National Economic Social Forum NESF

Implementation of the Home Care Package Scheme

Report 38 · September 2009

National Economic & Social Development Office **NESDO**

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Glossary

Care Needs Assessment: This is a process used to assess the needs of a person for care. Typically such a process asks questions about the physical and psychological health of the individual, and their ability to carry out activities of daily living.

Case Management: Case management is the development of individually tailored care plans, with a person-centred and multi-disciplinary focus, and delivered through a case manager or a team.

Co-payment: Principle of cost-sharing between the State and individuals, to fund their care.

Developmental Welfare State (DWS): The Developmental Welfare State report (NESC, 2005) sets out the policy framework for the development of an effective and world-class set of institutions and policies in the social sphere in Ireland. One of the central themes in the DWS is the development of citizen-centred services.

Expert Advisory Group (EAG): Services for Older People Expert Advisory Group (EAG) is an advisory group set up under the PCCC division of the HSE.

EAG Standards Guidelines: Refers to the Draft National Quality Guidelines for Home Care Support Services developed by an interagency group set up by the EAG (HSE Expert Advisory Group); comprised of the HSE, voluntary providers, private providers, groups representing older people, and hospital staff. These guidelines cover standards in home care provision (which would apply to home help and home care aspects of HCPs, but not medical care aspects).

Home Care Packages (HCPs): Home Care Packages provide care in the home, mainly for older people, who are at risk of admission to long-term care. Each package provides care to meet the needs of a particular patient, and can include home help, personal care, nursing and various therapies.

HIQA: The Health Information and Quality Authority, which was established to ensure quality standards in the provision of health and social care services.

Home Help Service: This service offers domestic help including light domestic work, shopping and cooking.

Long-Term Care Report (LTC report): Report of the Long-Term Care Working Group (2005) on the long-term care of persons aged over 65, which recommended that a central principle of policy going forward should be to support older people to remain in the community.

LHO: A HSE Local Health Office – the HSE is divided into 32 LHOs.

Long-Term care (LTC): A range of services needed for persons who are dependent on help with basic activities of daily living. It includes both residential care and care in the home.

Mentors: An individual or group of individuals who transmit effective policy implementation practices from one location to another.

OECD Review: *Public Management Review – Ireland: Towards an Integrated Public Service* (OECD, 2008) is a review commissioned by the Irish Government from the OECD to analyze the success of and challenges to the Irish public service.

Outcomes-Oriented approach: The framework for analysis of policy implementation outlined in the OECD review of the Irish public service. It means developing and implementing policy by focusing on the outcomes to be achieved (such as the number of older people who will live at home), rather than the inputs to this (such as the funding allocated).

Personal Care: Personal care needs include showering, bathing, dressing etc.

PCCC Working Group Guidelines: Guidelines on the implementation of the HCP policy, developed by the PCCC (Primary Community and Continuing Care) working group established by the PCCC directorate of the HSE in 2006.

PCT (Primary Care Team): The HSE is putting in place a Primary Care Strategy, which envisages teams of primary care workers (nurses, therapists etc) working with GPs to provide primary care services to the local community.

QPS: *Improving Delivery of Quality Public Services*, a report published by the NESF in 2006.

Tailored Universalism: Refers to the provision of services adjusted to an individual's needs/capabilities but also taking into account the capacity of their family and community to address their needs.



Preface by Dr. Maureen Gaffney

In 2008, the National Economic and Social Forum (NESF) was given a renewed mandate by the Government and asked to focus strongly on the Irish experience of policy implementation. At the Inaugural Plenary Session of the NESF in May of that year, I set out how we were going to approach this work¹. This present report is the first of a suite of four major reports focusing on this implementation agenda. A second report (on *Child Literacy and Social Inclusion*) will be published very shortly. The third report (*Community Participation in the Delivery of Public Services*) will follow. The final report which focuses on a prospective study of a major policy initiative – *County Louth: Ireland's First Age Friendly Strategy* – will track the implementation of this Strategy over a two-year period.

Over the past decade Ireland has been a remarkably innovative and entrepreneurial environment for policy-making. Like many other countries, we have struggled with the challenges of policy implementation - incomplete and patchy, undesirable and unintended consequences of implementation, or outright failure in implementation.

When we set out to study implementation, we identified many factors found to be central to success. These included the structural or *'hygiene'* aspects of the policy to be investigated such as:

- Clarity of policy objectives and desired outcomes, priorities, targets, design, costings and management all the way to and through implementation stage;
- The extent to which implementation issues delivery plans, timescales, milestones, project management, clear deliverables – were built into the policy design stage;

- The nature of the resources available for policy implementation, including the nature of the funding, the capacity of staff to deliver, the clear definition of roles and the time allocated to staff for delivery;
- To what extent the issue of accountability at every level in the system was clarified, monitored and enforced;
- How implementation success and failure is rewarded and sanctioned;
- Particularly in relation to cross-cutting issues, the extent to which all major stakeholders were involved in the design and implementation of the project, the quality of their consensus and communication;
- The nature of the relationships among internal stakeholders and their relationship to their counterparts in other related agencies;
- The nature of the service integration within the project and the processes that enable or impede that integration;
- The presence or absence of leadership and 'policy champions' at political, executive and agency level;
- The extent to which issues of central control and local autonomy were discussed and agreed before and throughout implementation;
- The quality of the information flow, general communication and coordination among the stakeholders;
- The impact of the policy, including its effectiveness in achieving the desired outcomes, as well as any unintended consequences;
- The quality of the internal and independent monitoring structures and mechanisms and performance indicators; and
- The adequacy and availability of monitoring data and the extent to which it is disseminated and used to modify the policy or its delivery.

We also identified the 'softer' but equally crucial aspects of implementation:

- Organisational culture;
- Organisational learning capabilities; and
- How policies are 'framed' and internalised by those responsible for implementing them. Particularly important is how they think about risk and accountability and how they frame their own role and the role of others involved in the process: important or incidental? Defensive or interdependent? Self-protective or open to learn?

It is remarkable how these factors have surfaced as critical in our analysis of how the Home Care Package (HCP) Scheme was implemented. I was particularly struck by our finding that, at an early stage, this was in many respects a well-thought out policy. Before the Scheme was launched, it was recognised that success of the policy depended on, among other things, a national standard approach, with clear criteria in terms of access, quality standards and availability; a standardised needs assessment framework; a national standard financial assessment framework and formal protocols for case management.

National guidelines on many of these issues were developed in early 2006, and covered the funding to be allocated under each HCP; means tests, care needs assessment, consultation and co-ordination with the older person and existing services; the mix of organisations to be involved in delivery; the collection of data, and monitoring and review based on that data. However, the present NESF study found that these guidelines have not yet been put into operation – despite the fact that the Scheme was introduced in 2006 and by the following year approximately 8,000 packages were being delivered.

In October 2008, a high level advisory group approved Draft National Quality Guidelines for Home Care Support Services, including rights, protection, home care support needs, staffing, governance and management issues. These guidelines still need to be progressed through several more stages before being implemented. Our report found that the delay in agreeing and implementing standardised procedures to be partly due to the high number of structures involved in making decisions, slowing the process down. Yet, at the same time, local level policy implementers have not been involved in all of these discussions, and neither have service users in any significant way.

In many ways, the Home Care Support Scheme is a success story and many older people in receipt of the packages are very happy with them. Inevitably, however, the lacunae in the implementation process have created a number of systemic problems that are clearly documented in this report. For example:

 In the absence of a standardised national approach, each Local Health Office (LHO) delivers the Scheme differently. There are significant variations by LHO in the eligibility criteria used to allocate HCP funding.

- The absence of co-ordinated procedures leads to inconsistencies, inequities and duplication of work. Double or even triple assessments of the care needs of an older person are often carried out - e.g. by medical staff in hospital, by the HSE community staff co-ordinating HCPs, and by the organisation appointed to provide the care. Similarly, double or triple means-testing of an older person can also occur, e.g. for home help services, for HCPs, and for a medical card.
- Little data is collected on the outcomes of HCPs, and what data is collected is rarely collated and analysed at national level. As a consequence it is difficult to learn from local implementation practices.
- There is very little focus on accountability in the policy documents or guidelines relating to HCPs. Instead, the focus is on setting up procedures, rather than delivering outcomes. Although dates for the delivery of aspects of the policy are outlined, there is no evidence of any repercussions when these deadlines are not met.
- There has been little focus on building a culture of high learning and interdependence. Some groups involved in HCP provision - LHOs, professional groups, private providers, and voluntary groups - appear to be defensive of their own work practices and wary of each other.

This report provides a set of recommendations as to how these problems in implementation can be addressed. It is a revealing picture of a good policy that has met with mixed success in its implementation. It is a picture that is likely to be mirrored in many other areas of policy in Ireland. We hope it may be a useful contribution in a policy landscape that is facing unprecedented urgent and rapid change in the immediate future.

Manuer Gattery

Dr. Maureen Gaffney, Chairperson, National Economic and Social Forum

Executive Summary

Introduction

- The NESF is now focusing on implementation of policy in its new Work Programme, in order to promote better outcomes from Irish policies, and to address the barriers that are holding up delivery of better quality services to the public.
- Many strategies and policies have been introduced in Ireland in recent decades, but implementation can be piecemeal and incremental. International studies have also found that there is often substantial slippage between the policy that is planned, and the process of putting those plans into action. So it is important to look not only at the outcomes of policy, but also at the processes which lead to these outcomes.
- This is why the NESF has decided to look in detail at the process of implementing a number of policies, in order to find out what practices support more effective policy implementation. This report focuses on a policy of particular relevance to older people, which is the Home Care Support Scheme. The learning from this case study of implementation, and others, will be drawn together to inform best practice on Irish policy implementation overall. Meanwhile, this NESF study on the processes used to implement the Home Care Support Scheme will complement the Evaluation of its outcomes, which has recently been commissioned by the Department of Health and Children.

The Home Care Support Scheme

4 The Home Care Support Scheme, which is more commonly known as the Home Care Package scheme, is operated by the HSE and provides care in the home, mainly for older people, who are at risk of admission to long-term care. The scheme is also available to other groups needing care in the community, such as those with disabilities.

- 5 Each Home Care Package (HCP) is tailored to the needs of an individual, based on their medical condition and the level of care required. Packages may therefore include the services of nurses, home care attendants, home helps and various therapies including physiotherapy services and occupational therapy services. Introduced in 2006, by December 2007, approximately 8,000 people benefitted from a package at any one time (PQ 15143-08), with total allocated funding of €120m in 2008. The HCP scheme represents a significant increase in the amount and type of care available for older people to remain at home.
- The HCP scheme is an administrative one, which means there is no automatic right to avail of it. Its provision also varies across the country. Each HSE Local Health Office (LHO) has responsibility for the operation of its own scheme, and so there are often variations by LHO in eligibility criteria, means of assessing a person's need for care, the financial value of a HCP, and what type of organisation delivers the care (such as the HSE, commercial agencies, and voluntary organisations).

NESF working methods

- 7 The NESF set up a project team of social partners to look more closely at implementation of the HCP scheme. Material was gathered through interviews with those working on HCPs, focus groups, questionnaires sent to HSE LHOs, and 100 submissions from the general public.
- 8 The Team decided to compare the HCP policy with the approach to policy development and implementation that was recommended in the OECD review of the Irish Public Service². This review argued that the development and implementation of Irish public policies should be more focused on the outputs and outcomes of those policies. Broadly speaking, an outcome is a result. A policy usually provides a wide range of results, and in the case of HCPs, these could range from reducing the proportion of older people in institutional care; to providing a greater quality of life for older people who are able to remain living at home. Traditionally, the focus of Irish policy has been on the inputs to the policies, with key inputs being funding and staff. This new focus which the OECD recommends is called an 'outcomes-oriented approach' to policy development and implementation.
- 9 The Team also looked at the recommendations of the Developmental Welfare State report (DWS) (NESC, 2005), on how to develop citizencentred services; and the NESF (2006) report on Improving the Delivery of Quality Public Services (QPS). It also decided to look at the influence of organisational culture on policy implementation.

