive at a system where allocations and expenditure can be tracked, analysed and compared at national, regional and local levels. The basis of this will be the development of a common coding system, and work on this should commence as a matter of urgency. |
| Prepare groundwork for individualised service provision | 3. A unique identifier should be put in place for those seeking or receiving services, consistent with plans for a wider health sector identifier, to facilitate individual needs assessment, person-centred planning and individualised budgeting. |

IMMEDIATE ACTIONS *continued*

- | | |
|-----------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Examine VFM findings | 4. Each agency should undertake an immediate and robust examination of the findings and key recommendations of the VFM Review, and draw up an implementation plan to give effect to the recommendations. The following recommendations should be advanced as a priority: |
| Audit of rosters | a. Agencies should immediately audit and critically review their rosters, and make necessary adjustments to rationalise staff deployment patterns across service units, consistent with client need and cost-effectiveness. |
| Skill mix | b. The appropriate mix of professional and non-professional staff needed to deliver services and supports should be determined through an examination of skills, functions and grades. Agreed national guidelines should be determined. |
| Unit cost base | c. The HSE and disability service providers should critically examine their existing cost base in the light of the findings and recommendations in Chapter 5 of the VFM Review. The HSE should also engage with disability agencies to establish the reasons for costs that remain higher than the average costs detailed in the Review. |
| Average costs | d. Pending the implementation of a resource allocation model, the HSE should work with agencies from 2012 onwards through the mechanism of the SLA process to reduce current direct pay costs to the levels set out in Table 5.18 (based on data given by agencies in respect of staff/client ratios on their 2009 SLA Schedule 3 returns). |
| Policy appraisal | 5. Appraisal of the new policy approach endorsed in Chapter 7 of this Review should be conducted according to Government guidelines on policy appraisal, i.e. the VFM Code. |
| Implementation plan | 6. Develop an implementation plan, taking into account the outcome of the policy appraisal, the scale of the organisational change required and the capacity constraints already referred to. |

9.3 KEY RECOMMENDATIONS BY CHAPTER

CHAPTER 3 : Framework for the delivery of disability services

GOVERNANCE AND ACCOUNTABILITY FRAMEWORK

- ✓ A re-configured governance framework should be put in place to take account of the new model of services and supports outlined in Chapter 7 of this Review. The elements of such a governance framework include:
 - processes for assessing needs;
 - processes for allocating resources;
 - processes for procurement and commissioning;
 - quality assurance systems, including processes for managing risk;
 - processes for performance management, review and accountability;
 - appropriate information systems;
 - management structure.[Recommendation 3.1](#)
- ✓ Information on complaints that do not fall under Part 9 of the Health Act 2004 should be collated at national level and be used by the National and Regional Disability Lead/Director to support the monitoring of service user outcomes. [Recommendation 3.2](#)

ADMINISTRATIVE FRAMEWORK

- ✓ A Director of Disability Services in the HSE should drive the implementation of the recommendations in this Review and should have sufficient decision-making authority to ensure that the necessary changes are implemented. He or she should have full accountability for all resources allocated to the disability sector. [Recommendation 3.3](#)
- ✓ There should be a clear line of responsibility for decision-making at local, regional and national levels, which is consistent with levels of responsibility for the Disability Services Programme's budget. [Recommendation 3.4](#)
- ✓ A national disability function in the HSE requires to be strengthened in the following areas:
 - greater authority over the regional and local distribution of funding and service delivery matters;
 - resource monitoring;
 - greater role in identification and dissemination of best practice;
 - more 'hands on' commissioning, including management and direction of the market for provision of disability services;
 - the formulation of operational policy and administration of national/Government policy;
 - appropriate information systems;
 - research, development and implementation of innovative interventions.[Recommendation 3.5](#)

- ✓ A strong change management function should be put in place at national level to lead, coordinate and manage the implementation of the very significant body of recommendations in this Review, including progressing the further work recommended in Chapter 7. This would require a Director of Disability Services who is personally responsible for driving the process, and who has the qualifications, skills and experience necessary at senior management level for this task. [Recommendation 3.6](#)
- ✓ Geographic-based service provision should be examined to minimise duplication of administrative effort by service providers, facilitate regional and local service delivery planning and management, and maximise service user choice. [Recommendation 3.7](#)
- ✓ The role and funding of agencies that are wholly or substantially engaged in representation rather than direct service provision should be re-appraised having regard to the recommendations in this Review on the person-centred approach. [Recommendation 3.8](#)
- ✓ The place of the Disability Services Programme should be appropriately situated within the newly emerging health management structures and the development of those new structures should be kept under close scrutiny in the short term. [Recommendation 3.9](#)

FUNDING FRAMEWORK

- ✓ Agencies that receive funding from the State for the delivery of services and supports to people with disabilities are accountable for that funding and the necessary systems and protocols should be put in place by the HSE to ensure full accountability and transparency on a standardised basis. [Recommendation 3.10](#)
- ✓ Resource allocation at national, regional and local level should be on the basis of programme budgeting, where the objectives, output and outcomes of each element of the budget are specified, rather than incremental budgeting based on the calculation of changes to the previous year's baseline. [Recommendation 3.11](#)
- ✓ The position of funding *places* rather than *people* should be reversed. [Recommendation 3.12](#)
- ✓ The commissioning process, whereby the HSE arranges for the provision of services, should be formally documented. Opportunities for procurement by competitive tendering should be explored wherever this would maintain or improve service user outcomes at the same or lower cost. The HSE should move beyond a model of commissioning services from individual providers to one where, even on a pilot basis, services are sourced using a competitive procurement process. [Recommendation 3.13](#)
- ✓ Gaps in the dataset collected at SLA level should be addressed, while continuing to exploit the simplicity and effectiveness of the Excel-based data collection mechanism. SLA data should be collated at regional and national levels. Data on outcomes and performance indicators should form part of the data collection process and be aggregated at regional and national level to allow effective monitoring of performance. [Recommendation 3.14](#)
- ✓ Summary SLA data should be collated and published annually. [Recommendation 3.15](#)
- ✓ The operation of the SLA process should be independently validated and audited. [Recommendation 3.16](#)

CHAPTER 4 : Inputs for the disability services

FUNDING

- ✓ Full transparency on all sources of funding (both Exchequer and non-Exchequer) for disability organisations is required. Sources of funding should be itemised by source of funding and reconciled to the total income for the organisation. This analysis should be mandatory by being made a condition of HSE Exchequer Grant Aid Agreements and Service Level Arrangements. It should be provided as part of a standardised expenditure and staffing reporting template. This should be introduced for the allocation process from 2013. [Recommendation 4.1](#)

AGGREGATE EXPENDITURE TRENDS

- ✓ **Overall:** As a medium-term priority (1 to 2 years), a common system of recording and reporting expenditure should be developed by the HSE and implemented across the sector, subject to budgetary constraints. This should include common general ledger coding for cost elements across disability providers. [Recommendation 4.2](#)
- ✓ **Regional:** The HSE should be capable of matching Disability Services Programme expenditure with individual LHO areas to facilitate a comparison of resource allocation across different geographical areas. One way to facilitate this would be to track geographical spending using a client identifier that is linked to address information. [Recommendation 4.3](#)

EXPENDITURE DRIVERS

- ✓ **Multi-Annual Investment Programme:** Any future development funding should be coded separately on SLA agreements to allow for an assessment of the impact of development funding relative to baseline levels of output. This should be introduced for the next iteration of the SLA agreements (i.e. 2013) (*see also recommendations in Chapter 8*). [Recommendation 4.4](#)
- ✓ **Staff numbers:** Staff numbers in Section 39 agencies should be monitored as part of a more comprehensive information-gathering and performance-monitoring system across the sector, i.e. potentially through the mechanism of the SLA process. A consistent periodic HR dataset on Section 39 agencies should be available by end Quarter 2, 2013. [Recommendation 4.5](#)

PROFILE OF PAY COSTS

- ✓ For agencies that derive over 50% of their income from the State, CEO salaries should be capped at Consolidated Scales CEO level. The salary level should also be commensurate with the size and complexity of the agency, so that the CEO of a medium or small provider should receive less than the CEO of a major agency. This requirement should also encompass the senior management of agencies. The remuneration of the senior management team should not be set at levels in excess of equivalent senior management scales in the HSE. These requirements should be conditions of HSE funding and should be introduced as part of resource allocation for 2013. [Recommendation 4.6](#)

- ✓ As a medium-term priority, opportunities for rationalising grade structures and creating flatter organisational models should be explored across disability providers, taking account of the work practice and skills mix flexibility measures under the Croke Park Agreement. [Recommendation 4.7](#)
- ✓ The HSE should begin the process of substituting non-professionally qualified care staff for professionally qualified care staff to achieve pay savings in the statutory and voluntary sectors. This will be consistent with the new person-centred model envisaged as the future direction of disability policy (see Chapter 7). [Recommendation 4.8](#)

PROFILE OF NON-PAY COSTS

- ✓ The HSE should agree upper limits on non-pay percentages for the most important key cost element headings, differentiated by services where appropriate, as a useful addition to the ongoing accountability framework for voluntary providers. This should be concluded by end Quarter 1, 2013. [Recommendation 4.9](#)
- ✓ Agencies should be required, and facilitated, by the HSE to explore opportunities to share services, including clinical, therapeutic and back office services (e.g. leasing buildings) as appropriate. This requirement should be mandatory and made a condition of Exchequer Grant Aid Agreements and Service Level Arrangements from 2013. [Recommendation 4.10](#)
- ✓ Agencies should introduce formal tendering arrangements for services, including professional services, where these arrangements do not currently exist. Joint procurement mechanisms at national level should be used. For example, the HSE should investigate the potential savings of central HSE procurement of significant items of expenditure for the agencies through the NPS (e.g. energy costs) or HSE purchasing frameworks. Service arrangements currently require funded agencies to utilise HSE contracts, but the HSE should publish information illustrating the extent of take-up by voluntary agencies of HSE and NPS central purchasing frameworks by end Quarter 1, 2013 to ensure best value is achieved in procurement expenditure. [Recommendation 4.11](#)
- ✓ As a medium-term measure, public transport should be used in all circumstances where it is an option. This can have benefits in terms of personal development for the service users and is also more efficient. This VFM Review is aware of some day services where almost all service users avail of public transport to attend services. Since clients in receipt of Disability Allowance are automatically entitled to the Free Travel Pass, there should be no additional cost burden at the individual level. [Recommendation 4.12](#)
- ✓ Similarly, service providers should examine the possibility of sharing transport resources on a cost-neutral basis with other local service providers/community groups, taking into account the recent announcement of plans by the Department of Transport to integrate local transport services. [Recommendation 4.13](#)
- ✓ The introduction of charges for transport to services (in the form of fares linked to distance) should be considered, even at a minimum contribution level. [Recommendation 4.14](#)
- ✓ As a general rule, policy or scientific research funded by agencies through HSE allocations should be commissioned directly by the HSE. In deciding research priorities, the HSE should be informed by a 'whole of Government' perspective, consistent with the recently published *Research Prioritisation Plan* (i.e. taking account of research underway at university, agency and hospital levels). Research not commissioned by the HSE as part of the SLA process should not be funded through HSE allocations from 2013. [Recommendation 4.15](#)

- ✓ To ensure that duplication across the NDA, HRB and publicly funded disability agencies is avoided, the HSE should engage with these bodies to determine research priorities and needs. In particular, research commissioned by the HSE (if any) in this way from the HRB and NDA from 2013 onwards should not be remunerated, but rather funded through their ongoing revenue allocations. [Recommendation 4.16](#)

ADMINISTRATION COSTS

- ✓ The HSE should investigate whether or not there are transferable best practice lessons from the low administration costs in the HSE's statutory services in the DNE region. [Recommendation 4.17](#)

GEOGRAPHICAL DISTRIBUTION OF RESOURCES

- ✓ The HSE should be able to match resource allocation to the location of clients so that a proper assessment of geographical resource allocation (at Local Health Office level) can be made. This would address the problem where funding routed through one LHO relates to clients located in neighbouring regions. The HSE should attach a geographical marker to client identification numbers to facilitate this analysis. [Recommendation 4.18](#)

EFFICIENCY INITIATIVES

- ✓ Some examples of efficiency initiatives across the statutory and voluntary sectors have been brought to the attention of the VFMPR Project Team. The HSE should select some examples of efficiency improvements and develop the evidence base relating to the extent of efficiencies achieved and how these were achieved, and publish a summary document by end 2012. [Recommendation 4.19](#)

CHAPTER 5 : How efficient are disability services?

OUTPUTS

- ✓ The practice of signing multiple Grant Aid Agreements and/or Service Level Arrangements should be phased out as the HSE is re-organised. This will reduce administrative burden on both the HSE and service providers, and give the HSE oversight, at national level, of all funding provided by it to each service provider. [Recommendation 5.1](#)
- ✓ The governance arrangements in place to support Grant Aid Agreements were not examined as part of this Review. The HSE should apply the governance recommendations in this Review to GAAs where appropriate. [Recommendation 5.2](#)
- ✓ Commissioning, market-shaping and capacity-building expertise should be developed within the HSE (see also Chapter 3). [Recommendation 5.3](#)
- ✓ A national protocol to govern the use of private for-profit providers should be drawn up by the HSE and robust service level arrangements should be put in place with each service provider. [Recommendation 5.4](#)

- ✓ The HSE should develop protocols and practices to ensure that private for-profit providers are required to provide the same level and quality of service as applies to the statutory and voluntary sectors, and should be subject to all relevant recommendations in this and other relevant reports. [Recommendation 5.5](#)
- ✓ Sufficient information should be collected by the HSE on services that have been commissioned or procured to allow cost-effectiveness to be analysed and monitored on an ongoing basis. [Recommendation 5.6](#)
- ✓ The resource allocation model recommended in this chapter should be applied by the HSE to private for-profit providers (see *Section 5.2.2*). [Recommendation 5.7](#)
- ✓ Common definitions of units of output should be developed by the HSE, supported by detailed business rules, to ensure that the same information is collected in the same format across agencies. Once a firm basis for data comparison and analysis has been identified, the HSE should examine the value for money, relevance and continued fitness for purpose provided by services which could not be addressed by this Review, such as respite services, multidisciplinary services, early intervention, home support, assisted living/personal assistance, and community-based support services such as the provision of information and advocacy, peer support, intermediary and enabling activities. [Recommendation 5.8](#)
- ✓ Methods of community-based respite care provision should continue to be explored by the HSE as an alternative to residential centre-based respite. [Recommendation 5.9](#)
- ✓ A targeted study into the efficiency and effectiveness of multidisciplinary and therapy services, including grade structures and workloads, should be considered by the HSE on completion of this VFM Review. This study should build on the work of the National Coordinating Group on the re-structuring of children's disability services, and the Report of the National Reference Group on Multidisciplinary Services for Children aged 5-18. [Recommendation 5.10](#)
- ✓ The recommended study on therapy services (see *above*) should investigate the degree to which the wider use of therapy assistants may support a more efficient and effective service, and whether there is a requirement for a national accredited therapy assistant training programme (or programmes). The study should also consider the feasibility of adopting national caseload benchmarks and the role of IT systems in performance measurement and caseload management. [Recommendation 5.11](#)

MEASURING THE COST OF PROVIDING SERVICES

- ✓ A common assessment method should be developed or adopted by the HSE and implemented by disability service providers on a national basis to determine the services that are required by an individual (see *Chapter 8 for the implications of this for the NIDD*). This process should take into account any relevant developments taking place in the wider Primary Care context, such as the work being undertaken in Services for Older People, and also the experience of implementing the assessment process under Part II of the Disability Act 2005. [Recommendation 5.12](#)
- ✓ The assessment process should identify clearly the outcomes to be achieved through the provision of the services or supports. Any measure of the degree to which assessed needs have been met should include an assessment of the outcomes achieved. [Recommendation 5.13](#)

- ✓ An adult's requirements for supports and services should be re-assessed at the individual's request, at key transition periods or following a change in the individual's health or personal circumstances, but in any event not less than once every 3 years in order to ensure that services are responsive to the changing needs of the individual. This re-assessment process should be practical and capable of being integrated into an agency's person-centred planning and manpower utilisation and deployment planning processes. [Recommendation 5.14](#)
- ✓ Providing for the changing needs of service users over the lifecycle should be recognised as an intrinsic part of the resource allocation process. A phased approach will be required to the implementation of a cyclical assessment process, given the capacity constraints of the present system to support such a model. Providing for the changing needs of service users will be subject to the same affordability constraints and resource prioritisation requirements that will apply to all resource allocation decisions. [Recommendation 5.15](#)
- ✓ The HSE should require service providers to implement a common method for assessing the amount of resources which an individual consumes (*see also recommendations in Chapter 4*). [Recommendation 5.16](#)
- ✓ National guidelines should be drawn up by the HSE on an activity-based costing methodology to facilitate client-based costing. [Recommendation 5.17](#)
- ✓ A method of uniquely identifying service providers and service locations should be implemented by the HSE in order to facilitate unit costing in the context of the SLA process. [Recommendation 5.18](#)
- ✓ Pending the introduction of more comprehensive data collection processes, the Department of Health and the HSE should agree on a revised SLA Schedule 3 dataset specifically for disability services for implementation as soon as possible, and in particular to collect information on key cost drivers identified by the VFM process, build on the dataset collected by the HSE for the purpose of this Review, and incorporate the lessons learnt through the VFM process. Data should be collected for all directly provided HSE services on the same basis as for non-statutory agencies. [Recommendation 5.19](#)

COST VARIATIONS

- ✓ Costs substantially below the average should be examined by the HSE to (i) ascertain if they are correct; (ii) identify whether there are any common characteristics (such as unit size, client mix or staff mix) that have contributed to the low cost; and (iii) having established whether the costs are accurate and due to efficiencies, and looked at whether the quality is acceptable, what lessons can be learnt. Similarly, costs that are extremely high should be examined to confirm the figures are correct and if so, the reasons why they are so high. [Recommendation 5.20](#)

UNIT COSTS

- ✓ **Geographical variations:** HSE allocations should be adjusted over time to ensure that regional allocations are made on a pro rata basis, based on a combination of service user numbers and types of services provided. In doing this, the HSE should retain the ability to make adjustments to reflect national policies or specific circumstances, once this is done in a transparent manner. [Recommendation 5.21](#)
- ✓ **Agency status:** Changes to the model of funding for disability agencies should take into account the overhead which will be incurred in agencies that are not members of a public service pension scheme. [Recommendation 5.22](#)

- ✓ **Staff characteristics:** Best practice guidelines should be developed or adopted by the HSE in respect of staff utilisation and deployment practices, with the aim of achieving the most productive match between staffing, service activity levels and client need, while supporting service quality and effectiveness. The guidelines should avoid being over-prescriptive so as to allow service providers to be responsive to new and innovative service arrangements. Indicative benchmarks should be established for staff/client ratios for different models of service and for different support needs, against which performance can be monitored. [Recommendation 5.23](#)
- ✓ In line with international developments, the mainstreaming agenda and the emerging policy proposals developed by this VMF Review's Expert Reference Group, skill mix should be examined by the HSE and by individual agencies to determine the extent to which service provision should be facilitated to move towards the provision of more flexible, person-centred supports. [Recommendation 5.24](#)
- ✓ As a precursor to the implementation of best practice guidelines, all agencies, including direct service units within the HSE, should be required by the HSE, within 6 months after publication of this VFM Review, to audit all rosters by documenting the number of clients and staff in each service unit for each hour of the day and night over a given period (to include a weekend). Each agency should submit details of the audit to the HSE and demonstrate to the HSE, as part of the SLA process, that they have critically reviewed each roster and made any adjustments necessary to rationalise staff deployment patterns across their service units, consistent with client need. [Recommendation 5.25](#)
- ✓ The HSE should, as a result of this exercise, be able to quantify the extent of efficiency improvements attained from this review of rosters (e.g. through reduced premia or overtime). [Recommendation 5.26](#)
- ✓ Agencies should not roster staff unless a service user's assessed support needs require the staff member's specific skill set and grade. For example, if the requirement is for a care assistant, social care worker or a basic nursing grade, then a Social Care Leader or a CNM Grade 1, 2 or 3 should not be rostered (except in exceptional circumstances). This applies to rosters during the standard working week, as well as during periods that attract premium payments. [Recommendation 5.27](#)
- ✓ Common IT solutions for rostering should be investigated by the HSE and initiatives such as the planned Donegal Integrated Service Area eRostering Project kept under review (this is a pilot project and still at an early stage of development). The feasibility of interfacing rostering, HR and payroll administration systems should also be considered within the HSE's overall IT strategy, so as to facilitate the monitoring and control of rostering practices and costs. [Recommendation 5.28](#)

FUNDING NEW AND EXISTING PLACES

- ✓ The practice of funding places on the basis of a flat rate fee should be discontinued and should be replaced on the basis of standard costs to be calculated by reference to the VFM Review data for a range of service types, set out in Table 5.18, pending the migration to the recommended resource allocation model in due course. [Recommendation 5.29](#)
- ✓ For the purpose of funding new and existing places, the elements that make up a package of services or supports should be capable of being disaggregated, so that the HSE has the flexibility to mix and match elements of services to best meet the needs of the individual. This might mean that funding is provided to purchase the residential element of an individual's supports from one provider and the day element (if required) from another, or that a place is funded with or without multidisciplinary care (e.g. where these services are not required, are sourced from a third party or are provided through community mainstream providers). The disaggregation of service costs will also facilitate development of the 'personal budget

model' referred to in the current Programme for Government, *Government for National Recovery 2011-2016* (Department of An Taoiseach, 2011). [Recommendation 5.30](#)

RESOURCE ALLOCATION MODEL

- ✓ A standard resource allocation methodology should be developed or adopted by the HSE, starting in 2012, building on the work done by this Review and the NDA. It should also take into account any overarching national decision on a resource allocation model for the wider primary, community and continuing care sector. Full migration to a national resource model will be a medium-term objective, which will require significant effort and strong change management skills. It will also require capacity issues to be addressed. [Recommendation 5.31](#)
- ✓ The methodology should support an equitable allocation of available resources, be transparent and be consistently applied, but also allow for innovation and flexibility on how needs are met and how resources are utilised. The methodology would be linked to the deployment of a standardised assessment method. [Recommendation 5.32](#)
- ✓ A resource allocation methodology should make provision for exceptional or non-standard levels of care, but should equally guard against too many places falling into the 'non-standard' category, and the HSE should develop a mechanism for monitoring this process. [Recommendation 5.33](#)
- ✓ The HSE at national level should engage in negotiation with the larger service providers on funding issues. As part of the implementation of any resource allocation model, there should be provision for the adjustment of funding through the mechanism of the SLA process to take account of increasing service user needs or decreasing service user numbers, wherever this applies. The result will be that the allocation may increase or decrease based on the standardised assessment of actual need, rather than on the basis of an incremental determination. [Recommendation 5.34](#)
- ✓ The migration towards an evidence-based resource allocation model should address the current cross-subsidisation of services and so should be carefully planned and monitored. [Recommendation 5.35](#)

FUNDING FOR NEW AND EXISTING PLACES: IMMEDIATE ACTIONS

- ✓ The most immediate priority is to move to funding on the basis of the lower average costs identified by this Review: pending the implementation of a resource allocation model, the HSE should work with agencies from 2012 onwards through the mechanism of the SLA process to reduce current direct pay costs to the levels set out in Table 5.18, based on data given by agencies in respect of staff/client ratios on their 2009 SLA Schedule 3 returns. This should be followed as soon as practicable (based on data availability and quality) by funding the full cost per place, including direct and indirect non-pay costs and indirect pay costs, on the basis of nationally determined average costs. It will be important that the HSE takes steps to ensure that agencies adopt a consistent approach to staff/client ratios and the categorisation of clients and costs by resource usage groups, together with the collection and apportionment of non-pay costs by service unit. This should provide for fairness and equity in the application of average costs for funding allocation purposes (see *Chapter 8 for SLA recommendations*). [Recommendation 5.36](#)

Note: 'Direct pay cost' is the cost of the staff who directly provide a day or residential service to an individual, and is calculated by dividing the total pay cost of a service unit on the SLA Schedule 3 form by the number of service users in that unit.

Table 5.18: Recommended target pay cost per place

Programme type	Level of support	Average annual cost per place: direct pay, 2009	Target annual cost per place: direct pay, including 5% reduction on 2009 costs
ID = intellectual disability P&S = physical and sensory disability			
Day services for adults with ID: Activation and day support	Intensive Support	€39,143	€38,000
	High Support	€23,260	€22,000
	Moderate Support	€15,811	€15,000
	Low Support	€8,787	€8,500
	Minimum Support	€5,465	€5,000
Day services for adults with ID: Work-like activities	Intensive Support	€18,908	€18,000
	High Support	€16,783	€16,000
	Moderate Support	€14,511	€14,000
	Low Support	€10,621	
	Minimum Support	–	
Day services for children with ID	Intensive Support	€29,399	€28,000
	High Support	€22,953	€22,000
	Moderate Support	€7,230	€7,000
	Low Support	€6,245	€6,000
	Minimum Support	–	
Day services for people with P&S disabilities only		€7,579	€7,000
5-day residential services for people with ID	High Support	€43,537	€42,000
	Moderate Support	€42,067	€40,000
	Low Support	€20,822	€20,000
	Minimum Support	–	
7-day residential services for people with ID	High Support	€92,077	€88,000
	Moderate Support	€57,757	€55,000
	Low Support	€35,059	€33,000
	Minimum Support	€21,489	€21,000
Residential services for people with P&S disabilities only		€68,645	€65,000

Note: The costs used in this table as the basis for cost comparison have been calculated using a two-step calculation process. See 'Calculation of Comparator Costs' in Section 5.2.3, Table 5.7 and Table A5.2 in Appendix 5 for further details.

Source: SLA Schedule 3 data (analysis by DoH Information Unit)

EFFICIENCY

- ✓ Quality service user outcomes that meet the stated objectives of the Disability Services Programme should be of paramount importance. Funding should be allocated on the basis of measurable service user outcomes and this should become part of the resource allocation process. The HSE should be responsible for ensuring that agencies are held accountable for the achievement of these outcomes.
[Recommendation 5.37](#)
- ✓ The achievement of measurable outcomes and quality for service users at the most economically viable cost should be an ongoing process and be subject to regular review and audit. Regular review meetings linked to the SLA performance monitoring cycle should be held between the HSE and the service providers

to discuss performance in this regard (see *Chapter 3 for details of the HSE's service monitoring procedures*).
[Recommendation 5.38](#)

- ✓ There should be a focus in every organisation in receipt of public funding on driving efficiency on an ongoing basis contingent on client need within a value-for-money framework. This should be coupled with a more sophisticated risk assessment and management process. [Recommendation 5.39](#)
- ✓ Driving efficiency within an organisation should be the responsibility of its chief officer, who will report to the HSE on efficiency gains on an ongoing basis as part of the SLA monitoring process. An organisation's achievements or otherwise in respect of efficiency should be taken into account by the HSE when negotiating the organisation's annual funding requirements. [Recommendation 5.40](#)
- ✓ The HSE should maintain a purchaser/provider split between the persons responsible for its commissioning function and the persons responsible for the direct provision of services. The relationship between the HSE's own internal disability service providers and the HSE's commissioning officers (ISA Managers/ Disability Managers) should to all intents and purposes be on the same footing as the relationship between the HSE and any other service provider. SLAs should be signed by the HSE's internal disability service providers and the same monitoring and accountability process should operate. [Recommendation 5.41](#)
- ✓ On completion of this Review, there should be an immediate and robust examination within each agency on the findings and recommendations of the Review and agency-level plans should be drawn up to put relevant recommendations into effect. At a regional and national level, the Consultative Fora will provide a platform through which the stakeholders can engage with the VFM Review and the actions that will emanate from it. [Recommendation 5.42](#)

CHAPTER 6 : How effective are disability services?

QUALITY

- ✓ Guidelines for a National Quality Framework should be developed. The framework should:
 - address standards, inspection or audit, monitoring, quality assurance systems, person-centred planning/outcome setting, and outcome measurement;
 - be implemented by each service provider.[Recommendation 6.1](#)
- ✓ In the absence of day service standards being set and monitored by HIQA, the HSE should establish a framework whereby they can satisfy themselves, within the context of the SLA process, of the quality of day services provided and outcomes achieved, through dissemination of quality assurance guidelines, self-evaluation and continuous quality improvement protocols. [Recommendation 6.2](#)
- ✓ Outcomes should be defined at personal, organisational and programme levels. Outcome measurement should be implemented at all three levels. [Recommendation 6.3](#)
- ✓ Agencies should be encouraged to engage in continuous quality assessment and improvement, preferably by the use of an internationally accepted methodology such as EFQM, CQL or CARF. Current work to develop an outcomes-focused performance framework for multidisciplinary therapy services for children and young people with disabilities may be instructive in this context. [Recommendation 6.4](#)

OUTCOMES

- ✓ A methodology for the measurement of outcomes and impacts should be developed or adopted, with the assistance of the National Disability Authority. In developing or adopting the methodology, the models currently being developed in Victoria (Australia), England, Scotland and the USA may provide useful templates. [Recommendation 6.5](#)
- ✓ Outcomes should be measured in the first instance by service providers as part of the assessment of the individual's person-centred plan. This data should feed into a tiered set of performance indicators at agency level and national level, and feed into resource allocation and performance monitoring processes. [Recommendation 6.6](#)
- ✓ Outcome measurement at national level should feed into a process of continuous assessment on the performance of discrete service and support types, and provide an input into the quality improvement process. Services and supports demonstrated not to be effective should be discontinued. [Recommendation 6.7](#)

HEALTH

- ✓ Information on health outcomes for people with disabilities should be collected on a national basis. The dataset to be collected should be identified with the assistance of the NDA and the data should be collated and monitored by the HSE at national level. [Recommendation 6.8](#)
- ✓ Responsibility for the care, safety and general well-being of people who lack full mental capacity should be considered in the context of the increasing move from congregated residential settings to State-supported independent living arrangements. The State's responsibility in respect of the health needs of people with disabilities, and in particular those with intellectual disabilities, should be examined and clearly articulated. [Recommendation 6.9](#)

RESIDENTIAL SERVICES

- ✓ The following recommendations in the Report of the Working Group on Congregated Settings (HSE, 2011) should be prioritised within the implementation process for the report:
 - no new congregated settings to be opened;
 - no new admissions to be made to existing congregated settings;
 - a new model of community-based supports to be put in place for persons moving from congregated settings.[Recommendation 6.10](#)
- ✓ It will be the responsibility of the HSE to monitor the results of the HIQA inspections of residential centres in due course and, where relevant, an agency's progress on meeting the action plans specified by HIQA. Adherence to HIQA standards should be incorporated into the SLA funding and monitoring processes. [Recommendation 6.11](#)

PERSONAL PROGRESSION, EDUCATION AND EMPLOYMENT

- ✓ Indicators should be developed to measure the effectiveness of the disability services in promoting personal progress through access to day services and supports. [Recommendation 6.12](#)
- ✓ The health sector should continue to be responsible for providing health-related supports to facilitate access to mainstream services in the following areas: education, employment, housing, transport, healthcare and community inclusion. The provision of personal assistance supports for adults who live in the community or therapy supports for children attending school are examples of the type of support in question. [Recommendation 6.13](#)
- ✓ In the absence of day service standards being set and monitored by HIQA, the HSE should establish a framework whereby they can satisfy themselves, within the context of the SLA process, of the outcomes and quality of day services through dissemination of quality assurance guidelines, self-evaluation and continuous quality improvement protocols. [Recommendation 6.14](#)

OUTCOMES – STAKEHOLDER CONSULTATIONS

- ✓ The future delivery of services and supports to people with disabilities should acknowledge the views of stakeholders – that choice, control, independence and community inclusion are the keys to an effective, person-centred service. [Recommendation 6.15](#)

CHAPTER 7 : How should supports and services be delivered in the future?

OBJECTIVES – ACHIEVEMENT, VALIDITY AND SUSTAINABILITY

- ✓ A more sustainable approach should be adopted to support the realisation of the vision, goals and objectives of the Disability Services Programme at service user level. [Recommendation 7.1](#)
- ✓ Greater transparency and accountability should become an integral part of the delivery and funding of services and supports. [Recommendation 7.2](#)
- ✓ Migration toward a more effective policy approach should take place within the constraint of reducing expenditure ceilings for the health sector and within the context of the prevailing national economic climate. [Recommendation 7.3](#)
- ✓ A comprehensive set of operational objectives should be developed that are specific to individual services and supports. The objectives should be realistic, meaningful and quantifiable. [Recommendation 7.4](#)
- ✓ Resource allocation should be linked to operational objectives and take account of the considerable logistical challenges involved. [Recommendation 7.5](#)

PROPOSED NEW DISABILITY VISION AND GOALS

- ✓ The following vision statement should be adopted as an expression of a revitalised and re-orientated Disability Services Programme:

To contribute to the realisation of a society where people with disabilities are supported, as far as possible, to participate to their full potential in economic and social life and have access to a range of quality personal social supports and services to enhance their quality of life and well-being.

[Recommendation 7.6](#)

- ✓ The vision should be underpinned by the following goals:
 1. Full inclusion and self-determination through access to the individualised personal social supports and services needed to live a fully included life in the community.
 2. The creation of a cost-effective, responsive and accountable system which will support the full inclusion and self-determination of people with disabilities.

[Recommendation 7.7](#)

FUTURE DIRECTION OF THE DISABILITY SERVICES PROGRAMME

- ✓ The person-centred model described in this Review should form the basis of the future direction of disability policy. [Recommendation 7.8](#)
- ✓ Pilot projects should be developed as proof of concept and run in parallel with current services as part of the migration towards person-centred services and supports, and their suitability for wider application subsequently evaluated. [Recommendation 7.9](#)
- ✓ The HSE should drive migration towards the new policy approach from 2013 onwards by requiring agencies to identify demonstration projects as part of their SLA negotiations and to commit to their implementation. Inputs should be clearly ring-fenced and fundable into the medium term. Adequate monitoring structures should be put in place in the HSE to follow up on progress as an integral part of the SLA monitoring process. [Recommendation 7.10](#)
- ✓ An individualised supports model has many facets and may be implemented in a number of ways. Further work should be undertaken by the HSE and the Department of Health to identify the precise features of the model proposed, taking into account that the model will be multi-form and multi-faceted, in order that it may be fully appraised and costed. [Recommendation 7.11](#)
- ✓ Where appropriate, clinical and therapy supports should be provided in a mainstream setting, i.e. provided by non-disability-specific providers. The precursor to this should be the establishment of the primary care network. [Recommendation 7.12](#)
- ✓ The HSE should further develop its business coding systems and structures so that it is capable of identifying allocations to, and expenditure by, its own directly provided services and voluntary disability agencies on supports and services for people with disabilities, at national, regional and local levels. [Recommendation 7.13](#)
- ✓ All funding should be allocated on the basis of a standardised assessment of individual need, which should be linked to the resource allocation methodology. [Recommendation 7.14](#)
- ✓ A unique identifier should be put in place for those seeking or receiving services, consistent with plans for a wider health sector identifier and a national health information strategy, to facilitate individual needs assessment, person-centred planning and individualised budgeting. [Recommendation 7.15](#)

- ✓ Since it will not be feasible for all assessed needs to be met in full by the HSE in the context of competing resources, the protocols for prioritising need, and deciding which needs are met and which are not, should be transparent, fair and equitable. [Recommendation 7.16](#)
- ✓ Cross-sectoral working will be crucial to the implementation of the revised model and will be an integral part of the planning process. The Department of Health and the health sector should continue to liaise with their colleagues in other Government departments and agencies to ensure that cross-sectoral working arrangements are prioritised and maintained. [Recommendation 7.17](#)

IMPLEMENTATION GUIDELINES

- ✓ A plan for migration towards revised policy objectives should be drawn up, with milestones, dependencies and critical path identified and a feasibility analysis and appraisal carried out. [Recommendation 7.18](#)
- ✓ Migration toward an alternative policy approach should take place within a value-for-money framework and within the context of the prevailing national economic climate. [Recommendation 7.19](#)
- ✓ Based on the high-level migration plan, a more detailed plan should be drawn up to implement any revised policy. [Recommendation 7.20](#)
- ✓ Further work is required to cost, prioritise and plan for the implementation of a revised policy approach. Work should commence on this without delay. [Recommendation 7.21](#)
- ✓ A full costings plan for the revised model of service should be produced. [Recommendation 7.22](#)

CHAPTER 8 : Performance Indicators

PERFORMANCE INDICATORS

- ✓ The Department of Health and the HSE should agree on a revised SLA Schedule 3 for 2013 data collection. [Recommendation 8.1](#)

As part of the revision process, the following measures are recommended:

- Data should be collected for all directly provided HSE services on the same basis as for non-statutory agencies. This change should be implemented for the 2013 round of SLA data collection. [Recommendation 8.1a](#)
- The SLA should be amended by the HSE, in consultation with the ODMH, to take account of the deficiencies highlighted in this chapter (unit of measurement, capacity *versus* actual comparisons, breakdown of staffing categories by the relevant subcategories and inclusion of intensity of care-related cost drivers, such as mobility, challenging behaviour and medical condition) for the 2013 round of data collection. Data on non-pay and overheads should also be collected so as to facilitate the calculation of service user and service unit costs. Costing and output data should be based on all funding sources and not just HSE funding. The SLAs should continue to be managed in an Excel-based mechanism. [Recommendation 8.1b](#)
- The revised SLA schedules should be presented by the HSE to service providers at seminars to support completion of the SLA templates, prior to launch of the new SLAs (i.e. Quarter 4, 2012). [Recommendation 8.1c](#)

- Data quality standards need to be developed and enforced by the HSE to ensure that the information base is fully reliable and validated. These standards should be developed by end Quarter 4, 2012. The standards should be clearly specified on the HSE website.
[Recommendation 8.1d](#)
 - The amended schedules should be accompanied by a document or detailed guide setting out the data quality standards and data definitions, including worked examples to ensure accurate completion of schedules. This suite of documentation should be finalised by the HSE by Quarter 4, 2012. [Recommendation 8.1e](#)
 - There should be independent periodic spot checks of SLA data at service provider level. These should be carried out by the National Disability Unit in the HSE. [Recommendation 8.1f](#)
 - The HSE's Internal Audit Unit should also carry out independent audits of the accuracy of SLA performance data. It would be helpful if an audit was carried out in 2015, once the revised agreements had been fully implemented and in operation for a year or two. [Recommendation 8.1g](#)
 - Data on outcomes and performance indicators (*as indicatively outlined in Table 8.3*) should form part of the data collection process and be aggregated by the National Disability Unit (by end Quarter 4, 2012) at agency (i.e. consolidated across all regional branches), regional and national level to allow effective monitoring of performance. [Recommendation 8.1h](#)
 - Any future development funding should be coded separately on SLA agreements to allow for an assessment of the impact of development funding relative to baseline levels of output.
[Recommendation 8.1i](#)
- ✓ As a general principle, data gathering (both once-off and recurring) should be rationalised across the HRB disability databases, the SLAs and any other HSE data collection tools, to avoid unnecessary duplication of effort and the creation of multiple potentially inconsistent or incompatible datasets. This principle should also apply to the DoH, NDA or any other bodies seeking to collect data relating to the Disability Services Programme. As a general rule, any data which is not required should no longer be collected to avoid administrative overhead for providers. In particular, given the central role of the SLA in performance data collection, unnecessary disability-related data collection by the HRB and the NDA should be curtailed where this arises. This raises into question the continued need for the HRB disability databases in their current form in the medium term. To address this issue, there should be a review of the resources currently engaged in data collection, the overall information requirements necessary to support monitoring and review of the disability services, the optimal contribution that SLA agreements can make to data collection and the remaining contribution, if any, that can be made by the HRB disability databases. The review should be led by the ODMH and completed by end Quarter 4, 2012.
[Recommendation 8.2](#)
- ✓ New performance indicators are required to better assess the performance of the disability services and address the gaps in outcomes and outputs measurement. The indicators described in Table 8.3 should be piloted by the HSE for a large disability service provider by end Quarter 4, 2012, with a view to early implementation in 2013. [Recommendation 8.3](#)
- ✓ The HSE should prioritise the comprehensive review of performance indicators scheduled for completion by the 4th Quarter of 2012. It is important that this review is advanced to completion by the HSE as soon as possible. The results of the review should inform the service planning and reporting process for 2013 so that improved performance indicators are reported during 2013. [Recommendation 8.4](#)

- ✓ The HSE should publish a summary report presenting aggregated performance analysis of the annual SLA data. This should be carried out in Quarter 1 of the year following the SLA reference period. The first report should be published in 2013. The report should incorporate:
 - geographic profiling of services;
 - trend information relating to key outputs and costs;
 - commentary about completeness and accuracy issues regarding performance information.