An outcomes-oriented approach to policy development

- Altogether, this NESF report recommends that the following six factors be taken into account when an outcomes-oriented policy is being developed and implemented:
 - i Strategy plans for the policy's implementation, with agreed outcomes;
 - ii Measurement of policy inputs (such as finance and staff), outputs (such as the number of services provided) and outcomes (such as long-term benefits for an individual), which is used to feed into regular monitoring and periodic evaluation of the policy;
 - iii Links between the outcomes produced and the budget allocated;
 - iv A good accountability and incentive structure;
 - v A focus on delivery, including delivery plans, equity in delivery, standards which are overseen and monitored, and innovative ways of delivering policies; and
 - vi Organisational culture.

This NESF report particularly stresses the importance of delivery plans, which are not a key focus of the OECD, DWS and QPS reports. It will also demonstrate the importance of 'softer' organisational culture issues, which have a significant influence on the ability of an organisation to implement policy in the most effective way.

Irish policy on Home Care Packages

- Irish Government policy since the late 1960s has been to support older people to remain at home for as long as possible. In line with this, in 2005, the Long-Term Care Report (Working Group on Long-term Care, 2005) recommended that home care packages (HCPs) be provided, for those at risk of (or currently in) residential care, who wished to be cared for at home. The report recommended that HCPs be introduced on the basis of a national standard approach, with clear criteria in terms of access, quality standards and availability. It also recommended the introduction of a standardised care needs assessment framework, a national standard financial assessment framework, formal protocols for case management and delivery of HCPs on a national basis, and an appropriate structure to ensure quality standards. Private sector providers were to be involved in delivering care.
- National guidelines on how to implement this HCP policy were then developed in early 2006, and covered the funding to be allocated under each HCP, means tests, care needs assessment, consultation and co-ordination with the older person and existing services, what organisations should be involved in delivering HCPs, monitoring and review, and data to be collected. However, these guidelines have not yet been put into operation.

To cover standards in home care provision (which would apply to the home help and home care aspects of HCPs, but not to the nursing and therapy aspects), in October 2008, the HSE Services for Older People Expert Advisory Group approved Draft National Quality Guidelines for Home Care Support Services. They are divided into five sections, headed rights, protection, home care support needs, staffing, and governance and management. These guidelines will need to progress through several more stages before being implemented.

Implementation of HCPs in different Local Health Offices

- The HCP scheme has been in existence since early 2006, but as guidelines to provide a standardised national approach to its implementation are not yet operational, each HSE Local Health Office implements the scheme differently.
- Many of those who have a HCP are very satisfied with the fact that they allow them to remain at home, or to support an older relative at home. This was underlined by many submissions from the public. However, there are also a number of problems with implementation of the HCP policy.
- First, many clients reported difficulties accessing information on HCPs. The funding allocated also does not meet all demands, and there are significant variations by LHO in the eligibility criteria used to allocate the HCP funding which they have, and in the average amounts paid under a HCP.
- Problems were also reported with the management and training of paid home care support workers, and also with the high number who could be caring for one individual, and the handovers between those home care support workers. Hours during which care was available were also variable. Some older recipients found it particularly difficult to manage being an employer of a home care support worker, where the option of a cash grant to employ a home care support worker of one's choice was available. These issues are relevant to standards around how care is provided.
- A number of management problems were also evident. For example, double or triple assessments of the care needs of an older person were often carried out e.g. by medical staff in hospital, by a Public Health Nurse co-ordinating HCPs, and by the organisation appointed to provide the care. Similarly, double or triple means testing of an older person also occurred, e.g. for home help services, for HCPs, and for a medical card.

- Meanwhile, little data is collected on the outcomes of HCPs, and this is rarely collated and analysed at national level, so it is difficult to learn from local implementation practices. LHOs also use different organisations to deliver some aspects of HCPs, such as the home help aspect. These organisations include the HSE, private agencies, and voluntary organisations, and different LHOs have different means of co-ordinating the various organisations, and of monitoring them. In terms of staff, some LHOs were allowed to employ staff to administer or manage HCPs, but others were not.
- 20 Many groups involved in HCP provision (e.g. different LHOs in the HSE, different staff groups in the HSE, private providers, and voluntary groups) appeared to be wary of each other, and were sometimes defensive about the value of their own work practices.
- Overall, lots of LHO variation in implementation was evident, leading to confusion and inequities for clients, and duplication for both clients and staff. This mirrors developments in other OECD countries, which have faced similar problems and dealt with them in a variety of ways.

How does development and implementation of HCPs compare with the outcomes-oriented model?

- The review of how HCP policy was designed and implemented shows that the strategy development for HCP policy followed best practice for outcomes-oriented policy in many ways. It provided a significant amount of funding to meet a need which had been identified in many earlier policy documents. Many of the factors which underline good strategy development (such as measurement of inputs, outputs and outcomes; evaluation and monitoring; co-ordination of organisations and procedures; competition in service delivery; tailored services delivered; standards for delivery; and equity in provision) were covered in the policy development. A variety of proposals and commitments were made to put these into practice.
- Provide a state of the state

What particular implementation problems were identified?

- One key problem is that the original policy on HCPs did not agree exactly how many would be provided; and the number since allocated is not sufficient to meet demand. This can be linked to the significant variations by LHO in the eligibility criteria used to allocate HCPs, and in the average amounts paid under a HCP.
- 25 Reasons for not agreeing how many HCPs would be provided include a lack of data to assess the need for HCPs, as noted in the Long-Term Care Report. There is also no specific legislative basis in relation to entitlements for all aspects of HCPs, including charging for them. There may also be a reluctance to commit to funding all the HCPs needed, or a fear that means tests could be politically unpopular.
- Another key problem is the absence of co-ordinated procedures, leading to duplication of needs assessment and means testing. Such procedures were asked for in the Long-Term Care report, but have not yet been agreed. On a related issue, quality standards for delivery, which would affect home care and home help where this is delivered under a HCP, and which could help with a number of problems in relation to management and training of home care support workers, are not yet agreed.
- Some reasons for the delay in agreeing and implementing standardised procedures are the high number of structures involved in making decisions, slowing the process down. Local level policy implementers are also not involved in all of these discussions, and few service users.
- 28 Another problem around implementation is that there is very little focus on accountability in the policy documents or guidelines which covered HCPs. Although the LTC report nominates organisations responsible for delivery, with dates for actions to be taken, there do not seem to be any repercussions when these deadlines are passed. Actions also focus on setting up procedures, rather than delivering outcomes.
- Guidelines drawn up to implement the HCP policy asked for a range of outcomes data to be collected, but these guidelines are not operational, and the data is not always gathered. Where it is gathered, it does not seem to be used at national management level. This makes it difficult to link performance to budget. Evaluation which will help assess this is now underway³. However, to date it seems that the priority given to collecting and using data to assess outcomes, and to learn from best practice, is not high. This does not allow best practice in implementation to be identified and spread. This is particularly important for HCPs, given that the decision was made to roll them out as quickly as possible, before guidelines on standardised implementation were agreed.

These practices also suggest that implementation and monitoring of the strategy around HCPs is less important than annual local spending targets. Deadlines and targets in relation to annual local spending are less likely to be missed. The research also showed a strong tendency for different groups working on HCPs to be loyal to their professional work group (e.g. private agency, voluntary group), or in the case of the HSE, with their local health office; rather than to the national HCP strategy.

Recommendations for the HCP policy

- 31 A number of recommendations are therefore suggested to improve implementation of the HCP policy.
 - First of all, outcomes need to be agreed. How many HCPs will be supplied, and by when? Key issues impacting on the number needed, such as eligibility, means assessment, and care needs assessment, should also be agreed.
 - ii Two types of data then need to be collected, both data for strategic development of the policy, and data on delivery of HCPs. Regular monitoring should also be carried out, and this and other data collected should be used in periodic evaluation of the policy.
 - iii The data should be linked to budget allocations.
 - iv **Accountability** needs to be strongly developed, with clear outlines of who is responsible for what, measurement of whether or not this is achieved, and a form of incentive/sanction to help ensure goals are achieved.
 - v Focus on delivery should include detailed delivery plans. These need to cover issues such as leadership, budget, implementation milestones, reviews, co-ordination mechanisms, communications with all stakeholders, methods of delivery, monitoring of delivery, links with clients etc. Standards for delivery need to be agreed and passed - both the standards under which HCPs should be allocated, and standards on how they should be delivered.
 - vi Attention needs to be paid to **organisational culture**, in particular the need to align all aspects of policy design, decision-making and working practices, so that sustainable implementation can occur.
- Finally, action on the above needs to be given greater focus and direction from the Centre, at both political and Departmental levels. A high-level committee chaired by the Minister of State with Responsibility for Older People, with representation from the main stakeholders, should be set up to drive forward these recommendations, with a particular focus on policy delivery.

The recommendations should achieve better results from present public expenditure in this area, and will not result in any major additional Exchequer costs.

What relevance does this study of this particular policy have for implementation overall?

- This study also has relevance for implementation in other policy areas. It suggests that the outcomes-oriented approach to policy development and implementation recommended by the OECD review of the Irish public services provides very good guidelines for strategy development and planning. These guidelines include – agreement on policy outcomes, measurement and evaluation, tying performance to budget allocation, and good accountability and incentive structures.
- 35 However, this NESF report also suggests that a stronger focus is needed on delivery to clients, as suggested in the Developmental Welfare State and Improving the Delivery of Quality Public Services reports. Detailed delivery plans need to be in operation, to link strategy and delivery, and to ensure that the sequence of steps needed to reach the final outcome are identified and put in place. Links between national policy makers and local policy implementers need to be developed to ensure that this happens effectively.
- Attention also needs to be paid to the underlying 'softer' organisational culture, and the effects that this has on implementation. Issues identified as problematic in policy implementation (in this case, difficulties making decisions about how to target care funding, dialogue which occurs at the expense of decision-making, a focus on annual budget procedures over strategic process, and loyalty to local group rather than to national strategy) are all difficult to change due to underlying organisational culture which does not reward changes in these behaviours. As implementation is a form of organisational change, then these cultural issues are essential to take into account to ensure that well designed policy is fully implemented.

Introduction

The NESF has decided to focus on implementation of policy in its new Work Programme, to gain better information on the factors which lead to successful delivery of policies, in order to promote better outcomes from Irish policies.

Many strategies and policies have been introduced in Ireland in recent decades, but implementation can be piecemeal and incremental. The recent OECD report on the Irish public service notes that Irish public sector reforms often focus on putting processes in place, but that more needs to be done to lead to improved outcomes and outputs (OECD, 2008). Such improved outcomes can be particularly key to enrich opportunities and outcomes for those who are socially excluded, the focus of the NESF's work since its establishment in 1993.

Policy implementation

What do we mean by policy implementation? It is the process of putting a policy formulated by decision-makers into action (Parsons, 1996).

And why is it important to look at implementation? There is often substantial slippage between policy plans and actual operations (Quinn Patton, 1978). Even though a policy exists, it might have no structures, processes or resources allocated for its implementation. Or in some cases the supports set up for its implementation might not be used. In addition, some parts of a policy may be implemented effectively, or implemented effectively in some locations although not all.

It is not surprising that such practices can lead to poor outcomes, and therefore ineffective policies and programmes. However, what happens between policy design and policy delivery is rarely examined, and is often an undiscovered 'black box'. It is crucial to delve into this black box, to find out why policy implementation is not achieving the results hoped for; or if it is, then how. So it is important to look not only at the outcomes of policy, but also at the processes which lead to these outcomes. This is why the NESF has decided to look at the implementation of a number of policies in more detail, in order to find out what supports effective policy implementation.

This new focus is supported by other work initiated by the Department of an Taoiseach on more effective implementation of public policy in Ireland. It has initiated two major projects to examine the issue.