[Recommendation 8.5](#)

- ✓ The ODMH should also publish a short annual report on disability services, drawing on all the various data sources available to it and reporting specifically on performance, i.e. linking objectives and funding, outputs, efficiency, outcomes and progress in developing datasets. The first report should be scheduled for completion in 2013. [Recommendation 8.6](#)

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APPENDIX 1

Membership: Value for Money and Policy Review Steering Group, Expert Reference Group and Project Team

Value for Money and Policy Review Steering Group

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Gerard Flood	External Member
James O'Dwyer	External Member
Bairbre Nic Aongusa, Director, Office for Disability and Mental Health, Department of Health (DoH)	
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APPENDIX 2

DISABILITY FINANCE BOOK

INTRODUCTION

This appendix outlines the objectives of the Disability Finance Book (DFB) and describes the methodology used to compile the data. It also highlights the limitations of the DFB and provides some additional analysis developed through the DFB but which was not included in the main body of the report.

PURPOSE OF DISABILITY FINANCE BOOK (DFB)

The DFB arose as part of the VFM Review of Disability Services. From an early stage, it was established from discussions at both Project and Steering Groups that a clear requirement existed for the HSE to have its own set of independent financial data in order to provide evidence to support the work of the Review. In particular, data was needed to address part of ToR 6 ('Identify the level and trend of costs and staffing resources associated with the disability services and thus comment on the efficiency with which it has achieved its objectives. Compare overall costs, including wage costs and non-pay costs, across the sector'). Data were also required to corroborate the data collection exercise, which was to take place through a process of engagement with service providers within and outside of the HSE.

The main objective in developing the DFB was to source data regarding expenditure and costs to support Chapter 4 of the Review. The main types of trend data sought for the evaluation period included:

- overall expenditure across the Disability Services Programme;
- regional distribution of expenditure by HSE region;
- pay and non-pay costs by sector (i.e. statutory and voluntary);
- detail on the distribution of non-pay costs by cost type across the various sectors;
- breakdown in expenditure by type of service.

Data and analysis from the HSE's financial Corporate Reporting System (CRS) were made available at the outset of the project and were agreed to be further developed as presented in the DFB document to the Project and Steering Groups in December 2010. It was decided that the data contained in the DFB would then be used alongside the two further primary sources of data, namely the Service Level Arrangement (SLA) Schedule 3 financial data and the Non-pay and Trend Data questionnaire (developed, sourced and completed specific to this Review).

CONSTRUCTION/SOURCES OF INFORMATION

The DFB is drawn primarily from the HSE Corporate Reporting System (CRS). CRS data had a number of limitations, which are described in more detail below. As a result, it was necessary to bring that raw financial data through a number of stages which would greater enhance and develop its usefulness at a more practical level. These stages were:

Stage 1	Historical data taken from the CRS under 'DIS' (Disabilities) Caregroup.
Stage 2	Addition of historical data from HSE Rosetta Recording system in relation to formerly ERHA-funded Section 38 (S38) agencies.
Stage 3a	Inclusion of Domiciliary Care Allowance, Blind Welfare Allowance and Mobility Allowance not coded to 'DIS'.
Stage 3b	Split out of St. John of God's between Disability and Mental Health, 75:25 respectively.
Stage 3c	Split out of remaining ERHA-funded S38 agencies between Caregroups, for example, Peamount Hospital and the Royal Hospital, Donnybrook
Stage 3d	Inclusion of corrections from 4 Regions. This involved significant input from Regional Finance Contacts and from S38 Finance contacts to validate the postings on CRS. Additionally, each Region provided a breakdown of all expenditure coded to Grants & Capitation under the Disability heading.
Stage 4	Addition of other standard Overhead charges to HSE statutory side. This process was designed to include certain expenditure codes that would traditionally have found their way into centralised reporting functions, such as Engineering Departments, Minor Repairs and Superannuation Costs. An additional €17m was added under this process in 2009 alone.
Stage 4a	Final realignment of GL Coding on HSE statutory side. This allowed for certain general codes such as 'Miscellaneous' on the HSE Statutory side to be further examined and coded more specifically.
Stage 5	Derivation of expenditure trend for Grant organisations. It should be noted that the scope of the CRS mainly covers the HSE statutory sector and 15 S38 voluntary agencies in the HSE DNE and HSE DML Regions. It does not include S38 agencies in other regions and does not include any S39 agencies. Therefore, it was necessary to derive expenditure-related information for these agencies.

The derivation process allowed for an approach whereby the majority of Grants & Capitation payments in the DFB would be converted into a set of meaningful accounts by organisation. This was achieved by identifying the Top 30 organisations that made up the majority of payments to the non-statutory sector and then applying various sets of rules to draw out meaningful conclusions. For example:

- using information provided in Annual Accounts of organisations, e.g. split of Pay/Non-Pay/Income, breakdown of Total Cost between Cost Categories, HSE Funded line in Accounts, Pension Costs, etc.
- use of ERHA-funded S38 expenditure data from CRS to provide a breakdown of spend in similar organisations, e.g. ID/P&S by annual expenditure ranges of up to €20m, €20m-€50m and over €50m.

ASSUMPTIONS

The following key assumptions underpin the accuracy and integrity of the DFB data:

- CRS is the best available primary source of financial information in HSE;
- additional information provided by regional contacts improves the quality of the original CRS data;
- the derivation process is consistent within size/complexity of organisation type;
- overhead apportionment is limited to Engineering and Superannuation.

In this respect, the HSE view is that HSE Support Costs, both local and central, may be used/enjoyed by both statutory/non-statutory sectors alike, for example, time given by local managers to managing Service Agreements and Payment regimens with non-statutory providers. Equally, many Corporate functions, such as the National Disability Office, as well as ICT, Capital and other Strategy areas, would inevitably support the non-statutory side.

LIMITATIONS

The following items could be viewed as limiting factors on the utility of the DFB:

- DFB Data is limited to 'DIS' categorisation with specific amendments notified by Areas. It may not include certain services provided in Local Health Office settings that cross traditional Caregroup boundaries, in particular, services provided via Therapy grades which may be traditionally embedded in Primary Care 'PRI' or Multiple Care Group 'MUL' Caregroup categories.
- There is little or no meaningful secondary costing mechanism in the HSE Local Financial systems. Therefore, the opportunity to reflect a fully inclusive cost of service through secondary cost apportionment is limited.
- The CRS system retains and hardcodes historical data, which will not then change when mapping changes occur, for example, moving costs from one Caregroup mapping to another during a given year. The CRS system is a reporting system only and possesses no Enterprise Resource Planning (ERP) functionality, as described below.
- The DFB was unable to source data relating to the distribution of expenditure by type of disability service or output (e.g. residential services, day services, etc) because expenditure is not coded by service on HSE systems.
- There was a high percentage of non-pay costs categorised as 'Miscellaneous' in both the voluntary and statutory sectors. This could potentially skew the distribution of costs by category since it was not clear what types of costs are included as 'miscellaneous'.

ENTERPRISE RESOURCE PLANNING

Enterprise Resource Planning (ERP) integrates internal and external management information across an entire organisation, embracing finance/accounting, manufacturing, sales and service, customer relationship management, etc. ERP systems automate this activity with an integrated software application, such as SAP.

There are risks associated with taking some of the more generalised expenditure trends. In particular, the fact that much of the activity, some €863m in 2009, was recorded as a one-line entry on the CRS under Capitation/Grants increases the risk that certain interpretations of expenditure trends within organisations may be mistaken.

The CRS reports data under different Pay Category headings to those reported at Annual Financial Statement (AFS) level within the HSE and at Schedule 3 SLA level; for example, the CRS heading 'Support Services' is broadly analogous to the AFS headings 'General Support Staff' and 'Other Patient & Client Care'. 'Maintenance Pay' costs are reported under 'General Support Staff' in AFSs, but have their own heading on CRS under 'Maintenance'.

The consistency and level of detail, within and across organisations, which gives rise to the information produced in the AFSs, can vary greatly and is a limiting factor in the derivation process.

SELECTION OF DERIVATION BASES USED

Organisation	Accounts information	Category split
Brothers of Charity	Specific figures at Pay/Non Pay Category level provided by BoC for 2009.	Further breakdown of individual Pay sub-categories is taken from ID Sector Apportionment basis over €50m.
St. John of God Hospitaller	Funding allocated in same manner as SJOG expenditure funded through former ERHA.	Funding allocated in same manner as SJOG expenditure funded through former ERHA.
Daughters of Charity Services (including St. Anne's Roscrea)	Funding allocated in same manner as DoC expenditure funded through former ERHA.	Funding allocated in same manner as DOC expenditure funded through former ERHA.
St. Michael's House	Funding allocated in same manner as St. Michael's expenditure funded through former ERHA.	Funding allocated in same manner as St. Michael's expenditure funded through former ERHA.
COPE Foundation	Specific figures taken from COPE AC 2009 as follows: Gross Expenditure taken as Operating Expenses Figure.	Reduced by DSFA funded Payments to Clients channelled through organisation and reduced by Depreciation/Amortisation adjustments.
REHAB Care Group	Used amounts returned by HSE Areas against P&S Sector €20m-€50m.	Used amounts returned by HSE Areas against P&S Sector €20m-€50m.
Irish Wheelchair Association	Specific figures taken from IWA AR 2009 as follows: Split of Pay:Non Pay 86:14; -Use the above split against Gross expenditure as identified by Areas as HSE-funded.	Totals by Pay, Non Pay, Income adjusted for Grant level recognised in HSE Accounts.
Sisters of La Sagesse Services (Cregg House)	Specific figures taken from Cregg House AC 2009.	Pay Category by ID Sector equivalent €20m-€50m; - Non Pay Category by Actual expenditure per Cregg House Accounts.
Carriglea Convent	Specific figures taken from Carriglea Cairde AC 2009.	Full Sub-category split carried out within Category and in line with ID Sector €5m-€20m.
Camphill Communities of Ireland	Specific figures taken from Camphill Accounts 2009.	Category split carried out as follows: Pay split out by reference to ID Sector €5m-€20m, except for Social Fund Contribution which was put directly into Superann; Non Pay identified by Cost Heading in Camphill Accounts.
Kerry Parents & Friends Association	Specific figures taken from Kerry Parents & Friends Association AC 2009.	Full Sub-category split carried out within Category and in line with ID Sector €5m-€20m.
Prosper Fingal	Specific figures taken from Prosper Fingal AC 2009.	Full Sub-category split carried out within Category and in line with ID Sector €5m-€20m.
SOS Kilkenny	Full organisation split carried out in line with ID Sector €5m-€20m.	Full organisation split carried out in line with ID Sector €5m-€20m.

The DFB was used to carry out additional analysis, contained in the main body of the report, due to the need to focus on the most relevant evidence and the requirement to restrict the length of chapters to a manageable level. The most relevant tables from the DFB are set out below. The data is all sourced from the DFB, with the exception of Table A2.4, which is sourced from the AFS (Annual Financial Statements) analysis.

Table A2.1: Annual gross expenditure on the disability services by type of provider, 2005-2009

Provider	2005 (€)	2006 (€)	2007 (€)	2008 (€)	2009 (€)
HSE	343,276,435	390,079,808	448,532,672	480,367,622	438,157,822
HSE-funded S38/S39	614,962,845	677,291,618	758,298,615	815,294,138	863,286,001
* ERHA-funded S38	377,282,411	405,303,709	452,855,089	482,867,323	485,432,649
* ERHA-funded Non S38	2,521,638	2,579,618	2,777,859	2,915,837	2,567,393
Grand Total	1,338,043,330	1,475,254,753	1,662,464,235	1,781,444,920	1,789,443,865

* Agencies funded through the former Eastern Regional Health Authority continued to be grouped together for administrative convenience.

Source: HSE, Disability Finance Book

Table A2.2: Pay, non-pay, income breakdown by funding source and location, 2009 (HSE)

Cost Sub Heading	HSE DML (€)	HSE South	HSE DNE (€)	HSE West (€)	Grand Total (€)
PAY COSTS					
Nursing	18,232,641	19,875,875	30,729,241	24,716,983	93,554,740
Support Services	16,507,917	13,072,349	26,599,964	28,645,907	84,826,136
Superannuation	4,048,424	5,255,581	7,537,148	8,059,582	24,900,735
Mgt/Admin	3,752,628	8,072,664	4,285,794	7,751,150	23,862,236
Paramedical	1,612,301	3,831,246	8,006,274	6,048,287	19,498,109
Medical/Dental	1,385,963	1,490,682	979,173	1,210,530	5,066,348
Maintenance/Technical	561,470	454,447	767,491	933,665	2,717,072
Total pay costs	46,101,344	52,052,843	78,905,085	77,366,105	254,425,376
Grants to Outside Agencies	10,940				10,940
NON-PAY COSTS					
Cash allowances	27,708,672	34,117,655	32,847,823	35,610,163	130,284,312
Medical/Surgical Supplies	306,245	1,483,817	344,702	4,666,575	6,801,338
Professional Service	601,449	58,260	3,573,039	1,393,298	5,626,047
Office expenses, rent	1,382,706	544,596	1,147,430	1,982,664	5,057,397
Miscellaneous	341,427	1,288,717	828,848	2,380,579	4,839,572
Catering	1,238,296	453,588	872,327	1,680,097	4,244,308

Cost Sub Heading	HSE DML (€)	HSE South	HSE DNE (€)	HSE West (€)	Grand Total (€)
Transport (Patient)	1,215,492	179,481	1,305,347	1,335,271	4,035,591
Maintenance	321,614	1,661,402	507,517	1,488,135	3,978,668
Heat, Power & Light	689,994	410,616	589,755	1,227,866	2,918,230
Supp. & Contracts, Other	399,179	78,037	2,082,856	97,674	2,657,745
Education & Training	87,488	752,895	46,440	1,749,184	2,636,007
Cleaning & Washing	637,738	400,251	541,684	1,017,752	2,597,425
Travel & Subsistence	234,349	345,830	513,795	816,884	1,910,858
Drugs & Medicines	385,820	528,258	122,158	670,170	1,706,405
Vehicles Running costs	189,430	78,517	204,208	365,904	838,059
Legal	146,287	295,680	1,883	362,207	806,058
Furniture, Crockery	174,628	61,290	40,082	290,529	566,529
Computer	28,554	48,658	148,708	326,589	552,509
Other Medical Equip.	44,179	14,252	241,095	243,351	542,876
Bedding & Clothing	155,410	82,294	105,456	55,994	399,154
Medical Gases	3,700	2,982	1,174	384,470	392,326
Vehicles Purchased	83,888	55,872	392	15,403	155,556
Bad & Doubtful Debts	–	10,842	143,344	–	154,186
Insurance	394	2,619	2,738	855	6,605
Laboratory	3,692	4	849	1,424	5,969
Other minor costs	7,090	45	116	524	7,776
Total non-pay costs	36,387,718	42,956,457	46,213,767	58,163,562	183,721,505
Income Total	-6,377,572	-10,008,363	-10,578,917	-12,428,419	-39,393,271
Grant Total	76,122,431	85,000,937	114,539,935	123,101,248	398,764,551

Source: HSE, Disability Finance Book

Table A2.3: Pay, non-pay for Section 38 agencies in the HSE DML and DNE regions, 2009 (excludes sources of income, i.e. net expenditure)

Cost Sub Heading	St. Michael's House (€)	St. John of God (€)	Daughters of Charity St. Vin (€)	Stewart's Hospital Services (€)	National Rehabilitation Hosp (€)	Cheeverstown (€)	Sunbeam House (€)	Central Remedial Clinic (€)	Sisters Of Charity of Jesus (€)	Kare (€)	Peamount Hospital (€)	Children Sunshine Home (€)	Royal Hospital DBK (€)
Nursing	14,770,201	34,463,501	46,776,957	10,025,008	6,104,000	17,525,895	3,631,302	1,942,351	10,223,549	1,371,044	4,922,967	2,886,692	2,408,524
Support Services	45,011,978	11,451,757	7,160,148	26,915,729	5,643,000	2,599,348	14,023,117	3,401,143	3,063,906	10,223,353	5,248,814	268,987	357,259
Mgt/Admin	8,229,350	7,661,203	4,566,543	2,835,941	2,686,000	1,280,514	1,531,120	3,224,057	1,898,496	1,478,755	885,963	485,106	222,062
Paramedical	6,057,202	6,916,284	3,161,914	1,733,989	6,516,000	1,505,344	297,174	5,230,557	856,353	964,909	1,348,502	392,200	594,641
Superannuation	1,647,986	4,615,328	2,136,420	4,245,340	1,937,000	244,078	–	1,963,390	394,769	791,814	844,781	78,224	
Medical/Dental	2,028,604	5,219,189	1,281,444	863,675	2,447,000	537,425	–	808,863	26,853	–	658,046	51,992	129,585
Maintenance/Tech.	914,234	977,374	1,402,802	422,442	549,000	154,165	–	52,813	426,805	241,714	418,667	50,700	41,377
Pay costs	78,659,553	71,304,635	66,486,228	47,042,124	25,882,000	23,846,768	19,482,713	16,623,174	16,890,731	15,071,589	14,327,740	4,213,900	3,753,448
Maintenance	1,455,210	1,671,604	934,065	2,821,295	684,000	459,224	757,737	706,951	648,408	653,739	683,578	94,532	200,844
Office Expenses	2,295,448	2,204,542	1,051,390	259,535	413,000	464,757	308,341	461,850	560,366	272,001	104,652	55,676	41,567
Rent													
Miscellaneous	2,764,559	1,342,341	1,053,430	217,965	259,000	339,759	554,227	698,981	195,548	78,491	109,445	–	57,061
Catering	1,374,813	1,504,621	1,383,124	1,230,900	635,000	440,291	491,458	245,250	293,522	158,471	379,465	61,301	129,395
Heat, Power & Light	1,005,454	1,120,610	943,047	1,045,843	438,000	382,164	274,680	306,500	410,150	188,023	371,627	59,700	50,741
Medical/Surgical Sup	329,971	246,580	629,699	–	499,000	196,229	–	–	97,443	–	219,794	35,679	98,085
Professional Service	388,615	488,848	–	133,377	235,000	62,897	208,655	85,000	57,885	24,677	4,308	77,088	15,638
Transport (Patient)	–	1,610,420	–	658,746	54,000	252,178	–	192,800	–	320,777	–	3,187	4,767
Cleaning & Washing	685,837	901,926	606,761	408,725	615,000	503,446	81,673	141,550	111,322	–	143,150	49,543	122,924
Education & Training	208,443	1,701,196	80,654	164,174	167,000	69,991	43,318	112,300	170,509	337,192	30,192	7,754	10,892
Supp & Contracts	–	–	–	–	2,399,000	175,471	–	–	–	–	4,379	7,635	
Other													
Travel & Subsistence	635,980	371,693	801,891	191,616	126,000	10,046	211,019	218,600	268,320	242,248	33,425	9,002	838

Cost Sub Heading	St. Michael's House (€)	St. John of God (€)	Daughters of Charity St. Vin (€)	Stewart's Hospital Services (€)	National Rehabilitation Hosp (€)	Cheeverstown (€)	Sunbeam House (€)	Central Remedial Clinic (€)	Sisters Of Charity of Jesus (€)	Kare (€)	Peamount Hospital (€)	Children Sunshine Home (€)	Royal Hospital DBK (€)
Drugs & Medicines	283,564	186,828	596,090	293,785	483,000	77,970	26,492	87,450	177,599	–	435,096	22,768	149,392
Insurance	637,907	771,493	710,314	294,342	93,000	269,994	250,213	175,500	192,019	122,672	55,519	33,231	18,162
Vehicles costs	635,337	145,569	-	213,817	7,000	57,258	208,937	140,100	–	–	26,297	3,846	1,943
Computer	158,596	526,682	195,669	91,275	275,000	52,735	–	–	–	125,091	115,304	52,318	20,885
Furniture, Crockery	97,814	283,665	70,984	33,671	45,000	128,280	85,302	111,750	31,654	112,683	23,399	16,607	21,858
Legal	34,671	18,992	–	30,501	4,000	55,669	–	5,000	–	19,242	154,286	21,918	2,492
Other Med. Equipm.	897	76,513	–	–	68,000	–	–	149,850	–	–	39,197	42,338	76,841
Bedding & Clothing	13,211	23,196	34,896	265,738	16,000	34,427	–	–	98,809	–	6,892	68	3,660
Audit	57,244	209,554	–	64,986	26,000	22,478	30,302	50,000	10,724	9,091	17,219	18,645	3,938
Medical Gases	–	–	–	–	29,000	10,109	1,553	–	–	–	27,979	3,074	12,481
Laboratory + X ray	–	72,397	–	–	249,000	–	–	–	–	–	248,245	–	–
Bank Interest	167,889	-	–	59,233	1,000	17,555	40,091	10,000	–	6,403	–	–	–
Vehicles Purchased	–	45,336	–	–	–	–	42,800	–	–	–	1,726	–	6,674
Bank loan & Finance	24	–	–	–	–	–	198,000	–	5,502	920	–	–	–
Bad & Doubtful Debts	–	1,028	–	–	6,000	–	–	–	–	–	–	13,250	–
Bank Charges	–	37,945	–	9,632	1,000	6,683	6,202	5,000	–	1,572	2,132	365	4,348
Non-pay costs	13,231,483	15,525,633	9,092,014	8,489,156	7,827,000	4,089,611	3,821,000	3,904,432	3,329,780	2,673,294	3,237,307	689,525	1,055,428
Total costs	91,891,036	86,830,268	75,578,242	55,531,280	33,709,000	27,936,379	23,303,713	20,527,606	20,220,511	17,744,882	17,565,048	4,903,425	4,808,876

Source: HSE, Disability Finance Book

Table A2.4: AFS expenditure by agency, 2006-2011

Agency	2006	2007	2008	2009	2010	2011
Charleville Care Project Ltd	102,688	105,760	111,176	109,373	104,889	100,694
Camphill Communities of Ireland	543,530	881,694	1,185,889	1,227,150	1,132,497	1,096,833
Disability Federation of Ireland	1,711,940	2,379,015	2,461,248	2,682,712	2,540,027	2,054,934
Children's Sunshine Home	3,980,152	4,383,341	4,403,549	4,408,759	3,997,496	3,906,360
Prosper Fingal Ltd	4,402,632	5,376,974	5,642,540	6,824,998	6,535,684	6,660,697
National Council for the Blind of Ireland	7,678,159	6,804,795	7,431,927	7,516,216	7,087,023	6,870,751
St. Christopher's Services	5,903,255	6,708,571	7,343,850	7,570,122	7,781,489	7,921,295
Kerry Parents & Friends Association	6,634,634	7,227,977	7,914,952	8,396,650	8,232,741	8,250,452
Acquired Brain Injury Ireland	4,930,121	6,487,887	7,694,247	8,089,649	8,608,859	8,493,703
Sisters of Charity	14,595,367	15,713,936	16,489,425	17,218,924	16,568,395	15,414,655
Sisters of La Sagresse Services	17,730,721	19,249,637	19,373,893	19,657,130	17,028,252	16,525,582
Central Remedial Clinic	16,309,880	17,967,103	18,871,631	19,196,419	17,308,187	16,817,160
KARE	13,481,400	15,935,664	17,288,228	18,074,476	16,915,803	17,122,403
Sunbeam House Services	19,098,994	20,972,224	22,103,274	22,389,885	20,467,977	20,217,744
Cheshire Foundation Ireland	21,868,806	22,687,918	24,147,011	25,867,391	22,825,316	22,803,208
Cheeverstown House Ltd	22,388,466	24,091,584	25,362,593	25,749,063	23,591,159	23,212,218
Ability West Ltd	20,451,189	22,220,242	24,059,588	24,254,470	20,934,587	23,304,085
Peamount Hospital	25,309,782	27,171,923	28,699,786	28,459,508	26,645,478	25,124,940
National Rehabilitation Hospital	24,659,104	26,377,360	27,801,419	28,455,692	26,804,202	25,591,922
Western Care Association	26,836,636	29,206,708	30,646,828	30,861,388	29,260,346	28,732,007
Irish Wheelchair Association	28,584,710	32,629,311	36,487,727	38,988,435	36,980,549	36,565,762
Enable Ireland	30,955,223	35,027,227	38,014,515	40,019,777	37,629,643	37,322,137
Sisters of Charity of Jesus and Marv. Muiriosa	38,143,504	42,313,099	44,646,437	44,616,905	42,268,399	40,789,017
Rehab Group	29,692,075	37,317,559	42,947,611	44,373,951	42,677,235	41,983,848
COPE Foundation	40,721,135	44,704,124	45,578,141	48,055,039	46,111,137	44,705,049
Stewart's Hospital	44,193,156	47,889,736	50,057,321	50,669,430	46,605,342	45,341,373
St. Michael's House	66,264,381	79,435,160	83,855,004	84,817,660	78,130,671	75,097,039
Daughters of Charity	92,632,136	101,469,658	106,974,587	110,729,993	99,232,057	97,835,102
St. John of God Hospitaller	126,408,606	143,458,329	149,657,981	150,735,327	140,402,104	135,415,460
Brothers of Charity Services	153,916,642	166,354,088	173,511,456	176,983,181	165,473,545	164,149,454
Total	908,417,084	1,010,169,589	1,068,302,586	1,094,316,962	1,017,341,062	997,370,950

Notes to Table A2.4

- (a) There may be some inconsistencies in the data, particularly in the early period when these records were first collected on a consolidated basis. Certain organisations were excluded for this reason, e.g. Sisters of the Sacred Hearts of Jesus and Mary, Headway, Sisters of Charity, Centres for Independent Living and others.
- (b) The above analysis is taken from the HSE's Annual Financial Statements for the period 2006 to 2011. The data are produced from Form N10, which summarises a range of expenditure headings.
- (c) Payments coded as capitations are not included in the above analysis.
- (d) The above analysis has not been adjusted for certain organisations which cater for service users other than those with a disability.

Source: HSE, AFS April 2012

APPENDIX 3

SUMMARY OF NON-PAY COSTS SPECIFIED IN THE TERMS OF REFERENCE (BASED ON RETURNS FROM 72 SPECIALIST DISABILITY SERVICE PROVIDERS)

Table A3.1: Administrative costs

Non-pay costs	Agency type	Total 2009 direct and indirect non-pay costs
Administrative/office overheads	HSE	€2,402,182
	Section 38	€8,031,948
	Section 39	€5,903,978
	Total	€16,338,108
Bank fees, interest, loans, leases	HSE	€10,792
	Section 38	€532,148
	Section 39	€479,857
	Total	€1,022,797
CEO, finance, corporate and HR	Section 39	€560,880
	Total	€560,880
Contribution to Headquarters' overheads	HSE	€96,274
	Section 38	€1,160,582
	Section 39	€1,479,227
	Total	€2,736,082
IT services and supplies	HSE	€162,303
	Section 38	€2,563,276
	Section 39	€2,255,036
	Total	€4,980,615
Professional services	HSE	€914,853
	Section 38	€3,940,554
	Section 39	€2,170,056
	Total	€7,025,464
Regional offices	Section 39	€45,560
	Total	€45,560
Staff education and training	HSE	€151,062
	Section 38	€3,259,922
	Section 39	€1,442,944
	Total	€4,853,928
Staff travel and subsistence	HSE	€572,479
	Section 38	€1,375,579
	Section 39	€871,905
	Total	€2,819,963
Grand Total		€40,383,397

Source: Questionnaires returned from 72 specialist disability service providers

Table A3.2: Expenditure on research , advertising and profile building

Non-pay costs	Agency type	Total 2009 direct and indirect non-pay costs
Advertising/staff recruitment		
	HSE	–
	Section 38	€419,189.27
	Section 39	€331,340.13
	Total	€750,541.24
Public Relations		
	HSE	€0.00
	Section 38	€27,234.75
	Section 39	€279,530.72
	Total	€306,765.47
Research		
	HSE	€0.00
	Section 38	€0.00
	Section 39	€226,828.98
	Total	€226,828.98

Source: Questionnaires returned from 72 specialist disability service providers

Table A3.3: Infrastructure costs

Non-pay costs	Agency type	Total 2009 direct and indirect non-pay costs
Maintenance and related costs		
	HSE	€1,870,868
	Section 38	€19,079,351
	Section 39	€4,858,822
	Total	€25,809,041
Heat, power, light, refuse/water rates		
	HSE	€2,513,646
	Section 38	€13,086,310
	Section 39	€3,770,871
	Total	€19,370,827
Major jobs		
	Section 38	€63,229
	Total	€63,229
Rent/leasing accommodation		
	HSE	€1,004,158
	Section 38	€9,454,980
	Section 39	€7,039,582
	Total	€17,498,720
Security		
	Section 38	€18,197
	Total	€18,197
Building costs		
	Section 39	€55,237
	Total	€55,237
Health & Safety		
	Section 38	€19,560
	Total	€19,560

Source: Questionnaires returned from 72 specialist disability service providers

APPENDIX 4

RANGE OF SERVICES PROVIDED TO PEOPLE WITH DISABILITIES

RESIDENTIAL AND RESPITE SERVICES

Residential services and supports

Residential services are provided on a part- or full-time basis. Residential supports may be provided in residential centres, in shared houses in the community or in individual support arrangements which enable the person to live independently or with other persons.

Residential centre-based respite and overnight accommodation

Residential centre-based respite is usually accommodation dedicated specifically for the provision of respite services.

Respite support hours

Respite supports encompass a range of options, including:

- non centre-based respite;
- home support hours;
- holiday and summer camps;
- after school services;
- day respite.

DAY SERVICES AND SUPPORTS

Day Care Programme

High support services primarily focused on providing a healthcare service to meet the specific needs of individuals.

Day Activation/Activity

A day programme that is essentially a support and therapeutic service designed to meet the needs of people through individual plans. The environment is designed to maximise the functional levels of service users. They provide a range of skills and activities, such as independent living skills, personal development, education classes, social/recreational activities and health-related and therapy supports. Day activation is essentially a programme that does not include work activity.

Active Community Participation/Inclusion

Programmes and supports specifically targeted towards the inclusion and active participation of service users in mainstream community programmes and activities. This includes participation in educational opportunities, sport and recreation involvement, social events, local partnership projects and advocacy initiatives.

A range of supports that promote and facilitate inclusion are provided to individuals and groups, such as accessing services, liaison, planning, coordinating and supporting attendance and active participation by service users.

Voluntary work

The volunteer serves in the community or for the benefit of the natural environment primarily because they choose to do so. A volunteer worker does not get paid or receive compensation for services rendered. Each person's motivation will be unique, but will often be a combination of the following: altruism (volunteering for the benefit of others), quality of life (serving the community because doing so makes one's own life better, e.g. from being with other people, staying active and having a sense of the value of themselves that may not be clear in other areas of life) and 'giving back' – a sense of duty or religious conviction.

Rehabilitative training

Rehabilitative training programmes are designed to equip participants with the basic personal, social and work related skills that will enable them to progress to greater levels of independence and integration in the community. These are approved programmes with whole-time equivalent (WTE) places allocated by the national Occupational Guidance Service Structure.

Education Programme

Programmes funded by the Department of Education and Skills, which enhance day service provision.

WORK AND EMPLOYMENT SERVICES

Open employment (no supports)

This is employment in the open labour market without additional supports. In some instances, a service user may be in open employment with no supports for part of their week; the service provider may have supported the individual to attain their job, but have now withdrawn all employment-related support.

Supported employment

Supported employment is paid employment in the open labour market with ongoing supports. The minimum wage applies and full employee status. Service users may be participating in the national FÁS-funded Supported Employment Programme or in Service Provider Supported Employment initiatives.

Sheltered employment

This is employment in an enterprise established specifically for the employment of people with disabilities and which is in receipt of designated funding from the HSE. It refers to employment under sheltered conditions, where workers have a contract of employment and are in receipt of the minimum wage.

Sheltered work – Therapeutic

A centre-based programme designed to provide constructive occupation for an individual or group, where work activity is a key element of the programme. The work is carried out in a centre/location designed for that purpose, but there is no third party involvement, i.e. no contract work, not open to public. Examples of this could be a day service that focuses on cooking/baking or art/craft. The product is consumed within the service and they may also hold a regular coffee morning to showcase their work and sell some of their products at nominal cost to encourage service users and prevent a build-up of stock. Service users may or may not receive allowances or discretionary top-up payments.

Sheltered work – Commercial

A day programme that involves work activity. In these situations, the public have access to the product or service, or contract work is carried out for a third party. Money is exchanged for goods or services. Service users may or may not receive allowances or discretionary top-up payments.

Sheltered Work-like work

A day programme that involves service users working within the HSE or service provider organisations in what could be described as work-like situations. This includes service users working in kitchens, maintenance work, landscaping, office, administration, post-room, catering, hospital shops, canteens, etc. Service users in this category receive a discretionary top-up payment for activities undertaken. The purpose of the discretionary payment is to give the service user a sense of worth and reward, and to provide them with an inducement to continue with the activity. It could be argued to be a payment, which is an important part of the therapeutic aspect of the work done.

External Work-like work (less than minimum wage)

A day programme that involves service users working in external like work situations. In most cases, the service provider sources the placement in an open employment setting as part of the individual's day programme. Minimum wage or Disability Allowance plus rules do not apply, but the employer normally makes a discretionary top-up payment, either directly to the individual or to the service provider to allocate at their discretion. Examples of this are service users working in supermarkets, fast-food chains, etc. Short-term work placements that are part of a recognised training programme are not included.

OTHER SERVICES

Assisted Living/Personal Assistant Services for people with physical and sensory disabilities include a range of personal supports for people with physical and/or sensory disability, such as:

- personal assistants;
- home support;
- assisted living support;
- home help.

Information advocacy and support services are often provided by agencies or services with expertise in particular conditions.

Medical and clinical therapies

Specialist services for persons with disability, which may be provided to individual services or in community settings. Specific services may be provided to particular age groups, e.g. early intervention.

Aids and Appliances

People with disabilities may be eligible for medical/surgical aids and appliances that facilitate and/or maintain mobility and/or functional independence. The HSE provides assistive devices to people with disabilities to enable them to maintain their health, to optimise functional ability and to facilitate care in their primary care setting.

Assistive devices such as medical/surgical aids and appliances are provided to individuals to:

- retain, restore and promote maximum independence;
- empower people to manage their own care to the best of their ability, i.e. intervene no more than is absolutely necessary;
- compensate for the absence of alternative support or complement existing supports;
- take full account of the risk to the individual if a service is not provided.

The statutory basis for the provision of assistive devices is the Health Act 1970 and is subject to specific eligibility criteria. Assessments are carried out by a range of multidisciplinary staff, including occupational therapists, physiotherapists and public health nurses.

APPENDIX 5

UNIT COST METHODOLOGY

1. Determine the methodology

- 1.1. Establish output units for major service delivery (programme) types.
- 1.2. Identify a preliminary set of high-level Resource Usage Groups on the basis of shared characteristics and similar resource usage.
- 1.3. Determine costs to be excluded (e.g. capital) or included (e.g. pensions) when using the data for the purpose of comparison.
- 1.4. Determine costs to be excluded or included when using the data for the purpose of establishing a fair cost per place, for a range of service types.

2. Consolidate SLA data

- 2.1. Consolidate SLA data from each LHO area and upload to statistical analysis software (SAS) package.
- 2.2. Apply preliminary data validation and identify gaps, data entry errors, data inconsistencies.

3. Calculate unit costs

- 3.1. For each agency, identify the service units that directly deliver services and those whose functions are administrative, service support (e.g. maintenance) or indirect service delivery (e.g. transport).
- 3.2. Identify the metric(s) for the apportionment of indirect costs.
Note: A metric based on the number of staff in direct service units is the metric which has been used for the preliminary analysis.
- 3.3. Identify the direct pay costs for service delivery units.
- 3.4. Re-allocate all indirect pay costs from administrative and support units to service delivery units.
- 3.5. Assess the feasibility of identifying direct and indirect non-pay costs for service delivery units.
- 3.6. If feasible, associate all direct costs with the relevant service units and re-allocate all indirect non-pay costs from administrative and support units to service delivery units.
Note: Where it is not possible to distinguish between direct and indirect non-pay costs, an apportionment will be made of total non-pay costs to service delivery units, using the same metric used at 3.2 above.
- 3.7. Calculate the cost for each service delivery unit (total of direct and indirect pay and non-pay costs, including all re-allocated administrative and support unit costs) and for each service user (service delivery unit cost divided by the number of service users in that unit, i.e. the average cost).

4. Populate Resource Usage Groups

- 4.1. Assign each service unit and service user to a Resource Usage Group, based on disability group, staff/client support ratios and/or programme type and programme detail.
- 4.2. For national level analysis, calculate a 'first cut' at the average cost of each Resource Usage Group by totalling the cost of providing services to each individual in that group.
- 4.3. After first pass at calculating averages, identify any results that may be the results of data errors, for follow-up and, if required, correction.
- 4.4. Calculate standard deviation, remove outliers and re-calculate the average unit cost.

5. Test and refine methodology

- 5.1. Test and refine unit costing methodology (apportionment metrics, removal of outliers, etc).
- 5.2. Test and refine structure of Resource Usage Groups.

6. Refine SLA data

- 6.1. Fill in any remaining gaps in the data and follow-up on any unusual results or obvious errors highlighted by the initial analysis.
- 6.2. Produce final, validated SLA dataset.

7. Conduct final analysis

- 7.1. Apply final analysis to the data.
 - 7.1.1. Compare service providers and models of service provision using the Resource Usage Group costs as a yardstick on an agency and a national basis.

RESOURCE USAGE GROUPS

The full set of Resource Usage Groups defined for the purposes of this Review are set out in Table A5.1.

Table A5.1: List of Resource Usage Groups

Programme type	Staff/Client ratio
Day services for adults with ID: Activation and day support	ID Day Intensive (1 to 1 or above)
	ID Day High (between 1 to 2 & 1 to 3)
	ID Day Moderate (between 1 to 4 & 1 to 5)
	ID Day Low (between 1 to 6 & 1 to 9)
	ID Day Minimum (staff to client ratio is 1 to 10+)
Day services for adults with ID: Work-like activities	ID Day Intensive (1 to 1 or above)
	ID Day High (between 1 to 2 & 1 to 3)
	ID Day Moderate (between 1 to 4 & 1 to 5)
	ID Day Low (between 1 to 6 & 1 to 9)
	ID Day Minimum (staff to client ratio is 1 to 10+)
Day services for children with ID	ID Day Intensive (1 to 1 or above)
	ID Day High (between 1 to 2 & 1 to 3)
	ID Day Moderate (between 1 to 4 & 1 to 5)
	ID Day Low (between 1 to 6 & 1 to 9)
	ID Day Minimum (staff to client ratio is 1 to 10+)
Day services for people with P&S disabilities only	
5-day Residential services for people with ID, including those with a physical, sensory or mental disability	ID Residential High (two staff on duty plus on duty night staff)
	ID Residential Moderate (two staff on duty plus sleep-in)
	ID Residential Low (staff on duty most of the time plus sleep-in)
	ID Residential Minimum (no sleep-in)
7-day Residential services for people with ID, including those with a physical, sensory or mental disability	ID Residential High (two staff on duty plus on duty night staff)
	ID Residential Moderate (two staff on duty plus sleep-in)
	ID Residential Low (staff on duty most of the time plus sleep-in)
	ID Residential Minimum (no sleep-in)
Residential services for people with P&S disabilities only	

DATA SOURCES

The primary sources used to produce the output data analysed in Chapter 5 were:

- 2009 SLA Schedule 3 forms;
- Non-pay and Trend Data questionnaires;
- HSE financial data, summarised in the Disability Finance Book (DFB – *see Appendix 2*);
- HRB data (NIDD and NPSDD).

The 2009 SLA Schedule 3 forms provided detailed information on pay costs at the level of Programme Type, Programme Detail and Service Unit. This was complemented by non-pay information at the level of Programme Type and Programme Detail in the non-pay questionnaire and by the pay, non-pay and total expenditure data in

the HSE's DBF. Data on service user numbers and dependency profile were obtained from the HRB databases, in particular the NIDD.

DATA ANALYSIS

The dataset used for the VFM Review was finalised on 6th October 2011. Earlier and less complete datasets were analysed by the Project Team to inform its deliberations and provide preliminary results. The data were imported into a statistical analysis software (SAS) package by a professional statistician in the Department's Information Unit, who provided extensive assistance to the Project Team and carried out the detailed calculations apportioning the pay and non-pay data and producing statistical reports. During the analysis process:

- Administrative and indirect service units have had their costs apportioned to direct service units, hence only direct service units are included in the relevant tables.
- Units with missing or invalid data in their SLA schedule in respect of *Disability Group*, *Programme Type* or *Programme Detail* were excluded from the tables.
- Units with zero or missing total pay costs were excluded in the calculations.
- Units with zero or missing total users were excluded from the tables.
- Out of a total of 3,581 units, 472 (13%) were classified as administrative and indirect service units, 2,962 (83%) were classified as direct service units and 147 (4%) were deleted as they had either zero or missing total pay costs.
- Of the 2,962 direct service units, 16 were excluded from the analysis as they had either zero or missing total users.
- Finally, of the remaining 2,939 units, 1,810 were placed into the Resource Usage Groups for analysis. The other units provide a range of services (such as multidisciplinary services, respite, home support, personal assistance) and were not included in the Resource Usage Groups. As outlined in Appendix 6 on 'Units of Output', difficulties with quantification of outputs in certain services meant that of necessity the Resource Usage Groups were confined to residential and day services only.