First, the Irish government financed the OECD to carry out a review of success and challenges in public service reform in Ireland. The resulting report, *Ireland: Towards an integrated public service*, was published in 2008 (OECD, 2008). Secondly, the Department of an Taoiseach carried out an Organisational Review Programme (ORP), looking at the capacity of three government departments to deliver its goals. Its report was published in Autumn 2008 (Dept of an Taoiseach, 2008).

Both of these projects indicate a useful range of issues to investigate in terms of policy implementation. The work of the OECD review in particular will be returned to in this project, as one of its key focii was how to develop a public service which focused on the outcomes of policy, which was judged to be of key importance in terms of policy implementation.

Policies whose implementation is being studied by the NESF

The Irish Government has attempted to introduce more coherence into policy through the social partnership process and the adoption of the life-cycle approach to policy within that. This approach was outlined in the NESC's *Developmental Welfare State* (NESC, 2005). It proposes that policies be organised around the framework of different stages of a person's lifecycle, in particular children, people of working age, older people, and people with a disability. Therefore the NESF decided to study policies which form part of this approach as set out in Towards 2016, the *National Action Plan for Social Inclusion* (*NAPinclusion*) 2007-2016, and the *National Development Plan 2007-2013*. One policy is being chosen for study from each of the four lifecycle stages. This report focuses on a policy of particular relevance to older people, which is the Home Care Support Scheme.

What is the Home Care Support Scheme?

The Home Care Support Scheme, which is more commonly known as the Home Care Package scheme⁴, is a scheme operated by the HSE which provides care in the home, mainly for older people who are at risk of admission to long-term care. Some people with disabilities have received home care packages, particularly through pilot schemes operated in parts of Dublin before 2006, but the scheme operated since is funded through the HSE's Services for Older People budget, and therefore is aimed particularly at older people.

⁴ Although the HSE website calls it the 'home care support scheme', it is rarely referred to as this. Indeed even the evaluation of the scheme commissioned by the Dept of Health and Children is entitled 'Evaluation of Home Care Packages'. This report will refer to them as home care packages throughout.

Each HCP is tailored to the needs of an individual, based on their medical condition and the level of care required. Packages may include the services of nurses, home care attendants, home helps and various therapies including e.g. physiotherapy services and occupational therapy services. In some packages there might be a greater emphasis on home care assistants while other packages may include a greater level of therapy and nursing, depending on individual need.

As it is an administrative scheme, there is no automatic right to the HCP scheme, nor to avail of services under it. No standardised national guidelines on how it should run are operational. Instead each HSE Administrative Area has responsibility for the operation of its own scheme. This means that schemes vary in different parts of the country.

In 2006 Home Care Packages were allocated €55m of funding from the HSE. This had gradually increased to an allocation of €120m to fund HCPs in the year 2008. In total, approximately 8,000 people were benefitting from a home care package at any one time in December 2007 (PQ 15143-08).

Project Team

The NESF asked for nominations from its four membership strands⁵ for a Project Team to look at implementation of the Home Care Package Scheme. Professor Tony Fahey of UCD chaired the Team.

The members of the Team are as follows:

CHAIRPERSON PROFESSOR TONY FAHEY, UCD

STRAND ONE

Mr Cyprian Brady, T.D. Fianna Fáil

Mr Seán Sherlock, T.D. Labour

Senator Jerry Buttimer Fine Gael

STRAND TWO

Ms Mary Sherry IFA

Mr Conor Farrell ICTU*

Mr John Brennan IBEC/Peamount Hospital

STRAND THREE

Ms Louise Richardson/Ms Christine O'Kelly Older Women's Network

Sr Sheila Cronin CORI

Ms Maireád Hayes Irish Senior Citizen's Parliament/Age Action

Mr Kris Dhondt Disability Federation of Ireland

5 Membership of the NESF is drawn from four strands – Oireachtas (TDs and Senators from both Government and Opposition parties); Employers, Trade Unions and Farming organisations; the Voluntary and Community sector; and Central Government, Local Government and independents.

STRAND FOUR

Cllr Paddy O'Callaghan

Dr Richard Boyle Institute of Public Administration

Mr Tom Leonard HSE

Mr Michael Murchan Department of Health & Children

Mr Enda Egan/Mr Sean Dillon Carer's Association

Professor Rose Anne Kenny Trinity College Dublin

NESF Secretariat Dr Anne-Marie McGauran

* Mr Conor Farrell resigned in January 2009, and was replaced by Ms Sylvia Ryan of the Congress Centres Network.

This Team was set up in September 2008, and met seven times.

Terms of Reference

From the beginning, the Team bore in mind the evaluation which was due to be commissioned by the Department of Health and Children of the Home Care Package scheme. This evaluation was begun in February 2009. Its aim is to: 'assess through quantitative and qualitative research that the objectives of Home Care Packages are being met in the most economically viable manner.' (Dept of Health and Children, 2008:4). This is being done through study of the management of HCPs at central (HSE) level; study of HCP delivery models in place in different HSE Local Health Offices, through examination of up to 950 case files; as well as questionnaires to both providers and recipients of HCPs.

The Department of Health and Children evaluation therefore very much focussed on the efficiency and effectiveness of the HCP scheme itself. Meanwhile, the NESF Project Team decided that the NESF work should look at the HCP scheme as a case study of policy implementation, and in particular examine whether or not the outcomes approach to policy development advocated in the OECD review of the Irish public service could be a useful guide to policy implementation⁶.

Therefore, at its early meetings, the Team agreed the following Terms of Reference:

'The purpose of this project is to examine the Home Care Support Scheme as a case-study of policy implementation, viewed from the perspective of an outcomes, or performance, oriented approach to policy formulation and delivery.

6 The Dept of Health and Children evaluation also concentrated more on those in receipt of HCPs, while the NESF research drew on the experiences of a wider range of people, including those who are not in receipt of HCPs.

The Project will:

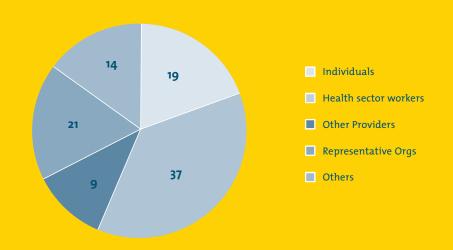
- i Examine the general characteristics of the outcomes/performance oriented approach and draw out the framework for analysis of policy implementation that it gives rise to, including criteria it identifies for measuring the degree to which policy implementation has occurred.
- ii Examine the development and formulation of the Home Care Support Scheme in that light, focusing especially on the nature of the objectives, resources and delivery systems specified in the policy as viewed in an outcomes/performance perspective.
- iii Examine the on-the-ground delivery of the Scheme in order to establish, as far as possible, the overall national degree of policy implementation that occurred, regional and local variations in the extent of implementation, and factors that might explain both the overall national outcome and sub-national variations.

Item 1 above will be based on desk research, item 2 on a mix of documentary analysis and interviews with key actors, and item 3 on relevant data analysis coupled with selected empirical case studies at regional and/or local levels.'

Working methods

The Team used a variety of methods to gather information.

A public call for submissions was made in January 2009. Altogether 100 submissions were received from interested organisations and individuals, and these are summarised in Annex 1 of this report. A list of the individuals and organisations who made submissions is given in Annex 2. These are summarized in the following piechart:



Graph 1 Who sent submissions? (n=100)

The piechart shows that those who sent submissions included individuals or relatives of individuals who had applied for or received HCPs, commercial and voluntary organizations delivering them, and staff of the HSE. This provided a wide range of viewpoints on HCP implementation, although many reported very similar experiences.

The Team also consulted a wide range of individuals and organisations throughout Ireland, including through four focus group meetings held around the country (with representatives from the Irish Senior Citizen's Parliament, and the Older Women's Network). The groups and individuals which were met by the NESF Secretariat are listed in Annex 3.

Desk-based research was also undertaken of written material on policy implementation, with particular reference to implementation of policy on home care for older people in Ireland and internationally. An analysis of SHARE data, a new data source with information on the health status and care of older people, was also commissioned, and this is included in Annex 5. Questionnaires were also circulated by the NESF Secretariat to identify the processes used to implement HCP policy in eight HSE Local Health Offices. The information gained from these different processes has been used to develop the Team's thinking on implementation of the HCP scheme, and the learning from this of relevance to overall policy implementation in Ireland.

Outline of the report

Following this introduction, Chapter one covers the first point of the Terms of Reference, by outlining what is meant by an outcomes-oriented approach to policy development, with particular reference to the OECD review of the Irish public service.

In Chapter two, the importance of delivery to clients is outlined, with reference to the NESC Developmental Welfare State report (NESC, 2005), and the NESF report on Improving the Delivery of Quality Public Services (NESF, 2006). The relevance of organisational culture is also discussed.

In Chapter three, the focus moves to point two of the Terms of Reference, looking at the development and formulation of the HCP policy in Ireland. Chapter four follows on from this by looking at the issues arising in local and national implementation of the HCP policy, covering part of point three of the Terms of Reference.

Chapter five then completes point three of the Terms of Reference by comparing what is happening in implementation of HCPs on the ground with the framework for an outcomes-based approach to implementation identified from the OECD, DWS and QPS reports. There is also an outline of factors which contribute to variations in degree of implementation.

Finally Chapter six makes some recommendations on how to improve implementation of the HCP policy, and then assesses the relevance of this particular study of HCP implementation for policy implementation overall in Ireland.

Acknowledgements

The Project Team would like to thank everyone who contributed to the report. It is particularly grateful to those who made written submissions, those who took time to meet the Project Team, and all those who attended and made presentations at the Plenary Session held in the Royal Hospital Kilmainham. The Project Team is also grateful for the assistance it received from a number of Government departments and State agencies. As with all NESF reports, wide consultation was a key feature of the work for this report and in this regard the Team was struck by, and very much appreciated, the level of engagement by so many people with the issues addressed.

Finally, the Team would like to record its fullest appreciation to Professor Tony Fahey, who chaired the Project Team, Mr Seán Ó h-Éigeartaigh, Director of the NESF, and Dr Anne-Marie McGauran, policy analyst for the Team: their experience and expertise ensured that the work of the Team was both productive and harmonious.

CHAPTER 1 An outcomes-oriented approach to policy development

Introduction

- 1.1 This Chapter will cover point 1 of the Terms of Reference, that is to 'examine the general characteristics of the outcomes/performance oriented approach and draw out the framework for analysis of policy implementation that it gives rise to, including criteria it identifies for measuring the degree to which policy implementation has occurred.'
- This will be done by outlining what is meant by an outcomes-oriented approach to policy development, with particular reference to the OECD *Public Management Review Ireland: Towards an Integrated Public Service* (OECD, 2008), a key study of relevance to delivery of all public services.

The OECD Review of the Irish Public Service

- 1.3 The OECD Public Management Review Ireland, which will be referred to as the OECD review in this report, was commissioned by the Irish Government from the OECD, to analyse the success and challenges of Irish public service reform. It outlined how Ireland's public service could best be prepared to meet upcoming economic and social challenges. This involved significant analysis of how the public service currently operates, what it does well, and what it could do better, in order to continue to deliver improved outcomes⁷ for citizens, to respond to shifting and complex societal needs, and to contribute to sustained economic success for Ireland.
- The OECD review found that the Irish public sector has started a significant process of reform, but also considered that this reform, with the introduction of initiatives such as the Strategic Management Initiative and Delivering Better Government, was very much focused on internal changes to the public service and its processes and procedures.

⁷ Broadly speaking, an outcome is a result. A policy usually provides a wide range of results, and different groups are usually interested in different aspects of the results. Taking the example of a home care package policy, a policy-maker may emphasise the outcomes which provide more care for older people to remain at home, within a set budget. Meanwhile an individual may be more interested in the outcome of greater quality of life which older people can gain from living at home.

Now these reforms need to be speeded up and better sequenced, and added to. In particular, improvements in project management and implementation skills are required. Greater focus also needs to be placed on citizens and their expectations, and on targeting delivery of services from their perspective so as to achieve broader societal goals. The Review particularly noted that the Irish public service needs to orient its performance more towards outputs and outcomes, by better integrating and utilising the systems and processes it has developed, so that it will be better placed to effectively identify and attain societal goals, along with citizens, business, unions and other actors.