CALCULATION OF COMPARATOR COSTS

Costs used in Chapter 5 as the basis of comparison (referred to as 'comparator costs') have been calculated using a two-step process:

- (i) The average cost of a service user place in an individual service unit is obtained by dividing the total cost of the unit by the number of service users in that unit.
- (ii) The results are then averaged across service units.

The purpose of this is to take account of the variable number of service users per unit. An alternative approach would be to average service costs across all service users on a national basis, regardless of service unit. However, this would not be an accurate reflection of the actual incidence of cost behaviour at service unit level.

Table A5.2: Calculation of adjusted average for use in data comparison – worked example using actual data

Support ratio = ID Day Intensive (1 to 1 or above)	Total No. of service users	Total cost	Average cost per service user (Total cost/Total service users)
Service Unit 1	10	€216,501.87	€21,650.19
Service Unit 2	3	€15,170.75	€5,056.92
Service Unit 3	1	€47,408.61	€47,408.61
Service Unit 4	1	€ 51,176.63	€ 51,176.63
Service Unit 5	1	€47,408.61	€47,408.61
Service Unit 6	1	€23,704.30	€23,704.30
Service Unit 7	1	€ 59,260.76	€59,260.76
Service Unit 8	4	€176,073.17	€44,018.29
Service Unit 9	6	€417,150.66	€69,525.11
Service Unit 10	5	€403,665.17	€80,733.03
Service Unit 11	2	€186,226.59	€93,113.29
Service Unit 12	16	€680,394.35	€42,524.65
Service Unit 13	1	€543,764.89	€543,764.89
Service Unit 14	2	€834,985.74	€417,492.87
Service Unit 15	1	€62,362.69	€62,362.69
Service Unit 16	1	€103,221.00	€103,221.00
Service Unit 17	6	€353,922.96	€58,987.16
Service Unit 18	2	€183,246.29	€91,623.15
Service Unit 19	4	€364,315.40	€91,078.85
Service Unit 20	23	€260,588.88	€11,329.95
Service Unit 21	1	€196,207.06	€196,207.06
Service Unit 22	13	€909,864.74	€69,989.60
Service Unit 23	7	€804,843.41	€114,977.63
Service Unit 24	6	€1,033,869.71	€172,311.62
Service Unit 25	1	€99,043.33	€99,043.33
Service Unit 26	4	€262,183.61	€65,545.90
Service Unit 27	17	€196,093.05	€11,534.89
Service Unit 28	2	€84,903.67	€42,451.83
Service Unit 29	4	€87,622.65	€21,905.66
Service Unit 30	12	€87,622.65	€7,301.89
Service Unit 31	1	€60,567.38	€60,567.38
Service Unit 32	43.6	€585,278.39	€13,423.82
Service Unit 33	41.2	€555,966.14	€13,494.32
Service Unit 34	27.8	€276,682.09	€9,952.59
Service Unit 35	25.2	€312,993.62	€12,420.38
Service Unit 36	3	€152,880.44	€50,960.15
Service Unit 37	3	€53,586.51	€17,862.17
Service Unit 38	11	€451,820.40	€41,074.58
Service Unit 39	4	€624,250.05	€156,062.51
Service Unit 40	0.32	€17,001.38	€53,129.32
Service Unit 41	31	€74,166.79	€2,392.48
Service Unit 42	3	€234,057.60	€78,019.20
Service Unit 43	2	€136,606.05	€68,303.02

Support ratio = ID Day Intensive (1 to 1 or above)	Total No. of service users	Total cost	Average cost per service user (Total cost/Total service users)
Service Unit 44	6	€415,019.09	€69,169.85
Service Unit 45	14	€924,621.74	€ 66,044.41
Service Unit 46	10	€280,298.30	€28,029.83
Service Unit 47	16	€783,953.17	€48,997.07
Service Unit 48	14	€78,946.11	€5,639.01
Service Unit 49	12	€627,394.72	€52,282.89
Service Unit 50	10	€36,371.27	€3,637.13
Service Unit 51	23	€36,371.27	€1,581.36
Service Unit 52	5	€142,298.99	€28,459.80
Service Unit 53	5	€269,716.89	€53,943.38
Service Unit 54	13	€813,937.32	€62,610.56
	482.12	€16,737,588.91	€3,764,767.57
Simple average cost per place (total no. of service users divided by total cost)		€34,716.65	
Comparator average cost per place (total of average cost per service units divided by the number of service units, i.e. 54)			€69,717.92

APPENDIX 6

UNITS OF OUTPUT

No.	Output type	Measure of output	Measure of capacity	Comment	Application
1	Residential	Number of users on a given date	WTE place available	Useful census approach. One service user is deemed to equate to one WTE residential place.	Should be reliable.
2	Day services	Number of users on a given date	WTE place available	Not a useful measure of quantity (e.g. days per person per week or WTE day place would be better). If staff assignment has been carried out on a WTE basis, it may be possible to calculate a per day per person cost. It is not clear how the capacity measure was calculated.	Only those specific day services that are carried out on a 5-day basis could reliably be compared using unit costing. Further checking required with HSE and checking basis of calculations for day services review.
3	Multidisciplinary	Number of users on the current caseload	None	Not a useful measure of quantity (hours per person per week would be better).	Need to investigate how many multidisciplinary hours each user consumes. It may be possible to derive rules based on profile of users and ratio of staff/clients for individual services, e.g. available staff hours. Further checking required with HSE.
4	Personal Assistants	Number of users over the year	Staff hours available per annum	Not a useful measure of quantity (hours per person per week would be better). Unit of capacity may capture all staff time as opposed to client facing time.	Need to investigate how many PA hours each user consumes. It may be possible to derive rules based on profile of users, e.g. available staff hours. Need to check with HSE.
5	Residential centre-based respite	Number of users over the year for the 12-month period prior to 28/2/2009	Number of bed nights per annum	Unit of capacity is useful. Unit of output not a useful measure of quantity (bed nights would be better) because the SLA does not record amount of service per user.	Firstly, accurate bed night data should be available from the HRB on an agency basis – total stock of bed nights used during the year would be the best comparator. The HRB will be contacted to obtain this information. The way in which respite services are funded will also need to be explored. Secondly, the unit costs per bed night as measured in the capacity field of the SLA could be calculated since this should also yield useful variations in costs.
6	Respite support Hours ID	Number of users over the year in the 12 months prior to 28/2/2009	Staff hours available per annum	Output measure not a useful measure of quantity (hours per person per week would be better). Unit of capacity may capture all staff time as opposed to client facing time.	Need to investigate how much respite support hours each user consumes. It may be possible to derive rules based on profile of users. Need to check with HSE.

Note: There are no outputs provided for management/administration services.

APPENDIX 7

EXPERT REFERENCE GROUP'S RECOMMENDATIONS ON CROSS-SECTORAL WORKING

[12.1.4] RECOMMENDATIONS FOR CROSS SECTORAL WORKING: ACCESSIBILITY

The Group notes the progress that has been made in improving the accessibility of the built environment and many of the commitments of the National Disability Strategy in this area have been met. A review of the Part M Building Regulations is completed. It is planned to have upgraded regulations and technical guidance signed into law by the end of 2010.

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

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

[12.2.3] RECOMMENDATIONS FOR CROSS SECTORAL WORKING: TRANSPORT

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

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

[12.3.4] RECOMMENDATIONS FOR CROSS SECTORAL WORKING: ADVOCACY

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

In terms of the provision of individualised supports as described in this policy, part of the process of working with a person to identify their support needs involves an amount of capacity-building with the individual in

terms of strengthening their skills to self-advocate. However, more systemic provision of advocacy services and capacity-building for people with disabilities and families (such as training) is within the remit of the CIB. The commitment to the provision of Personal Advocates with statutory powers under the Citizens Information Act 2007 should be reviewed in light of the development of the new National Advocacy Service for people with disabilities.

[12.4.6] RECOMMENDATIONS FOR CROSS SECTORAL WORKING: SMART TECHNOLOGY

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

[12.5.3] RECOMMENDATIONS FOR CROSS SECTORAL WORKING: SUPPORTING COMMUNITIES

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

[13.1.9] RECOMMENDATIONS FOR CROSS SECTORAL WORKING: HOUSING

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

[13.2.5] RECOMMENDATIONS FOR CROSS SECTORAL WORKING: EMPLOYMENT

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

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

[13.4.6] RECOMMENDATIONS FOR CROSS SECTORAL WORKING: **EDUCATION**

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

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

With regard to the inclusion of children with disabilities in mainstream pre-school, the Group notes the Cross-Sectoral Working Group that was established by the ODMH earlier this year to develop and agree a policy framework in this regard. The Group recommends that an appropriate implementation plan be developed on foot of the framework once finalised.

[13.5.5] RECOMMENDATIONS FOR CROSS SECTORAL WORKING: **PARTICIPATION**

The Group recommends that the ODMH work jointly with the relevant Departments and agencies, including the Department of Community, Equality and Gaeltacht Affairs, the Department of Justice and Law Reform, and An Garda Síochána, to ensure that people with disabilities will be supported to be fully included and to participate in their local communities and to be active citizens. In this regard, the Group notes the recent development by An Garda Síochána of a strategy for older people, which aims to ensure the needs of older people are being met with regard to policing, security and safety so that they remain active within their communities.

APPENDIX 8

EXAMPLES OF INNOVATIVE PRACTICE

There are many instances of projects that are already delivering better outcomes to service users, often at the same or lower cost to the organisation. Many of these projects are in the area of service provision and focus on ways to deliver a more effective service to the individual. Other innovations are testing administrative ways to improve service delivery while at the same time cutting costs.

NEW WAYS OF PROVIDING SUPPORTS

In general, these innovations involve considerable discussion and planning with the service user and their family to design a tailored package of supports to enable the service user to live a more independent life than would traditionally have been the case for clients of the organisation. The HSE has provided grants to Genio* to work with agencies on projects to move people from institutions to the community, or to become more independent in the community, and in particular to focus on closing an institution or hospital in its entirety. The funding is also being directed towards increasing the provision of cost-effective, family and community-based respite care.

A number of case studies that illustrate *personalised supports* projects are summarised below.

SUPPORT FOR INDEPENDENT LIVING

The HSE is working with Genio on foot of €2m funding to *'move people from institutions to the community, or to become more independent in the community where they belong, [enabling] an institution or hospital to close in its entirety. The funding will also be directed towards increasing the provision of cost-effective, family and community-based respite care, as an alternative to traditional institutional models'*.

Four individual case studies are provided below by an organisation that received funding to assist in moving service users from segregated community setting to independent living. In each case, significant improvement in quality of life and community involvement is reported, while in 3 cases the cost of supporting the individuals has decreased. A feature of these cases is that support needs reduced further once the individual adapted to independent living.

Note: *The costs given in the case studies in this Appendix are direct pay costs only.*

Details are given on a service provider that undertook a pilot to demonstrate how individuals might be supported to personalise their supports and design a life of their own choice. The individual service user decided on the areas of their life where they wanted support and on who would support them, and the service provider worked with the individual to turn this into reality.

* Genio is a non-profit organisation that works with the public, private and non-profit sector to stimulate and support social innovation in Ireland that has lasting impact.

ALTERNATIVE WAYS OF PROVIDING RESPITE SUPPORT

A Contract Families Pilot Scheme was supported by Pobal in 2007 under the Enhancing Disability Services Programme, under which two agencies in the West were allocated €500,000 over 24 months to pilot a home-based respite care service for people with disabilities who had high level needs. The project sought to build on the established 'short breaks' respite scheme known as Home Sharing, where host families accepted a person into their home for a number of overnight stays each month. Further details are given below.

BEHAVIOURAL TECHNIQUES TO ADDRESS CHALLENGING BEHAVIOUR

Some agencies have been very successful at working with people with challenging behaviour. An example is given in the case studies below of a service user (pseudonym 'Mary') with challenging behaviour who transferred from a setting where she was being managed on her own by two psychiatric nurses for 24 hours every day. Following a year of intensive intervention using various behavioural techniques, staffing numbers were reduced from a 2:1 staff/client ratio to 1:3 staff/client ratio. Approximately one year later, the service user agreed to share her house with two other clients who also presented with challenging behaviours. This had the effect of dramatically reducing the cost per place of this service, from approximately €470,000 per place to approximately €156,000 per place. This figure was further reduced to €40,000 when this group, along with others, moved to a not-for-profit housing association in 2007.

OTHER INNOVATIONS IN SERVICE DELIVERY AND ADMINISTRATION

Innovation has also been displayed in other areas of service administration and delivery, for example, the development of a team approach to the delivery of services to children.

A number of inter-organisational service delivery networks have developed in recent years to deliver collaborative services to children and young people with disabilities. In these networks, comprising both HSE and non-HSE personnel, early intervention and school-age services are provided by multidisciplinary teams. Healthcare professionals participating in these teams have been interviewed and have reported that the team approach has resulted in the provision of a more integrated, family-friendly service to a greater number of children, while at the same time making better use of existing resources.

CASE STUDY – CONTRACT FAMILIES

The Contract Families Pilot Scheme, which is provided by Agency A in association with Agency B, provides community-based care for adults and children with intellectual disabilities. The project was established in 2007 as a 2-year pilot and was awarded funding of €500,000 by Pobal under the Enhancing Disability Services Scheme. The project was developed from the existing Home Sharing Scheme, which facilitates families in the community to offer a home-from-home experience to people with intellectual disabilities. The Home Sharing Scheme has operated as a joint scheme between the two agencies since 1989. Similar projects are operating around the country.

Under the Contract Families project, host families enter into a contract to provide a certain number of sessions per month and are paid a retainer to ensure availability of a number of placements and a payment is made for each session. Travel expenses are paid in cases where Contract or Home Sharing families are asked to provide transport to facilitate the person to come to their home on placement. Payments for placements are paid according to the support needs of the person. The scheme uses the National Intellectual Disability Database

(NIDD) as a guide to the level of support a person requires. While all individuals availing of Contract Family placements require support and assistance to participate in day-to-day life, those on a higher rating on the NIDD are deemed to have more intensive support needs and Contract Families are paid a higher rate for these individuals. Pobal funding enabled the recruitment of 8 new Contract Families and additional Home Sharing families, and provided funding for the service. Housing adaptations, essential equipment and transport arrangements allowed the scheme to cater for people with physical disabilities. Up to 38 persons (children and adults) received a total of 383 sessions, including overnight and weekend care, 19 of which experienced home-based care for the first time.

One of the main benefits of the project is that it puts the person with the disability at the centre of service provision and enables them to be cared for in the community rather than in residential or institutionalised settings. The project facilitates and supports families in the community to work in partnership and to share in the care of a person with specific care needs. It allows the person with the disability a break from home and to enjoy the opportunity to participate in normal family and community events.

The future operation of the scheme is dependent on the availability of sufficient resources. Currently, Agency A is funding the scheme from within existing monies. The demand for Contract Family/Home Sharing placements outstrips the availability of places.

The official evaluation of this project (September 2009) concluded that the future roll-out of the Contract Families model of care will potentially bring about a number of strategic benefits for those who use the services of both Agency A and Agency B, including:

- more cost-effective use of combined resources to support the future development of Home Sharing and Contract Families schemes;
- better deployment of existing staff within a wider community context;
- the promotion and development of community-based respite services before recourse to centre-based respite;
- greater choice for people using the service and their families.

The evaluation concluded that the pilot scheme demonstrated the efficacy and cost-effectiveness of the model and, above all, the benefits of this model of service to host persons and their families. While the pilot scheme illustrated ways in which current resources could be used differently and to better effect, the evaluator noted that a more robust financial analysis would be required to reflect accurate and realistic costings.

Appendix 4 of the evaluation included a cost comparison between residential services and Contract Families, and found that the cost per hour of care between residential services and Contract Families was substantially lower in the latter. High-level costings quoted by Pobal in their report *A Guide to Enhancing Disability Services* indicated that the hourly rate for provision of respite within a residential service is €41.47, compared to €14.73 for Contract Families.

Following on from the above pilot project, a HSE-led Working Group on respite/residential care with host families in community settings was set up in late 2010 to examine the potential for this model of service to be rolled out throughout the country. The group consisted of representatives from the HSE, National Home Sharing Network and the Department of Health.

As part of its work, the Working Group carried out an overview of models of respite (less than 104 days per annum) and residential care for children or adults with disabilities on a part-time or full-time basis with host families in community settings nationally and examined the viability of such models for future development for

people with intellectual disabilities. 579 people with a disability currently avail of the service with a host family, of which 263 are children and 316 are adults.

The Working Group considered that service provision by a host family gives the person with a disability an opportunity to participate in the community in a socially inclusive manner and also has the advantage of offering their family a break from giving continual care and a chance to enjoy their own interests and space. While the Working Group could not definitively comment on the efficiency of this type of service model, it noted that the model could be provided in a cost-effective manner.

CASE STUDY - CHALLENGING BEHAVIOUR

Mary (*pseudonym*) has a long history of severe challenging behaviour. She had spent time as a child in Agency C after which she moved to England where she attended a service/school which proved unsuccessful due to her behaviour. She returned to Ireland and attended a service in the West of Ireland for one hour per week. She then returned to live with her mother in Co. [x] where her behaviour reached crisis point. She was subsequently admitted to a service on a 24-hour, 1:2 staffing level under the care of psychiatric nurses.

Agency C was approached to consider providing a service to Mary since the HSE was concerned about both the suitability and sustainability of the service she was receiving.

Mary was being managed on her own by two psychiatric nurses for 24 hours every day. These staff were paid on an overtime basis and worked their 'normal hours' in the HSE local Mental Health services, and had no experience in providing services to people with intellectual disability and challenging behaviour.

After some discussion and negotiation, Mary was admitted to Agency C in October 2003. Funding of approximately €470,000 was provided to support her. This figure included pay and employer's contributions totalling 80%, and approximately 20% non-pay, which included a contribution towards the furnishing of a house.

On admittance into Agency C services, Mary was placed in a hostel on her own with a 1:2 staff/client ratio given by RNID-trained nurses. This ratio meant that a total of 9 nursing staff were rostered to cover the 24 hour/7 day week service. Her behaviours deemed challenging at this time included a high frequency of verbal abuse, physical aggression, spitting and total non-compliance. She also maintained little or no eye contact with anyone.

INTERVENTIONS

A multidisciplinary approach proved ineffective because Mary would not engage or comply with any type of psychological or therapy assessment. Staff did find her very challenging since any interaction with her typically resulted in her responding with severe verbal abuse and physical aggression. The RNID-trained CNM, through years of experience in challenging behaviour, was able to identify that Mary's behaviours appeared to stem not only from her autism, but also from difficulties resulting from lack of exposure to positive social interaction. She had developed no interpersonal skills, which in turn left her socially isolated. Her failure to develop relationships meant that she had never developed any bonds or trust with another human being.

The initial goal was to establish a relationship with Mary based on mutual respect and trust, which was done with the CNM. Once this trust had developed over a period of time, various behavioural techniques (such as

differential reinforcement and limit-setting) were applied in dealing with her problematic behaviours. Mental health strategies, behavioural strategies and coping strategies were put in place for her. She was encouraged to maintain appropriate eye contact at all times; other approaches used included role modelling and reflective practice. Role modelling focused primarily on social interactive situations, whereby Mary was shown how to behave in a socially acceptable manner in various social settings. Her learning was primarily interactive and occurred within a social context, thus helping her to develop knowledge and values, but was based totally on the trusting relationship that she had developed with the CNM. This relationship proved to be the foundation and only motivating factor in improving her overall behaviours and enhancing her quality of life.

Mary was now ready for her first-ever psychological assessment, which she attended with the support of the CNM. She also had the support of a psychiatrist because she suffered from extreme anxiety and had not developed any coping mechanisms prior to her placement in Agency C.

Approximately one year later, she agreed to share her house with two other clients, who also presented with challenging behaviours. Staffing numbers were reduced from a 2:1 staff/client ratio to 1:3 staff/client ratio. This had the effect of dramatically reducing the cost per place of this service, from approximately €470,000 per place to approximately €156,000 per place. This figure was further reduced when this group, along with others, moved to a voluntary housing association in 2007. (This is a community development, consisting of 3 separate apartments within the one unit, which Mary shared with 11 other clients under the supervision of 3 staff.) This further reduced the cost per place, to approximately €40,000.

The skills Mary has developed through social learning have enabled her to cope better with everyday challenges. Her quality of life is enhanced and she is empowered through her social and emotional functioning. She has developed the ability to set control over her own life and develop relationships with many staff and with her peers. She continues to reside in the voluntary housing association and enjoys a varied and fulfilling life, which includes going abroad on holidays and having the confidence to cope with any social situation. All interventions necessary in supporting Mary to reach her present level of ability and enhanced quality of life were initiated, implemented and evaluated solely by RNID nurses.

CASE STUDY – AGENCY D, INDIVIDUALISED SUPPORTS

Agency D undertook a pilot to demonstrate how individuals might be supported to personalise their supports and design a life of their own choice. The individual service user decided on the areas of their life where they wanted support and on who would support them, and the service provider worked with the individual to turn this into reality.

PARTICIPANTS

Seven people were selected as participants for the pilot – 6 people who were already using the Agency's Adult Supports and one person who was due to leave school in 2010. The criteria for selecting the participants included the individual's desire to:

- play a key role in 'driving' the lifestyle they wanted and the supports they needed to facilitate this lifestyle;
- manage their own home;
- explore new life options and meet new people.

The individual service user decided on the areas of their life where they wanted support and on who would support them, and the service provider worked with the individual to turn this into reality. Areas of life where the individuals identified their personal support needs included:

- How to spend my day?
- Involvement with the local service?
- Get a job or not?
- Do I want my own home?
- Do I need clinical support(s)?
- Do I want paid or unpaid support(s)?

INDIVIDUALS' PERSONAL STORIES *(names have been changed to protect identities)*

John

'In 2010 my mother has worked with my life coach to design the best supports for me. This included developing a plan for the next stage of my life and interviewing for my support staff.

I have now begun the next stage of my life, which is a new experience for me and my family, support staff, life coach and respite staff.

I have a base that is a quiet environment; I have 1:1 support staff who are supporting me to have new experiences in my community. I also have some unpaid support to attend a basketball club, which is run in the evening. In time, I may have other unpaid supports in my life as I develop new interests.'

Ann

'I decided to share my apartment with someone who I have been friends with for a long time. We chose our support workers, who help us cook meals and keep the apartment tidy. We also have an Emergency Response Pendant, which means we don't need anyone to stay over with us.

I am involved in my community through my job, using the library, the local gym, going to the pub, involved in the Drama Society and using the local shops, etc. I have also decided not to attend the local service 5 days a week; I now just go in on a Friday.

I am glad I moved out of home, it is brilliant and I LOVE IT!'

Mary

'With support from my life coach, I have made a new friend. We go for meals, shopping trips and to each other's houses. We keep in touch on Facebook and by phone. This friendship is different from ones you make in local service.

My new friend and I are Liverpool fans. We are hoping to go to Liverpool to see a match in 2011, which would be great to go without my family. We are also planning to go to New York and we've started saving already.

I decided not to attend the local service everyday. I go in now on Wednesday to complete my FETAC cookery class. The rest of the week, I go to my two jobs and I have time off to myself. I go to a local art class on a Wednesday night and I am a member of a basketball team.'

CASE STUDIES – AGENCY E, INDIVIDUALISED SUPPORTS

Ann (*pseudonym*), a 51-year-old woman

When supported by traditional services ...

- Ann lived in a community group home with 2 other women. 7 hours of direct support provided each day.
- Did not know her neighbours. Socialised exclusively with people with an intellectual disability.
- With the exception of voluntary work in a local crèche, attended a traditional day service setting.
- Had a long-established pattern of very regular visits to her GP in relation to various ailments.
- Had to secure permission for family members to visit and stay overnight.

With individualised supports ...

- Ann now lives in her own (rented) 2-bedroom apartment by herself.
- Receives 3 hours of direct support each week – this has reduced from 15 hours at the outset of her transfer to individualised supports.
- Has a salary-earning job in a crèche for 5 hours a day, Monday to Friday.
- Pays all her own household bills.
- Has completed a Level 3 FETAC course to secure her employment in the childcare setting.
- Trains a local under-age GAA team, having acquired accredited training as a coach.
- Has gained many new friends and colleagues through her work and various voluntary roles (e.g. GAA, St. Patrick's Day Parade Committee).
- Has renewed and deepened her family contacts. Family members regularly visit and stay overnight. Has developed a relationship with nephews and nieces.
- Her personal and social identity is now grounded in her rich range of roles rather than in her status as somebody with an intellectual disability.
- Now rarely attends her GP.

- Direct costs formerly associated with her community group home: **€12,600**

- Cost of individualised supports: **€5,679**

Peter (*pseudonym*), a 54-year-old man

When supported by traditional services ...

- Peter lived in a community group home with 3 others. Supported by one staff at all times, including a 'sleep-over' staff during the night-time.
- No control over who was supporting him. Dependent on unfamiliar relief staff much of the time.
- Attended a traditional day service programme 4 days a week – on the 5th day was employed delivering a local newspaper (supported constantly by a staff member).

With individualised supports ...

- Peter is now living independently in his own home (rented) for the past 18 months.
- Centrally involved in recruiting, training and directing his support staff.
- No longer has live-in night-time support. Since moving to an individualised supports approach, there has been a progressive reduction in his need for support hours – reduced by 5 hours per week (even more when support workers are on holidays).
- On moving to an individualised-supports model, Peter was very clear that he wanted to retain his place in traditional day services. Has recently begun indicating that he wishes to sever links with the day programme (as he regards himself as being cast 'in a client role' there, rather than being in control of what is happening, also citing that he is now 'too busy'). Retains his Friday paper round, but no longer requires any staff support.
- Is developing an entrepreneurial proposal – recycling used clothes as industrial cloths.
- Is now working in a voluntary capacity in a local retail outlet each Tuesday afternoon.
- Exercises control over who is supporting him at all times.
- Significantly enhanced engagement and participation with neighbours and others in his community: has completed a computer course with local residents, is a member of the local Residents' Association, member of his housing estate Street Parade Committee and member of a walking club.
- Has taken on many new social roles – neighbour, employee, employer, volunteer.
- No reliance on unfamiliar relief staff.

- Direct support costs associated with the community group home: **€50,000**

- Direct support costs of individualised supports: **€25,000**

Margaret (*pseudonym*), a woman in her early 30s

When supported by traditional services ...

- Margaret lived full-time on an emergency basis in a community respite house (20 miles from her family home) following the death of her sole remaining carer.
- She was supported by 2 staff at all times, day and night – one ‘waking’ staff support and one ‘sleep-over’ during night hours.
- She shared her living space with different people each week.
- Was exposed to a high level of discontinuity and unfamiliarity in relation to staff members who were supporting her.
- Had been receiving ‘day services’ outreach during her time in a community respite house. She had formerly attended a traditional day service setting for 25 people, but had been discharged due to behaviour-management difficulties.
- Had presented as very volatile, challenging, and ‘unpredictable’ when living in the community respite centre. Staff members themselves describe it as ‘walking on egg shells’ throughout this time.

With individualised supports ...

- Margaret is now residing in her own home (rented) in her hometown.
- She is centrally involved in choosing her support team. Is now only supported by people who are familiar to and trusted by her.
- Has one support worker with her at all times, in addition to ‘sleep-over’ support at night-time.
- Family members provide her direct support on Sundays – to ensure the financial sustainability of the current arrangements.
- Margaret’s epilepsy is described as progressive and uncontrollable. While her behaviour continues to be challenging at times, her team of direct support workers now report that it is more predictable and that they have a deeper understanding into what triggers her distress and aggression.
- She no longer attends a day programme or has formal outreach support. She runs a stall in a local market on alternate Saturdays and spends much time during the week sourcing and preparing items for her stall.

- Comparable costs (direct support costs and excluding Sunday costs) when residing on an emergency basis in the community respite facility: **€306,831**

- Cost of direct individualised supports: **€144,337**

Note The costs of Sunday support currently being provided by the family would be €94,801 if the service was operating within the community respite model and she was residing there on an emergency basis. The actual financial value of the support the family are providing within the individualised supports model is approximately €24,000.

Brigid (*pseudonym*), a 57-year-old woman

When supported by traditional services ...

- Brigid resided in a large institutional unit for over 20 years. Subsequently moved to a community group home where she lived as one of a group of 4. There was always a staff presence in the house, including 'sleep-over' cover during night hours.
- Had 24 x 7 support.
- Attended a traditional day service where she was one of a group of 16.
- Led a life of very restricted experience and limited opportunity.
- Did not know any of her neighbours. Socialised exclusively with fellow-service users.

With individualised supports ...

- Brigid has returned to her native village where she now resides by herself in a rented house.
- Is now receiving only 58 hours of direct support per week – reduced from 168 hours per week over a 6-month period.
- Significant use made of assistive technology to optimise her independence and introduce more cost-effective monitoring and support.
- Employs 3 support workers.
- Owns her own car – which has been a significant entrée to her neighbours, some of whom are without transport, and greatly welcomes Frances' generosity in this regard.
- Has acquired many new skills, notably choice-and decision-making competencies.
- Has begun reconnecting with her extended family and is actively developing these relationships.
- Has developed a friendship with her neighbour.
- Has set up a cottage industry (jam-making), which she retails at local markets.
- Has joined numerous local community groups – a prayer group, an age-active group, a fitness club and a pilgrimage group.
- Has taken the lead in setting up a community knitting group.
- Rarely attends her GP.

- Direct support costs associated with the community group home: **€37,100**

- Cost of individualised supports **€61,288**, which includes her 24/7 direct support costs.

APPENDIX 9

RECOMMENDATIONS IN NDA'S ADVICE PAPER TO THE VFM REVIEW

The National Disability Authority (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 should be provided, as a priority, to meet the needs of children with disabilities in the family home;
- appropriate legislative action should 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 coordination 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 that are focused on independent living;
- an 'industry plan' to support the re-orientation of disability services may assist the implementation of the required changes.

APPENDIX 10

PROGRAMME LOGIC MODEL

Inputs	Activities (inputs into outputs)	Main outputs	Theory – how and why outputs contribute to outcome	Results	Targeted impacts (long term)
Management/admin staff					
<ul style="list-style-type: none"> HSE 	<p>Overall management of Disability Services Programme.</p> <p>Liaison with families, service providers, the Department of Health and other stakeholders</p>	<p>Equitable distribution of available funding to enable service providers to provide service.</p> <p>Policies and procedures to guide service delivery.</p> <p>Data collection and management to inform Government and future service development.</p>	<p>Funding is distributed on an equitable basis to ensure those needing services are not disadvantaged by reason of their place of residence or disability.</p> <p>Sets standards for service providers in relation to acceptance of clients, investigation of complaints, operation of services, staff recruitment, health and safety.</p> <p>Good data allow for better management of resources and planning for future needs.</p>	<p>The optimum quantum of services are available when and where needed.</p> <p>Ensures compliance with relevant legislation, seeks to protect rights of vulnerable service users and allows for investigation of complaints.</p>	<p>Appropriate services offered to service users.</p> <p>Waiting times kept to a minimum.</p> <p>Continuous improvement in services through the application of best practice.</p>
<ul style="list-style-type: none"> Specialist non-statutory disability service providers 	<p>Day-to-day service management, service planning, financial management, HR management</p>	<p>Residential, day, early intervention, multidisciplinary and other services provided in accordance with Service Level Arrangement.</p>	<p>Clients are provided with services to enable them to live as full a life as possible by providing residential supports, specialist health services, rehabilitative training and personal social services.</p>	<p>These services are delivered in as efficient and effective a manner as possible.</p>	<p>Services are as cost-efficient as possible and designed to meet the need of the service user.</p>
Service delivery staff					
<ul style="list-style-type: none"> HSE Voluntary agencies 	<ul style="list-style-type: none"> Assessing clients' needs 	<ul style="list-style-type: none"> Number of assessments of individual's need for services; 	<p>Accurate assessment of need allows services to be designed to meet the actual need of the client.</p>	<p>Just the right level of service provided.</p>	<p>Will allow a transition from wrap around 'cradle to grave' type of provision to supported community living.</p>

Inputs	Activities (inputs into outputs)	Main outputs	Theory – how and why outputs contribute to outcome	Results	Targeted impacts (long term)
	<ul style="list-style-type: none"> Organising, managing and delivering a range of services and supports, including residential, day, respite, personal assistance and multidisciplinary services. 	<ul style="list-style-type: none"> WTE residential places. 	Residential services provide accommodation for a vulnerable population who do not have the ability to provide for themselves.	People with disabilities have access to a standard of residential services that may not otherwise be available to them. Absence of this service could lead to homelessness.	Service users are provided with a range of options/services that enable them to live independently, in the community, in congregated settings or remain with family.
		<ul style="list-style-type: none"> WTE day places/number of days of services delivered; rehabilitative training places. 	Training services and day services maintain or improve an individual's ability to function and may lead to progression to further training opportunities and/or employment opportunities in either the open labour market or sheltered employment.	People whose disabilities may prevent them from accessing or benefiting from mainstream training opportunities can access specialist training that can lead to mainstream training or work/employment opportunities.	People with disabilities have the opportunity to progress through the continuum of education, training and employment supports to obtain greater skills/qualifications, leading to an increased ability to join the labour market and to participate in work and in society.
		<ul style="list-style-type: none"> Hours of personal assistant services provided; number of hours of home support provided. 	Personal assistance services and home supports allow service users to live independently, be a part of their community, use mainstream services and assist families to continue caring for an individual who may otherwise use residential services.	These services reduce reliance on more expensive residential services. They allow people choice about where they live.	<p>Increased involvement of people with disabilities in the community and using mainstream services.</p> <p>Supports families/carers providing care in the home.</p> <p>Reduces reliance on more expensive alternatives.</p>
		<ul style="list-style-type: none"> Hours of multidisciplinary support provided. 	Therapeutic interventions improve or maintain functional ability, thereby assisting the client to maximise their potential.	The therapy assists the individual to overcome or live with the condition or to restrict its effect on the person's life in so far as possible.	Increased involvement of people with disabilities in the community and using mainstream services.
		<ul style="list-style-type: none"> Hours of early childhood services provided; 	Multidisciplinary supports provided to children.	These services help the child's development and assist him or her to avail of educational opportunities.	Educational outcomes for children with disabilities are improved.

Inputs	Activities (inputs into outputs)	Main outputs	Theory – how and why outputs contribute to outcome	Results	Targeted impacts (long term)
		<ul style="list-style-type: none"> number of respite nights provided; number of respite hours provided; number of service users supported by service type. 	Respite services support families/carers in continuing to provide care for an individual who may otherwise use residential services.	Respite allows families/carers to have a break from caring responsibilities and may reduce reliance on more expensive alternative care.	People with disabilities are assisted to remain in their own homes and communities, and to be a part of society.
Other resources <ul style="list-style-type: none"> IT systems Aids and appliances Medical/surgical equipment and supplies 	<ul style="list-style-type: none"> Assessments for aids and appliances, procurement of and provision of aids and appliances. 	<ul style="list-style-type: none"> Number of aids and appliances issued. 	Use of aids and appliances, including technology, can assist a client to overcome some of the effects of their disability.	The effects of the disabling condition are reduced/service users are assisted in coping with their condition.	<p>Service users show long-term improvement in functional abilities and health outcomes due to specific therapy services.</p> <p>People with disabilities are assisted to remain in their own homes and communities, and to be a part of society.</p>
<ul style="list-style-type: none"> Buildings Administration Financial, current and capital <ul style="list-style-type: none"> DOH/HSE allocations; other Departments; private funding sources. 				<p>Most efficient and effective use of resources provided for service provision.</p> <p>Ability of service providers to account for resources provided.</p> <p>All statutory obligations met by service provider in relation to employment, standards, procurement, etc.</p>	

APPENDIX 11

STATISTICAL TABLES

Table A11.1: National Intellectual Disability Database (NIDD)
No. of people registered on the database by Local Health Office*, 2005-2009

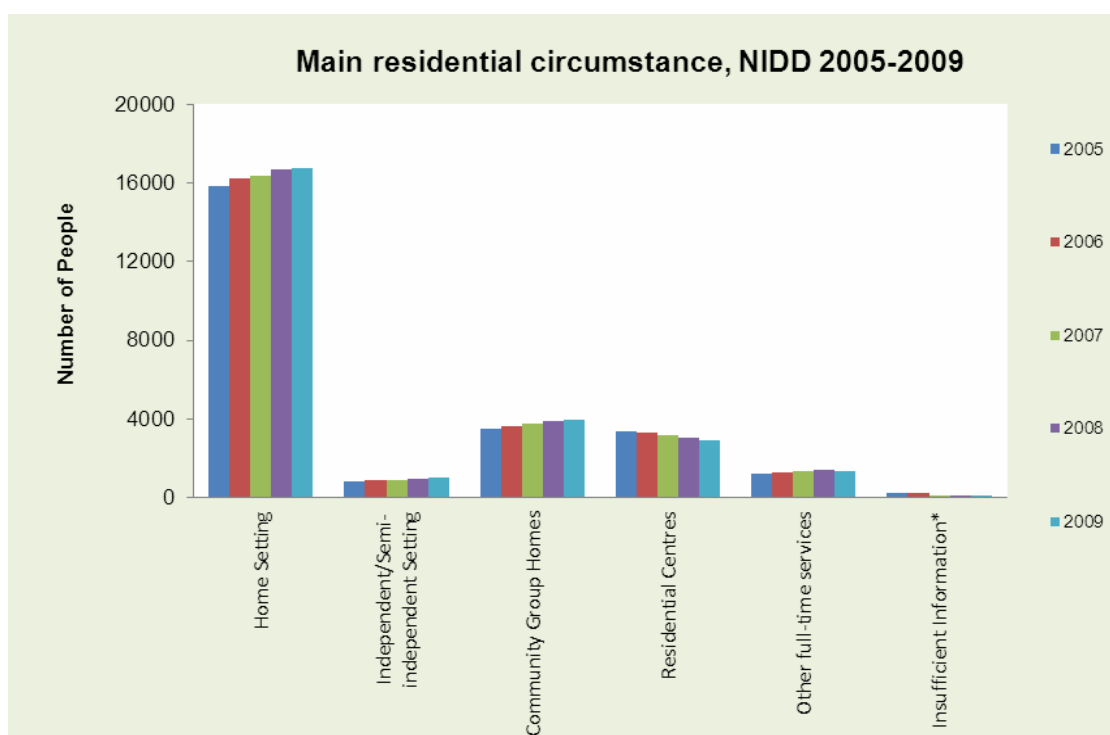
Local Health Office	Year				
	2005	2006	2007	2008	2009
East Coast Area 1	636	788	645	612	588
East Coast Area 2	287	257	334	306	301
South-Western Area 3	199	260	301	272	273
South-Western Area 4	840	935	754	578	654
South-Western Area 5	1,100	1,368	1,308	1,457	1,423
Northern Area 6	1,643	1,345	1,124	1,052	1,111
Northern Area 7	249	300	537	583	552
Northern Area 8	1,151	1,181	1,182	1,149	1,161
South-Western Area 9	1,112	1,219	1,317	1,270	1,284
East Coast Area 10	602	705	750	722	722
South-Eastern Area Carlow-Kilkenny	908	908	943	1025	1051
South-Eastern Area Tipperary SR	605	612	643	661	686
South-Eastern Area Waterford	693	674	684	821	800
South-Eastern Area Wexford	886	897	918	945	922
Southern Area Cork North Lee	1,940	1,973	1,564	1,526	1,437
Southern Area Cork South Lee	0	6	422	531	575
Southern Area North Cork	489	502	538	576	574
Southern Area West Cork	394	402	390	381	371
Southern Area Kerry	874	905	912	927	905
Mid-Western Area Limerick	1,014	903	902	957	950
Mid-Western Area Tipperary NR	700	697	685	672	652
Mid-Western Area Clare	510	494	462	454	453
Western Area Galway	1,522	1,529	1,587	1,616	1,585
Western Area Mayo	906	905	931	952	961
Western Area Roscommon	345	363	380	411	423
North-Western Area Donegal	925	895	889	926	955
North-Western Area Sligo-Leitrim	892	855	855	827	841
North-Eastern Area Cavan-Monaghan	583	589	582	603	606
North-Eastern Area Louth	930	969	972	1016	999
North-Eastern Area Meath	508	530	549	601	649
Midland Area Laois-Offaly	658	688	678	693	696
Midland Area Longford-Westmeath	797	843	872	893	900
Outside Ireland	19	21	3	8	6
Total registrations	24,917	25,518	25,613	26,023	26,066

* These figures represent the number who receive their main service in the LHO, which is not always their LHO of residence.