Performance management

- **1.5** As the OECD review has a strong focus on better policy outcomes, the Project Team decided to look in particular at how it recommends that better policy outcomes can be achieved through 'performance management'. Worldwide, there is an increasing focus on public sector performance, as governments deal with more challenging and complex societal demands, greater pressures for efficiency, and reduced budgets (Curristine, 2005). For governments to perform well, they need to have their internal operations well managed, and also to constantly adapt to changing circumstances. 'A performing State... is one that continuously reads its environment and adjusts how and what it does in response to new information' (Schick, 2002:4). So governments have been aiming to increase performance using a variety of mechanisms, including for example performance measurement in budgeting and management, relaxation of some administrative controls, delegation of responsibility to line agencies, changing modes of service delivery, and changes in public employment conditions such as the introduction of fixed-term contracts and performance related pay. Different countries are at different stages in this process.
- Curristine (2005) notes that traditionally, public sector bureaucracy performance was driven by ensuring compliance with set rules and regulations, controlling inputs, and valuing a public sector ethos. 'Inputs' here can be defined as 'anything a system... uses to accomplish its purposes' (Martin & Kettner, 1996:4). This includes money, staff, and processes, with process defined as 'the actual treatment or service delivery' (Martin & Kettner, 1996:4). A focus on inputs means there is detailed tracking of money spent, staff employed, and types of inputs, such as strategy development, meetings attended, consultations put in place etc. This helps to ensure financial accountability and stop corruption in use of funds.

- However, the problem with an overfocus on inputs, which Ireland traditionally has had, is that public sector employees tend to become more focused on the inputs and the processes, to the detriment of the results they are to achieve. In an inputs focused culture, there are typically weak incentives to use funds efficiently to meet objectives, which are not a key focus of the culture in any case. This is why the OECD review (2008) advocates a focus on achieving outputs and outcomes it is to help achieve better results for Ireland's society and economy. Interestingly, Schick (2002) notes that countries which have undergone rapid development usually experience the State as lagging behind development of the economy, which results in increased pressure on the public sector to perform better. This is evident in Ireland.
- 1.8 It is useful here to define outputs and outcomes. Outputs are 'anything a system produces' (Martin & Kettner, 1996:4), while outcomes are 'results, impacts and accomplishments' (Martin & Kettner, 1996:6). When these are measured, the effectiveness of a policy can be assessed. For example, in an early childhood education programme, an output would be the number of children attending the programme; while an outcome is their later performance in school. Looking at these issues provides good information on the efficiency and effectiveness of government programmes. Efficiency is usually associated with outputs (e.g. how many children attended a programme), and effectiveness with outcomes (e.g. if the programme was useful children will do better in school) (see Schick, 2002).
- 1.9 Researchers do however stress that public sector managers also need to keep inputs in mind. Without information on the inputs required to produce outputs and outcomes, it would be difficult for governments to assess how efficiently they are producing outcomes, and also to pinpoint and learn from best practice among different operators. For example, knowing the resources which different schools put into early childhood education programmes, and the later performance of the children who attended them, will provide the most comprehensive information on how government programmes are operating. So it is important to bear inputs, outputs and outcomes in mind in a performance culture.
- The next question which arises is what is a performance culture focused on outputs and outcomes like? Curristine, while noting there are many definitions of performance management, defines it as:

'a management cycle under which programme performance objectives and targets are determined, managers have flexibility to achieve them, actual performance is measured and reported, and this information feeds into decisions about programme funding, design, operations and rewards or penalties' (2005:131).

Within this there are various definitions of performance budgeting and management but the common theme is that governments are trying to 'adopt a results-based approach to both management and budgeting which shifts budgeting, management and accountability away from inputs towards a focus on measurable results' (2005:131-2).

- A review of the OECD report, as well as some other key literature (Curristine, 2005; Boyle, 2005; Schick, 2002) points to several features of public sector management which have a role to play in an outcomes oriented performance culture. These are:
 - Strategy plans with agreed outcomes
 - Measurement and evaluation,
 - Linking budgets to performance,
 - Accountability and incentive structures, and
 - Better co-ordination.

The characteristics of each of these from an output/outcomes focus will now be outlined.

Strategy plans with agreed outcomes

- 1.12 It is in this phase of performance management that the outcomes which are sought are determined. The OECD (2008) notes that ideally there would be a stronger chain of outcome planning in Ireland, with individual and division goals tied into departmental strategy plans and output statements. They note that currently Ireland's top-down National Development type plans are not always well aligned with the strategy statements which outline the goals and focus of public sector organisations and divisions.
- The OECD (2008) identifies the role of organisational output statements as a key mechanism to link plans and outcomes. The output statements can link financial and staffing requests to key outputs and outcomes. Good statements would strengthen the focus on policy results and so play a key role in developing a performance culture. Ideally the output statements would:
 - Have a limited number of clear, precise, measurable, high-level and strategic goals;
 - The strategic goals would then be broken down into several operational goals which anticipate the actions needed to achieve the high-level goals;
 - These operational goals should be quantified so that progress is measured and reported;
 - The operational goals should also be expressed as outputs, not inputs and processes; and finally
 - They should be reported on regularly (OECD, 2008:147).

- **1.14** Currently, there is considerable variation in the extent to which Irish government departments meet the standards which the OECD advocates in output statements. For example, the number of goals in Departmental output statements varies from 9 to 105. Some have quantified indicators, while others do not. The indicators are rarely benchmarked (i.e. linked to a fixed standard or target). In addition, many factors in the statements which are called outputs (such as developing action plans, participation in networks and meetings) are not actually outputs. Instead they are processes which could lead to outputs. However, producing output statements is a new requirement in Ireland, and experience in other countries shows that expertise grows over time. International experience also indicates that a number of problems are to be expected in this phase, including for example, difficulties setting objectives, difficulties setting targets, and too many targets (see Curristine, 2005). A further problem for Ireland is that at the moment not all agencies are required to produce output statements. The OECD recommends that this requirement be extended to agencies.
- **1.15** On operational goals which anticipate the actions needed to achieve the high-level goals, the OECD outlined four steps which are needed - vision and understanding; planning and design; communication; and sequencing. Sequencing involves taking into account all potential actions and their alternatives, then assessing the requirements for each action to be carried out, and any necessary steps which need to be put in place to meet these. They outline that it is not enough to have a clear vision for a policy. The supports that are needed for that policy to operate effectively must also be put in place. Looking at the policy to re-configure hospital care in the North East, the OECD notes that good primary care needs to be in place first. This would involve assessing likely population size and needs, the number of GPs likely to be available to provide such care, and good communication of relevant information to all stakeholders etc. The incentives for various groups to co-operate with the plans need to be aligned, and accountability for particular actions needs to be clear. In their four case studies of Irish policy, the OECD found that 'all four ... reveal failures in sequencing reforms'. While policy developers did consider all preconditions for reform and necessary levers for success, their choice of tactics to implement the strategy shows that they were not able to sufficiently act on this knowledge. However, although the OECD outline the importance of looking at sequencing and delivery, they do not provide much detail on the mechanics of how to do this.

Measurement and evaluation

- 1.16 A key part of implementing performance management is having information to assess what type of performance is occurring. This information is needed as an input for management, planning, resource allocation and decision-making. This is where the role of performance measurement comes in. Typically, Irish public sector organisations have collected most information on inputs, particularly financial ones, and processes. However, there is increased need for indicators which accurately measure outputs and outcomes as well. A good system of performance measurement would include input, output, outcome and context indicators. Boyle (2005) gives the following examples in relation to a programme to improve traditional Irish farmhouses:
 - Input indicators would measure the financial and staff resources used;
 - Output indicators would measure what is produced, including the number of applications, the number approved and rejected, and the average time taken to process an application;
 - Outcome indicators would measure the direct results and impacts of what is produced on beneficiaries – in this case the number of farmhouses improved; and
 - Context indicators would measure wider impacts on society, such as percentage of population in rural areas, or number of full-time equivalent jobs in agri-tourism.
- **1.17** Using indicators in this way can provide information on performance at several levels.
 - First, linking the output and input indicators can tell how efficiently the work is being done – e.g. how many staff process the applications, and how long does it take them?
 - Second, the output indicators show how well the organisation is doing in producing the things which it has most control over.
 - Third, the outcome indicators outline the direct effects of the scheme for beneficiaries.
 - Finally, the context indicators show some of the final impacts. These can track policy objectives, which in this case are reducing rural unemployment and rural depopulation.

- 1.18 This example shows why it is important to have indicators measuring inputs, outputs and outcomes. Linking the information from the various types of indicators allows measurement of overall efficiency and effectiveness in policy implementation. And even though, as Boyle (2005) notes, there is an attribution problem with context indicators, as rural depopulation and employment levels will be affected by a greater range of factors other than the specific programme to improve traditional farmhouses, they are important to monitor. They have relevance to the design and implementation of the programme, even to the extent of contributing to debate on whether or not the programme is needed in the first place.
- 1.19 To promote better performance, indicators should have measurable targets. Some authors use the acronym SMART to describe how targets should be set. This stands for Specific, Measurable, Achieveable, Realistic and Timely. A number of authors also advise independent monitoring of the performance measurement system, to assure its credibility and quality (e.g. Curristine, 2005). Finally, collecting such information is important to allow evaluations of the extent to which policies are efficient and effective in producing outcomes. This is also a key element of performance management, as such learning can feed back into development of the policy, as well as of related policies.

Linking performance to budgets

- One of the most important features of a performance culture is that the performance information collected is used in budget decisions.
 Performance budgeting means:
 - 'Including performance information in budget documentation...,
 - Linking expenditure to outcome/output targets,
 - Reporting performance against these targets and
 - Using the information to make decisions on future resource allocation' (Curristine, 2005:134).
- In Ireland, the OECD review (2008) notes that there could be stronger links between the budget preparation process and performance information which could strengthen focus on policy results. There is room also for discussion on the outputs that are to be achieved by budget increases. The review suggests linking the medium-term expenditure framework to output statements to enable more long-term planning and a greater focus on results. At the same time a budget ceiling on medium-term expenditure, which currently does not exist, would help overcome fears of overspending resulting from any relaxation of input controls. Using performance information in the budgeting process to cut funds to poorly performing programmes is not recommended by the OECD review. Instead, the use of this information could signal to the Department of Finance that there is a need to more closely monitor these programmes.

- Ireland is not the only country which needs to introduce stronger performance budgeting. Curristine (2005) notes that using her strict definition of performance budgeting above, it is rare. Instead only elements of this type of performance budgeting are evident in different OECD countries. For example:
 - 72% of the countries include non-financial performance data in budget documentation;
 - 71% including performance targets in their programmes although not all programmes;
 - 65% of countries include the results from these targets in main budget documents and/or annual financial documents.

The OECD review (2008) notes that an important issue in Ireland is the political nature of the budget, which means that there is resistance from certain groups to re-allocation of funding.

Accountability and incentives

- 1.23 The OECD (2008) finds that Irish public sector accountability systems are currently characterized by compliance with rules, but they need to be more focused on outcomes. A number of changes are needed to produce this. First, there needs to be better measurement of what is produced. This is dependent on the existence of both the better strategy planning and performance measurement system outlined earlier in this Chapter. Such clarity on the objectives and outcomes of policy, and measurement of the extent to which they have been met, is necessary to give an account of what has happened (see Boyle, 2005). This is a key part of a good accountability framework.
- Second, so that people can be *held to account*, performance and accountability structures should be aligned. Two things need to happen to support this
 - a) exactly who is accountable needs to be clearly determined, and
 - b) incentives need to be put in place to promote better performance.

On a), it is noted that 'linking individual['s] objectives to the organizational mission and objectives can help reinforce a performance culture and creates incentives for high performance' (OECD, 2008:175). A way of doing this is to have performance targets cascade down from the Dail or Department of Finance to the line Department and programme, and from there to an individual's or team's performance arrangements.

On b), the OCED (2008) notes that there is not yet the shift in systems and incentives that would support a move to a performance culture. The review does note a range of mechanisms, both positive and negative, that can be used to incentivise performance. These can be based around funding – such as increasing or reducing funding to an organisation, or providing bonuses or salary reductions to staff. Changes in flexibility can also act as incentives, for example allowing organisations to keep funds saved through efficiency gain, or allowing it greater flexibility to transfer funding between different operations within the organisation. Transparency is another means of incentivising organisations to perform better – it can allow public recognition or criticism of performance, as appropriate.

- 1.25 Third, there is a need for co-ordination of accountability. Both vertical and horizontal co-ordination is needed. Vertically, there needs to be clarity about the relationships between agencies, semi-state bodies and parent departments, including the roles and responsibilities of each. Lines of accountability in particular need to exist, so that all key actors know to whom they are responsible and for what. The range of organisations working on similar policy issues in Ireland means that without clear accountability there is increased danger of fragmentation and duplication within a policy area. Discussions with the NESF Project Team also noted that it is key for those accountable for implementing aspects of a policy to have the necessary resources to do so. Such clarity would also increase horizontal accountability. The OECD (2008), and Curristine (2005) also advocate an increase in the role of politicians in setting clear objectives and targets, and holding implementers to account. This is another aspect of horizontal accountability which could be strengthened in Ireland.
- Fourth, making accountability mechanisms and outcomes more transparent to citizens and to other public sector organisations can contribute to a stronger focus on performance. For example, if citizens and organisations are able to compare the results of different organisations delivering the same service against each other, this allows service gaps to be identified, and can increase standards, and satisfaction levels. (Canada already has a system to do this OECD, 2008:188).
- Again, the extent to which these aspects of an accountability framework are in place in different countries is quite weak. Curristine (2005) notes that generally there are few rewards and sanctions applied if a target is met or not met 46% of OECD countries do not apply these. And in only 20% of countries does failure to meet organisational targets have a negative consequence on the pay of the organisation head (OECD, 2008). The trend towards external auditing of performance information is also not strong (Curristine, 2008). Nonetheless, the mechanisms outlined above to increase accountability for performance would be a key part of an outcomes-focused implementation system.

Co-ordination

- 1.28 Curristine (2005) notes that Ireland has adopted an incremental approach to implementation of performance management, with a number of pilot schemes, and without movement towards full implementation of performance management across government. This may be a reason why the OECD review (2008) stresses the importance of more coherence and co-ordination in Ireland's approach to performance management.
- 1.29 First, the OECD stresses the need for more 'performance dialogue' among different organisations. Current performance dialogue between the Department of Finance, line departments and their agencies is often input-focused, concentrating on staff and finances. However, this should be replaced with:
 - a formal long-term performance dialogue, which
 - sets different types of targets and evaluation, and
 - makes links between inputs, processes, outputs and outcomes (OECD, 2008:178).

This dialogue would allow for shared understanding and ownership of performance and targets. It would also assist greater coherence and coordination in overall government policy.

- 1.30 Secondly, organisations also need to work together, in networks, to implement service delivery, and to share services. Less vertical silos and more horizontal networks are needed. This would mean more vertical and horizontal coherence between different initiatives throughout the system.
- 1.31 Thirdly, currently many policy documents on performance initiatives do not state the actual or even intended links between the different initiatives. For example there is poor horizontal coherence between Value for Money reviews and Strategy and Output statements. It is important to have a systemic approach to performance management. All aspects of the performance management framework need to be aligned into a coherent whole, to provide a supportive background for a widespread performance culture.
- Finally, the OECD review also outlines a number of other mechanisms which can be used to promote a performance culture. These are the quality, accessibility of and eligibility for services; improving service delivery through competition; and use of ICT. These, as well as co-ordination, are all relevant to improving delivery of services, and will be considered in more detail in the next Chapter.

Summary

- 1.33 To summarise, the OECD review identifies a number of key factors which should be taken into account in policy design and implementation, which contribute to outcomes-focused performance management. These are:
 - Strategy plans with agreed outcomes,
 - Measurement of inputs, outputs and outcomes; and evaluation,
 - Linking budgets to performance,
 - Accountability and incentive structure, and
 - Improving service delivery.

The first four of these elements of an outcomes-focused approach are particularly relevant to developing a strategy to ensure outcomes are met. The fifth relates to the connection with citizens. In fact, the information which was gathered during this review of HCP implementation suggested a strong need to focus more on the interface of delivery to clients, in developing an outcomes-focused approach to policy. Learning on this issue will be outlined in the next chapter. CHAPTER 2

Policy delivery and organisational culture

Introduction

- 2.1 The information which was gathered during this review of HCP implementation suggested that there was a need to look more at the process of delivery to clients, particularly at the interface between that delivery process and clients. However although the OECD (2008) review does consider the sequence of actions needed to ensure a policy is put into practice, it does not provide a very strong focus on this issue. For this reason it was decided to look at two particularly key reports in relation to delivery of public services in Ireland.
- The first of these reports is the *Developmental Welfare State* (NESC, 2005), as one of its main themes is the development of citizen-centred services, and so some of its recommendations were found to be particularly relevant to implementation of the home care package policy. The second is the NESF (2006) study, *Improving the Delivery of Quality Public Services*.
- The key issues highlighted in these two reports will be outlined first in this chapter, before moving on to outline some key aspects of a roadmap for policy delivery, and then the influence of organisational culture on policy implementation.

The Developmental Welfare State

- The Developmental Welfare State, which will be referred to as the DWS in this report, arose from a recommendation from the National Economic and Social Council that a framework be developed for Ireland to create an effective and world-class set of institutions and policies in the social sphere a developmental welfare state.
- DWS, like the OECD review, advocates a greater focus on policy outcomes, on linking budget to outcomes, on data collection and learning from it, and greater local co-ordination supported by a strong centre. However, on the issue of services, it is more comprehensive, and suggests a stronger focus for Government than the OECD review.

- First, the DWS recommends a framework of three overlapping areas of welfare state activity services, income supports and activist or innovative measures. But of these three, the DWS 'regards the radical development of services as the single most important route to improving social protection' (NESC, 2005: xix). It considers that such services are particularly important in times of 'lifestress' (and Chapter four will show how the level of dependency which moves a person towards institutional care is often a lifestress, both for the individual and their family).
- 2.7 Secondly, the DWS introduces the idea of services with 'tailored universalism', which is about providers adjusting their services to accommodate a more diverse public, including 'a public whose individual members have different requirements if they are to have an equal opportunity to benefit from the service' (p.203). 'The services themselves are not uniform outputs but are capable of gradation and adjustment to help diverse groups attain similar outcomes' (p.155). Under this approach, clients would dictate programme specifications, rather than the more traditional 'client meets programme criteria' approach. Tailored universalism would also involve taking into account an individual's capabilities, as well as strengthening the capacity of their family and local community to address social need. A number of these issues will be shown to be particularly relevant to the home care package policy.
- 2.8 Thirdly, the DWS envisages that the Government would ensure equity, and that the socially disadvantaged would benefit proportionately from services provided. It also suggests that 'the need to ensure that demand for publicly-funded services is tempered by awareness of the cost of supplying them is better met through arrangements such as differentiated charges through which the public system recoups some of its operating expenses' (p.203). As will be shown later, the issue of equity in relation to charges and costs is one that exercises many of those involved in implementation of the home care package policy.
- 2.9 Fourthly, the DWS says that for government, it is of 'paramount importance... to concentrate on specifying, attaining and monitoring the standards that should govern the various areas of service provision' (NESC, 2005:207). Standards should be jointly set, with this process co-ordinated by the State, eliciting agreement from among stakeholders as to what they can achieve and what standards will improve practice and performance. Such standards should be measurable, and be validly compared across diverse service providers (government, community and voluntary sector, or private providers). They should also be used as tools for systematic learning, both for what outputs are produced, and the processes used to do that. They should also be the basis for intervention by central authorities and for the allocation of budgets. This issue of standards will be shown to be of key importance for the implementation of HCPs.

- **2.10** This brief outline of the DWS therefore suggests four other issues which should be taken into account in planning and developing policies for delivery, particularly those policies related to human services. These are:
 - Tailored universalism in types of services delivered,
 - Standards for delivery,
 - Monitoring of delivery, and
 - Equity in provision.

Improving Delivery of Quality Public Services

- 2.11 Improving the Delivery of Quality Public Services (NESF, 2006), which will be referred to as QPS in this report, looks at how to put the citizen at the centre of service delivery. This NESF report is therefore very comprehensive, covering many issues which are important in terms of delivering quality public services. However two overall themes are evident in its discussion and recommendations. One is the management of the services, and the other is the interface between the service and the client (clearly with some overlaps between the two).
- **2.12** In terms of *service management* the following were recommended:
 - Improving outcomes of delivery,
 - Improving design and co-ordination of services,
 - The need to monitor and evaluate, and to learn from best practice,
 - Reporting on the outcomes of quality standards set, and learning from these,
 - Developing new models of service delivery,
 - Provision of greater choice of service deliverers,
 - Using technology well in delivery, and training staff better in delivery,
 - Provision of multi-annual funding, and resourcing providers in more innovative ways, and finally,
 - The need for better links between national policy makers and local deliverers. This would also involve a better balance between control and autonomy (centre vs local).
- **2.13** In relation to *interface with the client*, the following were recommended:
 - Equity in service provision,
 - The establishment of quality standards around service delivery,
 - Facilitating client access to services, through for example clear and accessible information, a broker or case manager who would advise clients, advocacy, and outreach,

- A continuum of services, so that transferring from one service to another is easier,
- Involvement of users in shaping services, and
- Redress and appeal mechanisms.

All of these should be taken into account when designing and managing services.

- 2.14 The issues identified under 'service management' parallel the issues identified in the OECD report as important to lead to outcomes-based policy, and this again affirms their importance for effective policy implementation. When looking at 'interface with the client', some issues in QPS were also flagged in the OECD report, such as involvement of users in shaping services, and a need to look at links between national policy and local level delivery. Similarly some of the QPS issues were also noted in the DWS, such as equity in service provision, and the establishment of quality standards.
- 2.15 Together, the three reports looked at (OECD, DWS and QPS) all indicate, to varying degrees, the need for a focus on *delivery to the client* to ensure good implementation of services. They indicate that a variety of issues can be considered under delivery to the client. Particularly key are:
 - equity in provision,
 - better planning for delivery, including the connection between policy makers and policy deliverers,
 - standards for delivery, and review of these,
 - client involvement in shaping of services, and
 - innovative means of delivery (e.g. facilitating access to information, use of private and other service providers, use of IT).

Roadmaps for Delivery

- 2.16 As well as considering the issues which are important for the client and need to be put into place when designing policy, it is also essential to consider what kind of process needs to exist so that the designed policy can be delivered. Policy implementation nearly always involves a process of organisational change, and that this does not happen all at once. Instead studies indicate a type of roadmap of delivery. A review of over 1000 studies of implementation by Fixsen *et al* (2005) outlined that the process of organisational change which characterises implementation of new practice or policy occurs in stages, as follows:
 - Exploration and adoption. During this stage, options for policy implementation are explored, and a decision is taken whether to adopt them (or not). In this stage, staff interest would be assessed, as well as level of resources, potential barriers to implementation etc.