Source: Health Research Board, National Intellectual Disability Database

Table A11.2: National Intellectual Disability Database (NIDD)
Main residential circumstance, 2005-2009

Type of residential setting	2005	2006	2007	2008	2009
Home setting	15,827	16,245	16,366	16,708	16,742
Independent/semi-independent setting	810	855	903	950	992
Community group homes	3,502	3,625	3,750	3,894	3,971
Residential centres	3,334	3,301	3,178	3,015	2,924
Other full-time services	1,237	1,255	1,334	1,381	1,356
Insufficient information*	207	237	82	75	81
Total NIDD registrations	24,917	25,518	25,613	26,023	26,066
* Includes those registered with no fixed abode					



Source: Health Research Board, National Intellectual Disability Database

Table A11.3: National Intellectual Disability Database (NIDD)
Multidisciplinary support services provided, 2005-2009

Number of supports provided	2005	2006	2007	2008	2009
Medical services	7,109	8,004	8,453	8,966	9,202
Nursing services	4,700	5,756	6,552	7,278	7,663
Nutritionist services	2,451	2,609	2,937	3,164	3,348
Occupational therapy	3,637	4,368	5,127	6,095	6,508
Physiotherapy	4,521	5,002	5,345	5,766	6,022
Psychiatry	5,888	6,188	6,130	6,639	6,728
Psychology	7,043	7,758	7,966	8,232	8,184
Social work	9,155	9,487	9,461	10,143	10,358
Speech and Language therapy	4,933	5,704	6,707	7,839	8,073
Other	4,639	5,025	5,419	5,836	6,012
Number of supports	18,399	19,152	19,799	20,971	21,223

Note: Therapeutic inputs are only recorded if the individual has received, or will receive, at least four inputs of that service in a 12-month period. The number of therapeutic inputs received exceeds the number of people since many people receive more than one input.

Source: Health Research Board, National Intellectual Disability Database

Table A11.4: National Intellectual Disability Database (NIDD)

Number of people registered on the database by age, gender and degree of intellectual disability, 2009 – National Summary

	Not verified			Mild			Moderate			Severe			Profound			Total		
	Gender			Gender			Gender			Gender			Gender			Gender		
	Female	Male	Total	Female	Male	Total	Female	Male	Total	Female	Male	Total	Female	Male	Total	Female	Male	Total
DML	279	378	657	898	1,149	2,047	1,306	1,621	2,927	375	520	895	139	176	315	2,997	3,844	6,841
DNE	119	202	321	679	925	1,604	1,007	1,161	2,168	377	457	834	67	84	151	2,249	2,829	5,078
South	240	371	611	1,075	1,481	2,556	1,111	1,563	2,674	512	622	1,134	167	179	346	3,105	4,216	7,321
West	150	214	364	1,054	1,396	2,450	1,194	1,447	2,641	474	695	1,169	87	109	196	2,959	3,861	6,820
	788	1165	1,953	3,706	4,951	8,657	4,618	5,792	10,410	1,738	2,294	4,032	460	548	1,008	11,310	14,750	26,060
	Not verified			Mild			Moderate			Severe			Profound			Total		
DML			34%			24%			28%			22%			31%			26%
DNE			16%			19%			21%			21%			15%			19%
South			31%			30%			26%			28%			34%			28%
West			19%			28%			25%			29%			19%			26%
			100%			100%			100%			100%			100%			100%

Source: Health Research Board, National Intellectual Disability Database

Table A11.5: National Physical and Sensory Disability Database (NPSDD)
Current residential services, 2005-2009

Current residential service	2005	2006	2007	2008	2009
Dedicated high support with nursing care (Older People)	47	44	41	23	20
Independent unit in a dedicated complex with low support	45	64	74	67	61
Independent unit in a dedicated complex with no support	6	11	16	18	17
Living in community in agency accommodation with agency support	44	60	65	66	63
Specialist unit (e.g. group home for people with brain injury)	24	26	24	31	32
Acute general hospital	29	32	40	32	20
District/Community hospital	46	67	67	60	56
Specialist hospital (e.g. NRH, Cappagh)	12	10	8	11	7
Mental health residential facility	19	18	17	16	17
Other	18	34	37	31	27
Living independently in community with high support (>10 hours)	0	1	1	2	2
Dedicated high support with nursing care (Intellectual Disability)	10	10	9	9	6
Living independently in community with low support	0	0	3	5	3
Living independently in community with house adapted or rehousing	0	0	1	1	1
Dedicated high support with nursing care (Physical and Sensory Disability)	39	63	69	86	77
Dedicated high support with nursing care and therapy services (Older People)	22	16	16	16	12
Dedicated high support with nursing care and therapy services (Intellectual Disability)	4	5	5	3	2
Dedicated high support with nursing care and therapy services (Physical and Sensory Disability)	160	180	181	169	160
Nursing home	92	119	148	195	228
Welfare home	12	17	15	12	11
Independent unit in a dedicated complex with high support	33	57	58	69	72
Total	662	834	895	922	894

Source: Health Research Board, National Physical and Sensory Disability Database

**Table A11.6: National Physical and Sensory Disability Database (NPSDD)
Day Service Use, 2005-2009**

Current day service use	2005	2006	2007	2008	2009
Mainstream schooling					
Mainstream baby and toddler group	154	154	156	114	82
Mainstream (without health-related services) pre-school	465	561	652	567	457
Mainstream (with dedicated class and with health-related services) pre-school	15	13	13	6	13
Mainstream (with health-related services) pre-school	46	54	70	64	65
Mainstream (with dedicated class, but without health-related) pre-school	18	11	16	16	3
Mainstream (without health related services) primary school	2,698	2,974	3,315	3,361	3,140
Mainstream (with health-related services) primary school	447	520	590	489	491
Mainstream (with dedicated class, but without health-related services) primary school	275	344	432	510	518
Mainstream (with dedicated class and with health-related services) primary school	310	328	319	233	173
Mainstream (without health-related services) secondary school	930	1,108	1,200	1,263	1,239
Mainstream (with health-related services) secondary school	83	113	132	138	174
Mainstream (with dedicated class, but without health-related services) secondary school	67	81	85	111	133
Mainstream (with dedicated class and with health-related services) secondary school	19	21	26	22	17
Specialist schooling					
Specialist (physical and sensory disability) pre-school	101	119	136	97	95
Specialist (intellectual disability) pre-school	34	42	43	21	20
Specialist (intellectual disability) residential primary school	7	5	3	1	1
Specialist (physical and sensory disability) residential primary school	16	17	16	13	10
Specialist (intellectual disability) day primary school	173	170	120	58	43
Specialist (physical and sensory disability) day primary school	270	322	321	248	233
Specialist baby and toddler group	84	110	108	37	20
Specialist (intellectual disability) residential secondary school	4	4	3	1	2
Specialist (physical and sensory disability) residential secondary school	32	37	40	27	20
Specialist (intellectual disability) day secondary school	45	47	45	32	33
Specialist (physical and sensory disability) day secondary school	81	116	134	129	123
Other schooling options					
Combined (specialist and mainstream) pre-school	12	12	15	6	8
Combined (specialist and mainstream) primary school	37	54	61	50	41
Primary school education provided at home	10	8	9	8	8
Combined (specialist and mainstream) secondary school	15	15	18	13	14
Secondary school education provided at home	7	5	5	3	3

Current day service use	2005	2006	2007	2008	2009
Third Level					
Third-level education	327	379	414	478	508
Employment/Training					
Sheltered employment	98	110	107	97	91
Supported employment	126	158	164	158	137
Sheltered work	134	169	169	145	137
Part-time open employment/self-employment	702	890	990	1,093	1,059
Full-time open employment/self-employment	1,308	1,775	2,025	1,860	1,741
Rehabilitative training	347	399	418	406	389
Vocational training	504	559	575	557	564
Activation					
Resource centre for the elderly	64	61	56	56	46
Resource centre for people with an intellectual disability	26	30	18	14	17
Resource centre for people with a physical or sensory disability	549	638	715	726	706
Social and recreational service (elderly)	77	71	59	43	40
Social and recreational service (intellectual disability)	18	19	11	12	9
Social and recreational service (physical and sensory disability)	403	461	502	632	659
Rehabilitation service (elderly)	8	8	6	6	5
Rehabilitation service (physical and sensory disability)	105	113	126	131	136
Special care unit (intellectual disability)	15	14	7	6	6
Specialised day service for people with head injuries	58	65	69	58	54
Other	281	330	333	340	313
Total	11,605	13,614	14,847	14,456	13,796

Note: An individual can have up to 3 day services recorded on the database, but only the first day service is included in this report.

Source: Health Research Board, National Physical and Sensory Disability Database

Table A11.7: National Physical and Sensory Disability Database (NPSDD)
Number of people registered by age group

	2005		2006		2007		2008		2009	
Age group	Frequency	%	Frequency	%	Frequency	%	Frequency	%	Frequency	%
0-17 years	7,039	31.4	7,807	30.4	8,373	30.8	8,546	31.3	8,043	30.7
18-34 years	3,592	16.0	4,269	16.6	4,470	16.4	4,650	17.0	4,645	17.8
35-54 years	6,297	28.1	7,266	28.3	7,567	27.8	7,384	27.0	7,054	27.0
55-65 years	5,501	24.5	6,347	24.7	6,775	24.9	6,723	24.6	6,427	24.6
Total	22,429	100.0	25,692	100.0	27,185	100.0	27,303	100.0	26,169	100.0

Source: Health Research Board, National Physical and Sensory Disability Database

Table A11.8: National Physical and Sensory Disability Database (NPSDD)
Number of people registered by type of disability

Age group	Physical disability	Hearing loss/deafness	Visual disability	Speech and/or language disability	Multiple disabilities	Refused
0-17 years	2,939	287	211	2,339	2,266	1
18-34 years	2,861	497	347	192	748	0
35-54 years	5,006	463	470	19	1,096	0
55-65 years	4,636	328	327	15	1,121	0
Total	15,442	1,575	1,355	2,565	5,231	1

Note: 'Multiple disabilities' refers to any combination of the 4 main types of disabilities recorded on the database – physical, hearing loss/deafness, visual, speech and language.

Source: Health Research Board, National Physical and Sensory Disability Database

Table A11.9: National Physical and Sensory Disability Database (NPSDD)
Number of people registered by HSE region of residence

	2005		2006		2007		2008		2009	
HSE region of residence	Frequency	%	Frequency	%	Frequency	%	Frequency	%	Frequency	%
Dublin/Mid Leinster	6,259	27.9	8,091	31.5	8,541	31.4	8,775	32.1	8,300	31.7
Dublin/North East	1,821	8.1	2,702	10.5	2,868	10.5	3,035	11.1	3,172	12.1
South	7,985	35.6	8,536	33.2	8,824	32.5	8,180	30.0	7,545	28.8
West	6,364	28.4	6,363	24.8	6,952	25.6	7,313	26.8	7,152	27.3
Total	22,429	100.0	25,692	100.0	27,185	100.0	27,303	100.0	26,169	100.0

Source: Health Research Board, National Physical and Sensory Disability Database

Table A11.10: National Physical and Sensory Disability Database (NPSDD)
Summary of levels of participation and service users' views on extent of participation

For those in part-time employment who completed Measure of Activity and Participation section of database form (n=759)					
Extent of Participation restriction in employment and job seeking			Extent that restriction bothered them		
	Frequency	%		Frequency	%
Refused	3	0.4	Not at all	31	4.1
Not applicable	92	12.1	A little	128	16.9
Not at all	284	37.4	A lot	221	29.1
Mildly	98	12.9	No response	376	49.5
Moderately	112	14.8	Refused	3	0.4
Severely	128	16.9	Total	759	100.0
Completely	42	5.5			
Total	759	100.0			
For those in full-time employment who completed Measure of Activity and Participation section of database form (n=1,223)					
Extent of Participation restriction in employment and job seeking			Extent that restriction bothered them		
	Frequency	%		Frequency	%
Refused	6	0.5	Not at all	20	1.6
Not applicable	183	15.0	A little	138	11.3
Not at all	718	58.7	A lot	157	12.8
Mildly	109	8.9	No response	898	73.4
Moderately	116	9.5	Refused	10	0.8
Severely	69	5.6	Total	1,223	100.0
Completely	22	1.8			
Total	1,223	100.0			
For those not in part-time employment who completed Measure of Activity and Participation section of database form (n=10,606)					
Extent of Participation restriction in employment and job seeking			Extent that restriction bothered them		
	Frequency	%		Frequency	%
Refused	126	1.2	Not at all	396	3.7
Not applicable	3,536	33.3	A little	1,227	11.6
Not at all	2,173	20.5	A lot	3,099	29.2
Mildly	484	4.6	No response	5,693	53.7
Moderately	749	7.1	Refused	191	1.8
Severely	1,357	12.8	Total	10,606	100.0
Completely	2,181	20.6			
Total	10,606	100.0			

For those not in full-time employment who completed Measure of Activity and Participation section of database form (n=10,142)					
Extent of Participation restriction in employment and job seeking			Extent that restriction bothered them		
	Frequency	%		Frequency	%
Refused	123	1.2	Not at all	407	4.0
Not applicable	3,445	34.0	A little	1,217	12.0
Not at all	1,739	17.1	A lot	3,163	31.2
Mildly	473	4.7	No response	5,171	51.0
Moderately	745	7.3	Refused	184	1.8
Severely	1,416	14.0	Total	10,142	100.0
Completely	2,201	21.7			
Total	10,142	100.0			
For those in mainstream education who completed Measure of Activity and Participation section of database form (n=326)					
Extent of Participation restriction in education and training			Extent that restriction bothered them		
	Frequency	%		Frequency	%
Refused	18	5.5	Not at all	11	3.4
Not applicable	24	7.4	A little	84	25.8
Not at all	140	42.9	A lot	47	14.4
Mildly	63	19.3	No response	164	50.3
Moderately	49	15.0	Refused	20	6.1
Severely	26	8.0	Total	326	100.0
Completely	6	1.8			
Total	326	100.0			
For those in special education who completed Measure of Activity and Participation section of database form (n=59)					
Extent of Participation restriction in education and training			Extent that restriction bothered them		
	Frequency	%		Frequency	%
Refused	2	3.4	Not at all	9	15.3
Not applicable	3	5.1	A little	8	13.6
Not at all	20	33.9	A lot	17	28.8
Mildly	2	3.4	No response	23	39.0
Moderately	15	25.4	Refused	2	3.4
Severely	10	16.9	Total	59	100.0
Completely	7	11.9			
Total	59	100.0			

Source: Health Research Board, National Physical and Sensory Disability Database

Table A11.11: Disability Services Programme
WTE staff employed in HSE and Section 38 agencies by HSE region

	Dec 2005	Dec 2006	Dec 2007	Dec 2008	Dec 2009	Nov 2010
Dublin Mid-Leinster	3,553.30	3,770.41	4,291.66	4,571.68	4,593.57	4,463.55
Dublin North-East	3,417.94	3,513.92	4,268.89	4,448.78	4,368.25	4,272.69
South	2,417.10	2,625.95	2,758.43	2,866.07	3,102.42	3,180.26
West	3,537.63	3,767.38	4,059.53	4,159.41	4,103.89	3,883.03
Total	12,925.97	13,677.66	15,378.51	16,045.94	16,168.13	15,799.53
Medical/Dental	13.71	16.66	61.7	60.58	62.78	60.55
Nursing	780.33	865.38	934.55	1,031.10	1,017.19	1,019.56
Health & Social Care Professionals	597.9	691.32	874.41	934.86	988.45	940.31
Management/Admin	301.15	320.98	400.07	423.41	398.24	387.29
General Support Staff	320.3	334.93	366.88	372.02	347.72	368.12
Other Patient & Client Care	1,539.91	1,541.14	1,654.05	1,749.71	1,779.19	1,687.72
Dublin Mid-Leinster	3,553.30	3,770.41	4,291.66	4,571.68	4,593.57	4,463.55
Medical/Dental	23.73	23.21	28.83	29.1	27.77	28.2
Nursing	905.09	930.42	1,250.86	1,248.59	1,233.45	1,269.25
Health & Social Care Professionals	752.7	794.86	852.03	898.06	897.75	904.33
Management/Admin	347.42	354.65	385.71	402.66	371.39	355.18
General Support Staff	418.07	415.43	445.7	454.75	451.48	429.16
Other Patient & Client Care	970.93	995.35	1,305.76	1,415.62	1,386.41	1,286.57
Dublin North-East	3,417.94	3,513.92	4,268.89	4,448.78	4,368.25	4,272.69
Medical/Dental	15.82	17.4	17.08	16.5	16.53	17.15
Nursing	596.5	612.88	641.79	633.34	677.6	715.15
Health & Social Care Professionals	445.58	474.17	502.75	531.74	564.49	581.65
Management/Admin	187.37	199	188.61	191.24	238.53	231.81
General Support Staff	257.33	267.39	280.91	269.24	265.08	263.4
Other Patient & Client Care	914.5	1,055.11	1,127.29	1,224.01	1,340.19	1,371.10
South	2,417.10	2,625.95	2,758.43	2,866.07	3,102.42	3,180.26
Medical/Dental	21.76	27.42	28.82	29.01	28.02	18.61
Nursing	1,019.10	1,085.68	1,161.23	1,153.33	1,166.70	1,171.04
Health & Social Care Professionals	608.7	645.89	669.11	710.3	703.01	555.77
Management/Admin	314.94	330.3	340.91	343.71	314.12	249.29
General Support Staff	307.44	291.03	294.55	297.29	286.94	265.61
Other Patient & Client Care	1,265.69	1,387.06	1,564.91	1,625.77	1,605.10	1,622.71
West	3,537.63	3,767.38	4,059.53	4,159.41	4,103.89	3,883.03
Total WTE	12,925.97	13,677.66	15,378.51	16,045.94	16,168.13	15,799.53

Source: HSE

Table A11.12: Disability Services Programme
WTE staff employed in HSE and Section 38 agencies by agency type (statutory/non-statutory)

	Dec 2005	Dec 2006	Dec 2007	Dec 2008	Dec 2009	Nov 2010
Health Service Executive	2,083.82	2,206.17	2,898.25	3,099.08	3,343.02	3,282.47
Voluntary Agencies P&C Services	10,842.15	11,471.49	12,480.26	12,946.86	12,825.11	12,517.06
Total	12,925.97	13,677.66	15,378.51	16,045.94	16,168.13	15,799.53
Health Service Executive	361.14	399.61	402.29	527.76	566.25	545.98
Voluntary Agencies P&C Services	3,192.16	3,370.80	3,889.37	4,043.92	4,027.32	3,917.57
Dublin Mid Leinster	3,553.30	3,770.41	4,291.66	4,571.68	4,593.57	4,463.55
Health Service Executive	542.77	548.85	1,110.18	1,181.28	1,152.35	1,197.11
Voluntary Agencies P&C Services	2,875.17	2,965.07	3,158.71	3,267.50	3,215.90	3,075.58
Dublin North East	3,417.94	3,513.92	4,268.89	4,448.78	4,368.25	4,272.69
Health Service Executive	114.88	124.58	148.66	150.97	364.68	417.08
Voluntary Agencies P&C Services	2,302.22	2,501.37	2,609.77	2,715.10	2,737.74	2,763.18
South	2,417.10	2,625.95	2,758.43	2,866.07	3,102.42	3,180.26
Health Service Executive	1,065.03	1,133.13	1,237.12	1,239.07	1,259.74	1,122.30
Voluntary Agencies P&C Services	2,472.60	2,634.25	2,822.41	2,920.34	2,844.15	2,760.73
West	3,537.63	3,767.38	4,059.53	4,159.41	4,103.89	3,883.03
Total WTE	12,925.97	13,677.66	15,378.51	16,045.94	16,168.13	15,799.53

Source: HSE

A11.13 Distribution of staff in section 38 and section 39 agencies by staff type - 2009

Staff type – 2009	Section 38	Section 39
	%	%
Nursing	24	15
Medical & Dental	0	0
Health & Social Care Professionals	24	26
Management / Admin / Clerical	8	10
Support Services	37	45
Other Patient & Client Care	7	3
Total	100	100

Note: Some of the differences in staffing categories may be due to coding differences across staffing types.