- Programme installation. At this stage, structural supports to implement the policy are put in place, such as funding, HR resources, policy development, referral mechanisms, and reporting mechanisms. Expected outcomes are also defined.
- iii Initial implementation. This is the stage of change, which is at the core of implementation. Change is now required in skill levels, organisational capacity, culture etc. At this stage, fear of change and inertia combine with the difficult work of implementing. This is a time when new practices may end, overwhelmed by the process.
- iv Full operation. This stage is reached once the new learning is integrated into practitioner, organisational and community practices and procedures. It is characterised by e.g. full staffing complements, full client loads and referrals flowing according to agreed-upon inclusion criteria.
- Innovation. Implementation of a programme in different sites can lead to new learning, and at this stage there can be opportunities to refine the implementation (although it is important to make sure that any innovation does not constitute 'drift' away from the core elements of the policy and its implementation components.)
- vi **Sustainability.** It takes two to four years to fully implement an evidence-based programme in a new setting – and then it needs to be sustained. This involves, for example, replacing staff who leave with others who are as effectively trained and skilled. Funding streams also need to be maintained. External systems (political alliances, champions) can change, and the challenge is to ensure the policy survives long-term.

Core components of implementation

2.17 Obviously quite an amount of work is needed to move from the first stage of implementation to the last. Fixsen *et al* (2005) outline the key parts of a roadmap to get there. First, to ensure that effective policies are being implemented, it is necessary to identify what Fixsen *et al* call the 'core components for intervention'. These are the most indispensable interventions in a programme, which are essential to achieving good outcomes for clients. At first, it can be difficult to decide what interventions are the most important to replicate among the many variables contained within a policy or procedure, even one that has been the subject of extensive research in its original location. However, knowledge is accumulated over time. Each attempted implementation of a programme reveals further information about what its key interventions are.

2.18 Studies have found that identifying the core interventions needed for implementation saves time and resources which could be wasted attempting to implement a variety of interventions which do not produce the desired outcomes (Fixsen *et al*, 2005:25). Fixsen *et al* also list a number of studies which have found that local adaptations of core interventions are not inevitable, and instead it is possible to implement the same core interventions in a wide variety of different locations (outlined in Fixsen *et al*, 2005:25). These studies do note that once the key interventions for successful implementation have been identified, then it is possible to alter some other aspects of implementation to suit local sites.

Implementation drivers

- **2.19** The core components of intervention identified then need to be supported by what are called 'implementation drivers'. These drivers provide support for the interventions to be carried out. They are:
 - Staff selection (it is important to select those with the right skills and motivations),
 - Pre-service and in-service training of staff,
 - Ongoing consultation and coaching with staff,
 - Staff and programme evaluation,
 - Facilitative administrative support (good leadership), and
 - Systems interventions (working with external systems to ensure that the finance, HR and organisational resources required are available).
- 2.20 These implementation drivers do not work in isolation for example, it has been found that training on its own (dubbed 'train and hope') is not at all as effective as training linked to ongoing consultation and coaching (Fixsen *et al*, 2005:40). The drivers need to work together to provide effective support for good interventions to be implemented.
- 2.21 The role of mentors (called purveyors by Fixsen *et al*) is particularly important in helping core interventions and implementation drivers be put in place. As outlined above, a mentor is an individual or group of individuals who actively works to effectively implement a practice or policy. They transfer knowledge as a process, rather than as a one-off activity, by helping to recreate a complex set of routines in a new setting and to keep it functioning.

- 2.22 In a new implementation site⁸, a mentor begins by assessing the readiness of the interested organisation with questions about its history, current resources, current staffing patterns, and relationships with key stakeholders. In addition, s/he assesses potential barriers to implementation relating to e.g. funding, staffing, referrals. The result of the exploration stage is a clear implementation plan negotiated with the organisation, with tasks and timelines to facilitate the installation and initial implementation of the programme. This is followed by training, and on-going coaching by the mentor. After this the mentor follows up by regular contact with the implementation site, evaluation of staff and actions, and learning from monitoring and feedback. With experience, the mentor or mentor group can learn to change approaches that do not work early in the process, and avoid later problems. In addition, an experienced mentor can describe to the managers of an implementation site the problems likely to arise and the solutions that can be applied.
- **2.23** Attention to all of these practices helps to ensure that an effective staged delivery plan for policy implementation is in place.

Organisational culture

- **2.24** Meanwhile, it is very important to consider the organisational culture of the body charged with implementation. Otherwise, as Fixsen *et al* (2005) point out, the outcomes of policy implementation may veer towards *paper implementation* or *process implementation*, rather than full *performance implementation*.
- 2.25 Paper implementation means adopting new policies and procedures, but not progressing further. This can be especially prevalent when outside groups are monitoring compliance and much of their monitoring focuses on a paper trail. In such a situation organisations are able to adopt policies but do not put operational routines in place which will move towards changes in policy implementation. Process implementation does involve putting new operating procedures in place, such as training, supervision, and changes in reporting etc. However, this work is not linked to new practices. For example, training can take place which is not followed up, supervision might be unrelated to what was taught in training, and data might be collected which does not affect decision-making. Finally performance implementation is where procedures and processes are put in place so that identified change takes place which benefits clients and the organisation. Although Fixsen et al do not expand on this, a number of other researchers have outlined how performance implementation is more likely to occur when organisational culture is considered during the change process.

⁸ The 'site' is any location in which a policy is being delivered. This could be a geographical site, such as a Local Health Office area; or it could be a smaller site such as a school, community centre, hospital etc.

- **2.26** Policy-making and implementation involves a political context, many different actors, often with conflicting goals and values, and multiple sites of implementation. All of these actors operate in organisations with different cultures, and there is growing and abundant evidence that organisational culture has powerful effects on the thinking, behaviour, expectations, motivation and learning capacities of those who work in them.
- 2.27 There is growing evidence and experience that without engaging with the culture of an organisation, change or resistance to change cannot be fully understood or managed. The most significant risk danger faced by those trying to implement policy change is not fully appreciating the depth and power of culture.

What is organisational culture?

- 2.28 Culture is commonly understood as the values and norms of an organisation. It can be formed by a deliberative process, for example, by the imposition of the beliefs, values and assumptions of the founders and key leaders that made the organisation successful, which is consolidated and modified by subsequent leaders. Primary embedding mechanisms of culture include:
 - What leaders pay attention to, measure and control;
 - How leaders react to critical incidents and crises, particularly incidents that are emotionally charged or anxiety producing;
 - Deliberate role modelling and coaching;
 - Allocation of rewards and status; and
 - Recruitment, selection and promotion.

There are also secondary articulation and reinforcing mechanisms, such as organization design and structure, stories and myths, and formal statements of organizational philosophy, and values.

2.29 Cultures become so stable and difficult to change because they represent the accumulated learning of a group – the ways of thinking, feeling and perceiving the world that have made the group successful by their own lights. This approach helps to show why, for example, attempts to instil a 'culture of accountability' in an organisation have often come adrift even though all stakeholders may hold espoused values of accountability. Significant elements among those stakeholders may hold deeper tacit assumptions about risk, how success is measured, and the dependability of other people that are in conflict with the espoused value. Understanding how such tacit assumptions are formed and persist lies in the understanding and investigation of the formation of culture.

- 2.30 A further complexity is added by the fact that large organisations rarely have a unitary culture. Whenever a group has enough common history, a culture begins to form. Thus, cultures are formed at the level of departments, teams and work groups. Similarly, cultures arise in functional groups, for example, professional and expert groups and 'communities of practice' that share common experiences. Cultures also form at regional and local levels. The process of culture formation operates differently within each of those units, forming distinct sub-cultures⁹. As a consequence, organisational learning and organisational change is difficult because it has to engage with these different sub-cultures.
- 2.31 Any attempt at implementing new policies and initiatives often acts to surface the deeper aspects of an organisation's culture or sub-cultures. Many change efforts, policy initiatives and programmes fail not because of faulty conception or content, and despite having succeeded in some locations but because they fail to understand the deep assumptions or 'frames' of the local culture. It could be argued that many of the failures in policy implementation in the public services could also be traced to the new policy being seen simply as a set of tools or a management initiative that was never internalised into the local culture.

Organisational culture and work in the health sector

2.32 • Some of the issues identified by organisational psychologists as influencing organisational culture include defences such as projection and splitting (Mosse, 1994:4). This is a defence mechanism whereby unwanted characteristics are ascribed to another person or group. This can be evident in a number of ways in health care organisations. For example, there are different and conflicting models of care for dependent, including older, people. These include the warehousing model, which views the patients as dependent, and with care focused on prolonging life; and the horticultural model, which considers that patients can develop their potential, and so care is focused around this. Both models contain inadequacies, and both encompass a level of guilt around the social death sentence passed when people enter residential care. It is possible for different healthcare professions in an organisation to promote different models (for example physiotherapists or occupational therapists may promote a horticultural model, while nurses may promote a warehousing model), and this can lead to clashes (Zagier-Roberts, 1994b).

- 2.33 Obholzer (1994) also outlines how healthcare system styles of management are increasingly separating care-giving staff from decision-making. There are more layers of managerial staff involved in decision-making, and a lot of their time is wasted on committees and bureaucracy. He argues that this is a way for managers to avoid face-to-face contact with patients and their ailments, and the effects of the decisions they make to live within allocated budgets.
- 2.34 To add to these psychological divisions among different groups of health sector workers, as more care is moving out of residential institutions into the community, care is then provided by a large range of different agencies, and so more co-ordination is needed between all of them. If this does not occur, more gaps and/or overlaps in care are likely to occur (Zagier Roberts, 1994c).
- 2.35 Other defences which can arise include difficulties in defining the 'primary task' of the organisation. The primary task is the task an organisation must perform if it is to survive. For human services organisations, at its simplest, the primary task is usually to enable people who enter the organisation in one state (e.g. ill) to leave it in a different state (e.g. better). However, in institutions which exist to help people, there are usually multiple tasks to carry out, and often conflicting assumptions both inside and outside the organisation about what the primary task might be. This can lead to vague definitions of the primary task which the organisation is set up to do, or a tendency to define methods of work rather than what these methods are supposed to achieve (Zagier Roberts, 1994a). Different parts of the organisation might also have different views as to what the primary task of the organisation is. Where an organisation's primary task is not clearly defined, the result can be inadequate task definitions, which provide little guidance to staff or managers about what they should be doing, how to do it, or whether they are doing it effectively. There is then a danger of division among the groups within the organisation, or the emergence of some other primary task unrelated to the one which the organisation was originally set up to carry out.
- 2.36 Overall, these factors can lead to a considerable number of divisions between different groups organising and providing healthcare. This can lead to conflict and rivalry, which obviously can interfere with effective implementation of programmes. Clearly, organisational culture can have quite an impact on the extent to which planned policies are implemented.

Key factors for an outcomes-focused approach to policy implementation

- **2.37** So putting together the key issues identified from the OECD review, the DWS and the QPS, as well as material on organisational culture, provides a list of six key issues which are relevant to an outcomes-focused approach to policy implementation, and against which the development and implementation of the HCP policy will be compared. These are:
 - Strategy plans with agreed outcomes,
 - Measurement of inputs, outputs and outcomes; and monitoring and evaluation using this measurement,
 - Linking budgets to performance,
 - Accountability and incentive structures,
 - Focus on delivery to the client, particularly:
 - equity in provision,
 - plans for delivery, including national-local links,
 - standards for delivery, and review of these,
 - client involvement in shaping of services,
 - innovative means of delivery (e.g. facilitating access to information, use of private and other service providers, and use of IT), and
 - The role of organisational culture.
- 2.38 In line with the Terms of Reference, the way the HCP policy was designed and implemented will now be assessed in relation to these six key issues. Originally it had been planned to use the key issues identified in the OECD model only, but it became clear during the work that it was also necessary to focus more, first, on delivery to clients, for which the DWS and QPS provided a more comprehensive model; and second, on the role of organisational culture.

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Introduction

CHAPTER 3

3.1 In this Chapter, the focus moves to point two of the Terms of Reference, which is to 'examine the development and formulation of the Home Care Support Scheme... focusing especially on the nature of the objectives, resources and delivery systems specified in the policy as viewed in an outcomes/performance perspective.' This Chapter will start by outlining in detail what home care packages are, and then move on to how the policy was designed. In Chapter four, the implementation of the policy will be outlined; and in Chapter five, an assessment will be carried out of the extent to which both the design and implementation of HCP policy reflect the key issues advocated in the OECD (2008) review of the Irish public service, the Developmental Welfare State (NESC, 2005) and Improving the Delivery of Quality Public Services (NESF, 2006).

Outline of Home Care Packages

- 3.2 As outlined in the Introduction, the Home Care Package scheme provides care in the home, mainly to older people who are at risk of admission to long-term care. They form part of €4.7 billion allocated in the National Development Plan 2007-2013 for a range of measures to help older people to live independently in their own homes and communities for as long as possible, including home care packages, the home help service, meals on wheels, community intervention teams and respite/day care services (Government of Ireland, 2007).
- Each HCP is tailored to the needs of an individual, based on their medical condition and the level of care required. Packages may include the services of nurses, home care attendants, home helps and various therapies including physiotherapy services and occupational therapy services. In some packages there might be a greater emphasis on home care assistants while other packages may include a greater level of therapy and nursing, depending on individual need¹⁰.

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¹⁰ See the HSE website - http://www.hse.ie/eng/Find_a_Service/Older_People_Services/Benefits_and_Entitlements/Home_Care_ Packages.html

- As it is an administrative scheme, there is no automatic right to the HCP scheme, nor to avail of services under it. As standardised national guidelines on its implementation are not operational, each HSE Local Health Office (LHO) there are 32 nationally has responsibility for the operation of its own scheme". This means that schemes vary in different parts of the country. For a start, the budgets of the LHOs vary (see Chapter four). Means of accessing the scheme also vary by area. Some LHOs employ case managers or co-ordinators specifically to manage and allocate the HCP budget, although this is not the case in all areas. Then there are different methods of assessing eligibility to receive the package. Some LHOs use means tests to allocate the packages.
- 3.5 The amount and type of care received through a HCP can also vary by area. Issues such as resources, the personnel available to deliver services, demand in each area and individual needs all influence that. Delivery mechanisms also vary. There are four main types:
 - Direct provision by the HSE, usually through staff directly employed by the LHO;
 - Services provided through private commercial agencies, but paid for by the HSE;
 - Services provided through community and voluntary groups, and paid for by the HSE; and
 - Cash grants, which allow people to use the funding to organise their own care. However, this arrangement is no longer available in many areas.

In some areas, the package may consist of a combination of direct services and cash payments. Overall, 28% of new HCP recipients received a cash grant to organise their own care in December 2008 (HSE, 2009c).

- In several areas the HSE has had a list of 'preferred providers' which meet set HSE standards in provision of the homecare support aspects of HCPs. These providers are usually commercial agencies, but also include voluntary groups. For example, the list for Dublin and Mid Leinster includes 12 providers, two of which are voluntary groups and ten of which are commercial providers. These organisations responded to a request for tender to be on a preferred providers list, to provide homecare supports. HCP co-ordinators, and/or individuals who are approved to receive a HCP, can choose a care provider from the organisations on this list. The list of preferred providers in the Dublin and Mid Leinster region has now elapsed, but a tender to develop such a list at a national level is being prepared.
- 3.7 In 2006 Home Care Packages were allocated €55m of funding from the HSE. By 2008, this had increased to an annual allocation of €120m to fund HCPs. In total, approximately 8,000 people were benefitting from a home care package at any one time in December 2007 (PQ 15143-08).

¹¹ As outlined by the Citizen's Information Board – see http://www.citizensinformation.ie/categories/health/health-services-for-older-people/home-care-packages-for-carers, accessed 24 June 2009

- 3.8 This funding represents a very significant increase in support for care in the home, and provides a much greater range of home care than was available previously, as HCPs are focused particularly on provision of medical care (although home help and personal care services are also provided). This allows people who are much more highly dependent to remain at home.
- 3.9 The variations by LHO in how the HCP policy is implemented will be considered in detail in Chapter four. Meanwhile, this Chapter will focus on how the policy was designed.

Background to the HCP policy

- As outlined earlier, it is the wish of most older people to continue living in their own homes for as long as possible (NESF, 2005). This is supported by a range of State policies, with *Towards 2016* outlining that part of its vision for older people is that 'every older person would have adequate support to enable them to remain living independently in their own homes for as long as possible' (Government of Ireland, 2006: section 32.1). This is not however a new focus of Irish policy on older people. In 1968, the *Care of the Aged Report*, the first major national report on services for older people, which was written by an inter-departmental committee, stated that 'It is better, and probably much cheaper to help the aged to live in the community than to provide for them in hospitals or other institutions' (Stationery Office, 1968:13). The report recognised that this would require a wide range of services, such as domiciliary nursing, and therapy in the home.
- 3.11 In line with this, in 1970, the home help service was introduced via the Health Act, and developed in various health boards. However, this was circumscribed as health boards were empowered, rather than obliged, to provide home help (Lundstrom & McKeown, 1994). This meant funding for home helps was not guaranteed, and had to compete with other services, leaving it in a weaker position. In addition, as the home help service was organised locally there were no definite or uniform conditions and types of support. This is still the case, and as will be outlined in Chapter four, HCP provision follows similar patterns.
- **3.12** In 1988 *The Years Ahead*, the Report of the Working Party on Services for the Elderly, was published. This national policy document set objectives and made proposals for the management of services for older people, and set out national norms for the provision of these services. Once more, it underlined the wish of many older people to remain at home. The report's four main principles were to:
 - maintain older people in dignity and independence at home,
 - to restore to independence at home those older people who become ill or dependent,

- to encourage and support the care of older people in their own community by family, neighbours and voluntary bodies, and
- to provide a high quality of hospital and residential care for older people when they can no longer be maintained in dignity and independence at home.

The report made a range of recommendations, including that Health Boards should be legally obliged to provide or make arrangements to provide services to maintain people at home who would otherwise require care in another setting. This recommendation was not implemented, and in fact a review of how the report's recommendations were implemented found that there was no increase in the proportion of resources devoted to community services in over ten years (see NCAOP, 1997). However, individual health boards throughout the 1990s produced policy documents focusing on this wish for older people to remain in their own homes, and services to support it (Leonard, 2008).

- **3.13** In 2001, the Health Strategy, *Quality and Fairness: A Health System for You,* which set out a blueprint for development of the healthcare system, proposed a number of specific actions relating to older people. These included strategy planning to respond to the needs of older people, an expansion of services, clarification and simplification of eligibility criteria, integrated funding to support care in the home, greater integration of care services, involvement of older people in care design, and more emphasis on quality standards (see NESF, 2005).
- 3.14 Following this, in 2003, the national agreement, Sustaining Progress, which covered the period from 2003 to 2005, included ten special initiatives to provide a new way of addressing major crosscutting policy issues of special concern. One of these special initiatives was on care, for children, people with disabilities and older people. In relation to care for older people, the key commitment in Sustaining Progress was to set up a working group to examine the strategic policy, cost and service delivery issues associated with the care of older people. This working group was to produce a study examining the future financing of long-term care in Ireland, to be published early in 2003 (see Government of Ireland, 2004).
- 3.15 The Working Group was duly set up, chaired by the Department of an Taoiseach, with representation by senior officials from the Departments of Finance, Taoiseach, Health and Children, and Social and Family Affairs. Its Terms of Reference were to:
 - identify the policy options for a financially sustainable system of longterm care; and
 - rationalise the range of benefits, services and grants (both statutory and non-statutory) currently in place, and address associated issues.

This work was to take into account the findings of the Mercer and O'Shea reports, two reports published in the early 2000s, the former on financing of long-term care, and the latter reviewing the Nursing Home Subvention Scheme (see Working Group on Long-Term Care, 2005).

3.16 The Working Group focused on people over 65 in need of care, and recommended that a central principle of policy going forward should be to support older people to remain in the community, and considered that a target of 4% of people aged over 65 in long-term residential care should be achievable in the medium term (Working Group on Long-Term Care, 2005: 11). It agreed its 'Long-Term Care Report' at the end of 2005 and submitted it to Government in January 2006. It is this policy report which recommends the introduction of HCPs, and the conditions under which they should be introduced and developed, and so will be outlined in detail in the following sections.

HCPs as proposed by the Long-Term Care Report

- **3.17** The LTC report stated that 'the Group believes that there should be a move towards the provision of home support packages... focussed... on older people currently in residential or hospital care, who have the capacity to return to their homes, and at people in the community who are considered to be at risk of requiring residential care in the absence of such intervention' (p.7). 'This should be on the basis of a national standard approach, with clear criteria in terms of access, quality standards and availability', although 'each package will be tailored to the needs of the recipient, taking account of his or her particular circumstances and the presence or otherwise of a carer'. Requirements for specialised equipment should also be covered if appropriate. In proposing this, the Group noted that an evaluation of pilot home care packages which had been in operation in Dublin for two years previously was taken into account.
- **3.18** The report stated that HCPs should be introduced through 'an initial targeted approach in order to allow further work take place before decisions can be made on a longer-term programme of services' (p.7). In line with this, a formal evaluation of the new HCPs was to be completed by mid 2007, covering their costs and benefits, delivery models, outcomes for recipients, availability of family or other informal care, impact on recipients, family carers and acute hospitals. Detailed information was to be collected by the HSE to inform this evaluation. This included information on the number of dependent people over 65 by level of care need, the quantity of community services currently being provided and the extent to which these are used by the same person, geographic breakdown of need and service availability, the number of dependent older people with informal care available to them and the hours of care provided, the capacity of older family carers, and quantification of therapeutic needs.

- 3.19 This evaluation (commissioned by the Dept of Health and Children in early 2009) also plans to generate figures for the range, distribution and average cost of caring for older people in the community. These costs were not known at the time that the Long-Term Care Report was being written up (although quite considerable data was available on the financial costs of residential care), but were considered necessary in order to take decisions on future financing of LTC. The report outlined that the potential costs of HCPs would depend on demand/need, the average cost of a HCP, the supporting infrastructure of community services, and the administrative costs of HCPs. However, there was no comprehensive assessment of need available at the time. Therefore the report put forward various estimates, ranging from 70,000 older people in the community needing care (an estimate from the Mercer report), to a figure of approximately 15,800 people needing intensive HCPs (based on Scottish figures which found that 2-3% of those aged 65-79 need intensive home care, and 5% of those over 80). The latter amount was later adopted within the HSE as an informal target to be met by 2015.
- **3.20** A number of other systems were also to be put in place for implementation of HCPs. These were
 - a standardised care needs assessment framework¹²,
 - a national standard financial assessment framework (as co-payment was recommended, based on an individual's financial resources)¹³
 - formal protocols for case management and delivery of HCPs on a national basis¹⁴, and
 - an appropriate structure to ensure quality standards (p.8).
- **3.21** Section 9 of the report outlined that all but the latter were to be set up by mid 2006, i.e. within the first six months of providing HCPs (see p.16), while no deadline date was given for standards development. Two of these issues, the standardised care needs' assessment and the standard financial assessment framework, were also to be developed for residential care.
- **3.22** In terms of delivering HCPs, private sector providers were to be involved, and there was to be an emphasis on providing sufficient skilled staff. As part of the overall LTC approach, a staff planning exercise was to be carried out by end 2006, to assess the amount of staff needed.

¹² This is a process used to assess the needs of a person for care. Typically such a process asks questions about the physical and psychological health of the individual, and their ability to carry out activities of daily living.

¹³ Co-payment means that the State and the individual each pay for part of the individual's care. A standard financial assessment framework is necessary to ensure that this is organised in a standard and equitable way.

¹⁴ Case management is the development of individually tailored care plans, with a person-centred and multi-disciplinary focus, and delivered through a case manager or a team.