Source: Non pay questionnaires issued for purposes of review

A11.14 Service Level Arrangement Pay Data, by Agency Type and Programme Type

Programme Type	HSE			S.38			S.39			All service providers		
	Total Staff	Total No. of Places	Total Pay Costs	Total Staff	Total No. of Places	Total Pay Costs	Total Staff	Total No. of Places	Total Pay Costs	Total Staff	Total No. of Places	Total Pay Costs
ALS/PA - P&S	72	702	€ 1,425,631	5	100	€ 197,777	851	2,461	€ 33,465,313	927	3,263	€ 35,088,722
Day	435	1,925	€ 19,012,507	3,035	10,317	€ 145,092,498	1,546	7,253	€ 68,372,752	5,015	19,495	€ 232,477,757
Management / Admin.	345	2,610	€ 16,376,053	1,065	32	€ 66,585,847	486	5,922	€ 28,776,492	1,896	8,564	€ 111,738,392
Multi Disciplinary Supports	708	29,628	€ 38,663,405	783	32,151	€ 56,535,131	592	25,851	€ 34,784,622	2,083	87,629	€ 129,983,158
Other	188	2,150	€ 7,509,144	1,544	3,413	€ 77,079,002	292	14,638	€ 12,970,220	2,024	20,200	€ 97,558,366
Residential	2,130	1,519	€ 95,931,206	6,196	5,484	€ 344,823,591	2,199	1,787	€ 107,658,192	10,525	8,790	€ 548,412,990
Residential centre based respite	155	902	€ 8,213,747	393	2,175	€ 21,539,407	470	4,899	€ 22,608,128	1,019	7,976	€ 52,361,282
Respite support hours ID	118	649	€ 3,934,529	118	1,102	€ 6,155,080	145	1,282	€ 6,830,582	381	3,033	€ 16,920,191
Grand Total	4,150	40,086	€ 191,066,223	13,138	54,773	€ 718,008,333	6,581	64,092	€ 15,466,302	23,869	158,950	€ 1,224,540,858

NOTE – A place may be full-time or part-time. The number of places does not equate to the number of individuals who are receiving a service. One person may avail of more than one service place or service type. An individual may attend a day activation service for part of the week and a work-related activity for the remainder. He or she may also be receipt of respite support, or a full-time residential placement, or multi-disciplinary support. Each of these service places would be counted separately in the above table.

Source: SLA Schedule 3 data (analysis by DoH Information Unit)

A11.15 Service Level Arrangement Pay Data, by Staff Category and Programme Type

Agency	Staff Category	Programme Type					Programme Type					Grand Total
		ALS/PA - P&S	Day	Management / administration	Multi Disiplinary Supports	Other	Residential	Res centre based respite	Respite support hours ID			
HSE	Admin	€ 39,569	€ 1,381,339	€ 11,072,858	€ 2,436,174	€ 964,245	€ 968,530	€ 11,151	€ 52,065	€ 16,925,931		
	Medical	€ -	€ -	€ 130,997	€ 2,163,810	€ 123,336	€ 625,549	€ -	€ -	€ 3,043,691		
	Nursing	€ -	€ 4,715,421	€ 3,178,085	€ 3,958,436	€ 454,357	€ 51,561,511	€ 4,715,362	€ 672,532	€ 69,255,705		
	Health &Social Care	€ -	€ 539,769	€ 747,760	€ 28,841,547	€ 70,457	€ 616,321	€ 394,992	€ -	€ 31,210,845		
	Support	€ 1,386,062	€ 12,375,977	€ 1,246,353	€ 1,263,439	€ 5,896,750	€ 42,435,295	€ 3,092,241	€ 3,209,933	€ 70,906,051		
	Total	€ 1,425,631	€ 19,012,507	€ 16,376,053	€ 38,663,405	€ 7,509,144	€ 95,931,206	€ 8,213,747	€ 3,934,529	€ 191,066,223		
S.38	Admin	€ -	€ 4,194,570	€ 46,704,395	€ 3,207,257	€ 5,796,457	€ 683,227	€ -	€ 150,197	€ 60,736,103		
	Medical	€ -	€ -	€ 1,356,776	€ 4,496,810	€ 3,262,289	€ 157,359	€ 6,353	€ -	€ 9,279,586		
	Nursing	€ 65,974	€ 26,703,596	€ 8,812,303	€ 3,290,983	€ 14,435,214	€ 134,382,945	€ 10,020,251	€ 2,043,388	€ 199,754,653		
	Health &Social Care	€ -	€ 7,990,968	€ 4,997,977	€ 43,363,450	€ 13,137,983	€ 105,413,877	€ 5,579,471	€ 2,570,943	€ 183,054,669		
	Support	€ 131,803	€ 106,203,364	€ 4,714,396	€ 2,176,631	€ 40,447,059	€ 104,186,183	€ 5,933,332	€ 1,390,552	€ 265,183,321		
	Total	€ 197,777	€ 145,092,498	€ 66,585,847	€ 56,535,131	€ 77,079,002	€ 344,823,591	€ 21,539,407	€ 6,155,080	€ 718,008,333		
S.39	Admin	€ 3,003,214	€ 7,142,151	€ 24,869,287	€ 3,640,633	€ 3,293,061	€ 5,761,901	€ 1,228,657	€ 1,785,557	€ 50,724,461		
	Medical	€ -	€ 75,612	€ 131,061	€ 187,549	€ -	€ 29,622	€ -	€ -	€ 423,844		
	Nursing	€ 67,889	€ 6,102,039	€ 317,914	€ 1,349,206	€ 568,932	€ 8,241,216	€ 3,668,296	€ 560,645	€ 20,876,138		
	Health &Social Care	€ 374,704	€ 10,108,202	€ 2,397,340	€ 25,656,197	€ 2,680,960	€ 46,048,421	€ 9,189,173	€ 723,849	€ 97,178,847		
	Support	€ 30,019,507	€ 45,047,297	€ 1,060,890	€ 3,951,037	€ 6,427,266	€ 47,577,032	€ 8,522,001	€ 3,760,530	€ 146,365,560		
	Total	€ 33,465,313	€ 68,372,752	€ 28,776,492	€ 34,784,622	€ 12,970,220	€ 107,658,192	€ 22,608,128	€ 6,830,582	€ 315,466,302		

Agency	Staff Category	Programme Type								Grand Total
		ALS/PA - P&S	Day	Management / administration	Multi Disiplinary Supports	Other	Residential	Res.centre based respite	Respite support hours ID	
Total Pay Costs – Admin		€ 3,042,783	€ 12,718,060	€ 82,646,541	€ 9,284,063	€ 10,053,763	€ 7,413,658	€ 1,239,808	€ 1,987,819	€ 128,386,496
Total Pay Costs – Medical		€ -	€ 75,612	€ 1,618,833	€ 6,848,169	€ 3,385,625	€ 812,529	€ 6,353	€ -	€ 12,747,121
Total Pay Costs – Nursing		€ 133,863	€ 37,521,056	€ 12,308,302	€ 8,598,625	€ 15,458,503	€ 194,185,672	€ 18,403,910	€ 3,276,566	€ 289,886,497
Total Pay Costs – H&S.Care		€ 374,704	€ 18,638,938	€ 8,143,076	€ 97,861,194	€ 15,889,400	€ 152,078,620	€ 15,163,637	€ 3,294,792	€ 311,444,361
Total Pay Costs – Support		€ 31,537,372	€ 163,626,638	€ 7,021,640	€ 7,391,107	€ 52,771,075	€ 194,198,510	€ 17,547,575	€ 8,361,014	€ 482,454,931
Total Pay Costs		€ 35,088,722	€ 232,477,757	€ 111,738,392	€ 129,983,158	€ 97,558,366	€ 548,412,990	€ 52,361,282	€ 16,920,191	€ 1,224,540,858
Agency	Staff Category	Programme Type								Grand Total
		ALS/PA - P&S	Day	Management / administration	Multi Disiplinary Supports	Other	Residential	Res.centre based respite	Respite support hours ID	
Total Pay Costs - Admin		0.25%	1.04%	6.75%	0.76%	0.82%	0.61%	0.10%	0.16%	10.48%
Total Pay Costs – Medical		0.00%	0.01%	0.13%	0.56%	0.28%	0.07%	0.00%	0.00%	1.04%
Total Pay Costs – Nursing		0.01%	3.06%	1.01%	0.70%	1.26%	15.86%	1.50%	0.27%	23.67%
Total Pay Costs - H&S.Care		0.03%	1.52%	0.66%	7.99%	1.30%	12.42%	1.24%	0.27%	25.43%
Total Pay Costs – Support		2.58%	13.36%	0.57%	0.60%	4.31%	15.86%	1.43%	0.68%	39.40%
Total Pay Costs		2.87%	18.98%	9.12%	10.61%	7.97%	44.79%	4.28%	1.38%	100.00%

Source: SLA Schedule 3 data (analysis by DoH Information Unit)

A11.16 Total Service Places by Region, Disability Group and Programme Type

Region	Disability Group	Programme Type							
		Residential	Day	Res. centre based respite	Respite support hours ID	ALS/PA - P&S	Multi Disiplinary Supports	Other	Total
Dublin Mid-Leinster Total	Autism only	80	64	64	2	0	249	267	726
	ID	1,419	3,032	387	370	1	3,197	853	9,259
	ID & Autism	91	187	200	0	0	249	216	943
	ID & P&S	12	272	25	5	9	0	76	399
	ID, P&S, Autism	10	150	0	0	0	276	0	436
	Multi	576	1,310	243	157	33	6,923	1,409	10,650
	P&S	332	584	578	0	692	4,066	5,527	11,779
	Total	2,520	5,599	1,497	534	735	14,960	8,348	34,191
Dublin North East Total	Autism only	18	0	0	0	0	314	0	332
	ID	1,240	2,673	1,009	756	0	1,973	321	7,972
	ID & Autism	11	249	0	46	0	290	2	597
	ID & P&S	379	0	5	18	20	322	421	1,165
	ID, P&S, Autism	25	130	110	0	0	0	0	265
	Multi	42	360	89	164	14	4,338	422	5,429
	P&S	163	808	931	0	349	16,304	7,757	26,312
	Total	1,878	4,220	2,144	984	383	23,541	8,923	42,072
South Total	Autism only	37	48	0	0	0	166	0	251
	ID	1,087	2,302	357	58	0	5,723	19	9,546
	ID & Autism	187	562	243	211	0	6,702	1	7,906
	ID & P&S	133	243	64	0	0	379	138	957
	ID, P&S, Autism	8	151	0	0	0	799	0	958
	Multi	215	444	322	0	0	741	2	1,724
	P&S	60	119	1,003	0	300	666	78	2,226
	Total	1,727	3,869	1,989	269	300	15,176	238	23,568
West Total	Autism only	1	0	14	0	0	403	146	564
	ID	1,336	1,637	385	262	0	3,628	863	8,111
	ID & Autism	545	863	631	153	0	5,318	1,856	9,366
	ID & P&S	61	230	5	0	153	797	20	1,266
	ID, P&S, Autism	151	573	82	564	0	3,620	2,275	7,264
	Multi	80	1,045	73	136	0	6,612	1,913	9,859
	P&S	162	1,057	939	0	1,450	7,408	2,094	13,110
	Total	2,336	5,405	2,129	1,115	1,603	27,786	9,167	49,541

Region	Disability Group	Programme Type							
		Resid- ential	Day	Res. centre based respite	Respite support hours ID	ALS/PA - P&S	Multi Disiplin- ary Supports	Other	Total
	Autism only	136	112	78	2	0	1,132	413	1,873
	ID	5,082	9,644	2,138	1,446	1	14,521	2,056	34,888
	ID &Autism	834	1,861	1,074	410	0	12,559	2,075	18,812
	ID &P&S	585	745	99	23	182	1,498	655	3,787
	ID, P&S, Autism	194	1,004	192	564	0	4,695	2,275	8,923
	Multi	913	3,159	727	457	47	18,614	3,746	27,662
	P&S	717	2,568	3,451	0	2,791	28,444	15,456	53,427
	Total	8,461	19,093	7,759	2,902	3,021	81,463	26,676	149,372

NOTE - A place may be full-time or part-time.
The number of places does not equate to the number of individuals who are receiving a service. One person may avail of more than one service place or service type. An individual may attend a day activation service for part of the week and a work-related activity for the remainder. He or she may also be receipt of respite support, or a full-time residential placement , or multi-disciplinary support. Each of these service places would be counted separately in the above table.

Source: SLA Schedule 3 data (analysis by DoH Information Unit)

APPENDIX 12

COMPLAINTS MECHANISMS

STATUTORY COMPLAINTS SYSTEM

Part 9 of the Health Act 2004, which came into effect on 1 January 2007, established a new structure for making and processing complaints in respect of the operations of the HSE and non-statutory service providers. A review procedure was also established. Under the new structure, any person who is, or has been, a service user of a health or personal social service provided by the HSE or a non-statutory service provider may make a complaint to the HSE. Anyone who is seeking or has sought the provision of such services may also make a complaint. There is a 12-month time limit, running from the time of the cause of complaint, for the making of a complaint.

Complaints may only relate to actions concerning *fair and sound administration* and the person concerned must have been adversely affected by the action giving rise to the complaint. Certain matters are excluded from the complaints process, such as matters that are the subject of legal proceedings or matters relating to the exercise of clinical judgment, the consequent action taken by the HSE or a non-statutory service provider on foot of such clinical judgment or where a complaint was previously brought to another body.

COMPLAINTS PROCEDURES UNDER PART 9 OF THE 2004 ACT

Procedural requirements for the making of complaints in respect of *fair and sound administration* were established in secondary legislation by the Health Act 2004 (Complaints) Regulations 2006. The Regulations include guidance on the appointment of Complaints Officers, the investigation of complaints, the making of requests for review of investigation outcomes and the undertaking of reviews.

The HSE's administrative complaints procedure has 4 stages:

- local resolution of verbal complaints;
- local investigation of complaints by the HSE or the non-statutory service provider, as appropriate;
- HSE internal review;
- independent review by the Ombudsman or the Ombudsman for Children, where relevant.

COMPLAINTS PROCEDURES UNDER PART 2 OF THE DISABILITY ACT 2005

Part 2 of the Disability Act 2005 provides a statutory entitlement to:

- an independent assessment of health and educational needs;
- a statement of the services (Service Statement) which it is proposed to provide; and
- the right to pursue a complaint through an independent redress mechanism if there is a failure to provide these entitlements.

Grounds for complaint are:

- Type 1: Person does not have a disability.
- Type 2: Assessment not commenced on time or completed without undue delay.
- Type 3: Assessment not conducted in manner conforming to standards.
- Type 4: Contents of Service Statement.
- Type 5: Failure to provide a service specified in service statement.

Part 3 Complaints:

The grounds available to complain under this part of the Act are:

- Section 25: Access to Public Buildings
- Section 26: Access to Services
- Section 27: Accessibility of Services supplied to a public body
- Section 28: Access to Information
- Section 29: Access to Heritage Sites.

Since taking responsibility for Complaints under Part 3 of the Disability Act, the Disability Complaints Officers have received 4 complaints.

CLINICAL INDEMNITY SCHEME

All clinical claims arising from the diagnosis, treatment and care of patients in publicly funded health services, including disability agencies, are handled by the Clinical Indemnity Scheme (CIS) operated by the State Claims Agency. In addition to the management of clinical claims, the Agency also has responsibility for advising and assisting enterprises in the adoption of effective clinical risk management procedures, risk reduction strategies and dissemination of best practice in patient care and safety. A key feature of the CIS is electronic incident reporting to a national database (STARsweb) maintained by the State Claims Agency, which holds records of adverse clinical incidents and 'near-misses'. Categories used to record incidents and near-misses in respect of disability agencies include: medication incident; treatment incident; consent/confidentiality incident; infection control incident; equipment/device incident; records/documentation incident; absconson; self-harm; slips/trips/falls; unplanned events; violence/harassment/aggression; other.

Details on the CIS website show a total of 6,751 incidents in 2008.* The most commonly reported incident was violence/harassment/aggression, which accounted for 2,832 incidents or 43% of the total; incidences of slips/trips/falls came to 1,785 (26%); complaints categorised as 'other' totalled 557 (8%); self-harm totalled 548 (8%); and unplanned events came to 418 (6%). The remaining incidents totalled 611 (9%).

OTHER COMPLAINTS

Complaints that are not about fair and sound administration do not come within the remit of the statutory complaints system established under Part 9 of the 2004 Act. Complaints concerning allegations of abuse against HSE staff members, for example, are managed under a separate HSE policy framework. Under that framework, the HSE is obliged to conduct an internal investigation into all allegations of abuse. Again, according to its own policy, where reasonable grounds are found for suspecting that an offence has been committed by a staff member of the HSE, the matter must be reported by the HSE to the Gardaí. This is in addition to any remedies a person may have under the civil law.

The Project Team was unable to source any data from the HSE regarding the number or nature of general complaints made in respect of its own services or the services provided on its behalf.

* See <http://www.stateclaims.ie/ClinicalIndemnityScheme/publications/2010/BalancingRiskSeizingOpportunities.pdf> (accessed June 2012)

APPENDIX 13

SPECIALIST DISABILITY SERVICE PROVIDERS FUNDED UNDER SECTION 38 OF THE HEALTH ACT 2004

Brothers of Charity Services

Central Remedial Clinic (CRC)

Cheeverstown House

Children's Sunshine Home

Cope Foundation

Daughters of Charity – Intellectual Disability Services

Sisters of Charity – Kilkenny

KARE

National Rehabilitation Hospital

Peamount

Sisters of Charity of Jesus and Mary

Wisdom Services (*formerly known as Sisters of La Sagesse Services, Cregg House*)

Carriglea Cairdre Services (*formerly known as Sisters of the Bon Sauveur*)

St. John of God Hospitaller Services

St. Michael's House

Stewarts' Hospital Services

Sunbeam House Services

APPENDIX 14

SPECIALIST DISABILITY SERVICE PROVIDERS* FUNDED UNDER SECTION 39 OF THE HEALTH ACT 2004 (INCLUDES AGENCIES WITH SERVICE LEVEL ARRANGEMENTS ONLY I.E. IN RECEIPT OF FUNDING IN EXCESS OF €250,000)

Ability West

Acquired Brain Injury Ireland

Advocates for Personal Potential (APP)

Anne Sullivan Foundation for Deaf/Blind

Ard Aoibhinn Centre

Ardee Day Centre

Aspire (The Asperger Syndrome Association of Ireland)

Autism Initiatives

Autism West

Avalon Centre

Ballyfermot Home Help

Barrow Valley Enterprises for Adult Members with Special Needs (BEAM)

Brainwave (The Irish Epilepsy Association)

Carrickmacross Parents & Friends of the Mentally Handicapped – Steadfast House

Catholic Institute for Deaf People (CIDP)

Centre for Independent Living (CIL) – Cork

Centre for Independent Living (CIL) – Donegal

Centre for Independent Living (CIL) – Galway

Centre for Independent Living (CIL) – Laois/Offaly

Centre for Independent Living (CIL) – Longford

Centre for Independent Living (CIL) – Mayo

Centre for Independent Living (CIL) – Sligo

Centre for Independent Living (CIL) – Tipperary

Centre for Independent Living (CIL) – West Limerick

Centre for Independent Living (CIL) – Westmeath

Cheshire Ireland

Clann Mór

Clones Branch of Mentally Handicapped – Cairde

CLR Home Help

Cluain Training & Enterprise Centre

Co Action West Cork

Cork Association for Autism

County Roscommon Disability Support Group Ltd.

County Wexford Community Workshop Ltd. (CWCW)

Dara Residential Services

DeafHear

Delta Centre

Disability Federation of Ireland

Dochas (Hope for People with Autism)

Drumlin House Training Centre

Enable Ireland

Festina Lente Foundation

Gheel Autism Services

Headway (Ireland) Ltd – The National Association for Acquired Brain Injury

Holy Angels Day Care Centre

Inclusion Ireland

Irish Association for Spina Bifida and Hydrocephalus (IASBAH)

Irish Guidedogs for the Blind

Irish Kidney Association

Irish Society for Autism

Irish Wheelchair Association (IWA)

Kerry Parents & Friends Association

Kilkenny Association for Severely Mentally Handicapped Adults (KASMHA House)

Lakers Social & Recreational Club Limited

L'Arche Ireland

Lorrequer House Home for the Handicapped

Midway (Meath Intellectual Disability Work for Advocacy for You) Ltd.

Molyneux Home for the Blind

MS Ireland (The Multiple Sclerosis Society of Ireland)

Muscular Dystrophy Ireland

National Association of Housing for Visually Impaired

National Council for the Blind of Ireland (NCBI)
National Federation of Voluntary Bodies
National Learning Network Ltd.
North Tipperary Disability Support Services Ltd.
North West Parents & Friends
Open Door Day Care Centre
Order of Malta Ireland
Peacehaven Trust Ltd.
Persons with Disabilities in Ireland
Post Polio Support Group Ireland
Praxis Care
Prosper Fingal
Quest Brain Injury
Rehabcare
RK Respite Services Ltd.
SOS Kilkenny Ltd.
Simon Community – Dundalk
Spinal Injuries Ireland
St. Mary's Centre (Telford) Limited
St. Catherine's Association Limited
St. Christopher's Services Ltd.
St. Cronan's Association Limited
St. Gabriel's Centre
St. Hilda's Service for the Mentally Handicapped
St. Joseph's Foundation
St. Joseph's School for the Visually Impaired
St. Margaret's Centre
St. Paul's Hospital & Special School
Walkinstown Association
Waterford Intellectual Disability Association (WIDA)
Western Care Association