- **3.23** Further development of housing for older people, home helps and respite care was also considered necessary for HCPs to be fully successful. The Report outlined that informal care should be seen as complement to informal care provision. Both of these factors are in line with the approach taken to home care policy internationally, with many countries aiming to integrate various types of State supports for long-term care, as well as linking with the support provided to older people by family and other unpaid carers (see OECD, 2005).
- 3.24 Following completion of the LTC report, funding of €55m was introduced for HCPs in the 2006 budget, to provide approximately 2000 packages at an average value of €525 per recipient. As proposed in the report, they were to be targeted at older people living in the community or who were inpatients in an acute hospital, and who were at risk of admission to long-term care. They could also be offered to older people who were in long-term care but who wished to return to their homes. This first tranche of funding was followed by a further €55m allocated in the 2007 budget. For 2008, €120m was allocated, and 4,710 home care packages were in operation, benefitting 11,987 people in each year, and with approximately 8,990 in receipt of HCP services at any one time (HSE, 2009c). This is a very significant amount of funding, which facilitated a goal of policy for over 40 years to be more fully realised.
- 3.25 Meanwhile, progression of a number of the strategic implementation supports specifically the standardised care needs assessment, financial assessment, case management protocols, and the HCP evaluation were also included as commitments in *Towards 2016: Ten Year Framework Social Partnership Agreement 2006-2016* (see Government of Ireland, 2006). A range of mechanisms were set up to develop these, as outlined in the following sections.

HCP implementation guidelines developed by the PCCC Working Group

- 3.26 First, a Working Group was established by the PCCC (Primary, Continuing and Community Care) Directorate of the HSE, on request from the Department of Health and Children, to develop guidelines on how to implement the HCPs across the country. (These guidelines will be referred to as the PCCC Working Group guidelines). The guidelines, completed in April 2006, covered who the HCPs were aimed at, the funding to be allocated under each HCP, means tests, how referrals would work, assessment of the needs of the older person, the schedule of services to be provided to each older person, consultation and co-ordination with the older person and existing services, different types of HCP provision (including cash grants), monitoring and review of HCPs, and the data to be collected on them (see Working Group on Home Care Packages, 2006). The following sections will outline the detail of these, although it is important to note that the guidelines are not yet operational, an issue which will be explored more fully in Chapter five.
- **3.27** The guidelines outlined that 'the priority will be older people living in the community or who are inpatients in an acute hospital and who are at risk of admission to long-term care. The home care packages will also be available to those older people who have been admitted to long-term care and now wish to return to the community. In addition, the packages will be offered to people who are already using existing core services, such as home helps, but need more assistance to continue to live in the community' (p.4).
- 3.28 The guidelines set the average cost of a HCP at €525 per week, although they allowed this amount to be exceeded in exceptional cases. A financial means test was also included. Single people with an income of €292 or less per week (€484 per couple), with the first €20,000 of savings disregarded, would receive full funding for a HCP. Where a person's assessed income exceeded that amount, a sliding scale of financial provision would be provided (p.3). A form for applicants to complete on this was provided.
- **3.29** The guidelines stated that the first point of contact for those seeking a HCP should usually be the PHN (Public Health Nurse) in Community Services. Referrals to the PHN should be accepted from all sources, including individuals, families, carers, GPs, PHNs, hospital or other medical personnel.
- **3.30** In relation to a comprehensive multi-disciplinary assessment of the needs of the older person, the Guidelines noted that at the time of writing the HSE was in the process of drawing up a national assessment tool for all services for older people. This was being carried out by another working group. Until this was finalised, the individual LHOs were asked to use their existing assessment tools in relation to HCPs. This meant that a standardised needs assessment was not put in place, and so different LHOs used different ones.

- **3.31** Each person receiving a home care package was to have a Schedule of Services drawn up for them, setting out in writing all the services and supports they required over seven days, and with details of the formal and informal care being received. The older person's opinions were to be taken into account when devising their Care Plan, which would set out the agreed actions to be undertaken by all services, supports and care staff (the Guidelines do not outline how or if the Schedule of Services and Care Plan differ, and it is not clear how they do). The guidelines also state that, at the time of writing, the HSE was in the process of drawing up national documentation on this, and in the interim individual LHOs were asked to use existing documentation in the context of HCPs. Again this would lead to different LHOs using different formats.
- **3.32** The guidelines outlined that HCP services can be provided directly by the HSE, by voluntary organisations or by private sector providers, or through a mix of these. SLAs (service level agreements) should be in place for the services delivered by the voluntary or private sector providers, and these should specify at a minimum the services to be provided, as well as the monitoring and evaluation arrangements to apply.
- **3.33** Cash grants could also be paid to an older person or their representative, although it was not intended that they be used to pay informal carers (except in very exceptional circumstances where all other care options had been fully exhausted). Where cash grants were given, the schedule of services and care plan was to be accepted by the older person and his/her representative, before any cash grant was approved. The HSE needed also to ensure that the person or their representative had the ability to manage a cash grant and to take responsibility for organising suitable services; as well as understanding their legal responsibilities as an employer. General provisions for regular review and monitoring of these payments and the services purchased were also outlined.
- **3.34** It was also outlined that each HCP needed on-going and regular review by the relevant PHN or case manager. This is to ensure that the HCP meets the older person's needs. Such reviews could result in the HCP being increased, decreased, continued or discontinued, or the referral of an older person to another service. In addition, on-going monitoring and evaluation of the HCPs was needed to ensure feedback and consultation with HCP recipients, the suitability of care being provided, and to assess changes in the older person or in the care arrangements.
- **3.35** More strategically, a range of data was outlined to be collected by each LHO, so that the HSE could monitor and review the effectiveness of HCPs overall. This data is outlined in Table 3.1 below.

Table 3.1 Data recommended to be collected on HCPs by each LHO, in 2006PCCC Working Group Guidelines

The following information will be collected on a monthly basis:

Number in receipt of HCPs (incl. grants) at end of the month by LHO area and Administrative Area

Number of recipients who have benefited from Home Care Packages, year to date, by LHO area and Administrative Area

Age profile of recipients (<65, <80)

Average weekly cost of Home Care Package

Range of weekly costs of Home Care Package

Cash grants: Numbers availing of Cash Grants as part of HCP; Average Rate of cash grants this period; Range of Cash Grants year to date (highest rate paid/lowest rate paid)

Average hours per week in a HCP

Number of wholetime equivalents (year to date) assigned to HCPs

Total spend on WTEs¹⁵ (year to date)

Breakdown of WTEs recruited into various home support services, the number of hours provided by discipline and the cost; Breakdown of expenditure by service/support type

Overall expenditure on HCPs

Numbers discharged from acute hospitals with a Home Care Package

Sources of referral – Acute Hospital, Community, Other

Number of HCPs ceased this month

The following information will be also recorded, and evaluations undertaken:

Reasons for ceasing – transfer to continuing care; condition improved; deceased; transfer to acute care; other

Reviews of cases

Questionnaires and interviews with clients and their [informal] carers

Questionnaires to staff involved with HCP

Monitor suggestions/comments cards received

Monitor complaints

| For the formal evaluation of Home Care Packages planned for 2007, details of each patient availing of a Home Care Package are to be collected, including: | | |
|---|--|--|
| Date | and detail of initial assessment of needs leading to HCP | |
| Date | and details of subsequent re-assessments | |
| Outc | ome of assessment/review – any changes in health status and/or level of dependency | |
| Age o | of care recipient | |
| Gender | | |
| Level | Level of dependency – medium, high, maximum | |
| Was | patient previously in residential care? | |
| Was | patient previously in an acute/hospital setting? | |
| Infor | mal care being provided, if any, and by whom | |
| Deta | ils of service being provided (Schedule of Services and costs) | |
| Leng | th of time patient is in receipt of HCP (start and finish dates) | |
| Whe | re package has ended has patient been admitted to residential care | |
| | | |

Source: Working Group on Home Care Packages, 2006: 13-14

Guidelines on Quality Standards for Home Care, developed for the Expert Advisory Group on Services for Older People

- The PCCC Working Group guidelines did not cover quality standards in relation to HCPs. However, a different group has been working to develop standards for home care services, particularly home help services, provided by the HSE, voluntary and private providers alike. These standards would apply to the home help and home care support elements of HCPs, although not to the professionals providing home supports as part of a HCP, such as nurses and paramedics.
- **3.37** An interagency group to develop these draft standards for home care services was set up by the Services for Older People Expert Advisory Group (EAG), which was an advisory group set up under the PCCC division of the HSE. This interagency group represented the HSE, voluntary providers, private providers, groups representing older people, and hospital staff, and had developed draft standards for approval by the EAG in November 2008. These Draft National Quality Guidelines for Home Care Support Services (referred to from here on as the EAG Standards Guidelines) are over 40 pages long, and are divided into five sections, headed rights, protection, home care support needs, staffing, and governance and management (see Expert Advisory Group on Older People, 2008). They focus on the standard of care given to an older person.

- **3.38** Under Rights, these Guidelines recommend that clients be provided with good information, through a client's services guide. Clients also have a right to be consulted and to participate in organising their home services, and their consent should be obtained. They should be assisted to make their own decisions. Clients should be treated with dignity and privacy, and all information which home care support workers or care organisations are privy to should be kept confidential. A good complaints system should also be in operation.
- **3.39** Under Protection, safe working practices for home care support workers are outlined, as well as practices to protect clients from abuse and neglect. Guidelines for the security of client finances and client homes are also provided.
- 3.40 On Home Care Support needs, a guide to needs assessment (covering how to assess Activities of Daily Living, Instrumental Activities of Daily Living, and existing family & other support) is given; as is a guide on a home care support plan, which outlines the work which will be undertaken by the home care support worker. It is also recommended that a client record be kept in the home, where the time and date of every home care support worker visit, and of significant occurrence during visits, is recorded. Guidelines on giving medication are also included. This section concludes by outlining the importance of continuity in relation to home care support workers.
- **3.41** The fourth section of the Guidelines covers issues in relation to staffing, such as the HR policy of service providers, staff induction training and development, and supervision of staff.
- **3.42** The final section contains standards on governance of providers, including that provider premises, management and planning systems should be consistent and well-managed; that the accounting and financial procedures of the providers should be good; that accurate and up-to-date records should be kept by them; that there are good policies and procedures in place in provider organisations; as well as an effective quality assurance system.
- 3.43 An implementation plan for these guidelines is currently being developed by the HSE Services for Older People Governance Group. Some of the guidelines can be implemented without statutory requirement and it is intended that progress will be made in these areas as a matter of priority.

Summary

- **3.44** In summary, policy on older people in Ireland has for many decades espoused the wish for older people to remain in their own homes for long as possible. Early supports for this included the ability for health boards to provide home help services, since 1970. It was only in the mid 2000s that significant funding for more comprehensive services were provided in the form of HCPs. HCPs were developed on the basis of recommendations from the Long-Term Care Report, agreed in 2005 by an interdepartmental working group set up to identify the policy options for a financially sustainable system of long-term care; and to rationalise the range of benefits, services and grants then in place for long-term care.
- 3.45 That report outlined several supports to be put in place to implement HCP policy. Guidelines on how these supports could operate were developed in more detail by two working groups, one focusing solely on HCPs, and the other on home care supports, which forms part of some HCPs. Although both the LTC report and both sets of guidelines are comprehensive and well planned, neither set of guidelines is currently operational (an issue which will be discussed in more detail in chapter five), leaving HCP policy without national standardised guidelines for its implementation. In that context, in the next Chapter, we will look at how HCP policy has been implemented on the ground, with particular reference to the client interface.



CHAPTER 4

Implementation of HCPs in Local Health Offices

Introduction

4.1 This Chapter will concentrate on the first part of Point Three of the Terms of Reference, which is to 'examine the on-the-ground delivery of the [Home Care Package] Scheme in order to establish, as far as possible, the overall national degree of policy implementation that occurred, [and] regional and local variations in the extent of implementation'. The remaining part of Point Three of the Terms of Reference, 'factors that might explain both the overall national outcome and sub-national variations', will be examined in Chapter five. Meanwhile, this present chapter will draw heavily on material received in the submissions, and on information gathered from those met by the NESF Secretariat in the course of this research.

Positive benefits of HCPs

4.2 The first point to emphasise is how beneficial people who receive HCPs find them. The majority of those met, and the majority of submissions received, whether they were from individuals, organisations involved in home- and community-based care, or HSE staff, were positive about the introduction of HCPs and their potential to improve the lives of older people. Indeed they represent a large amount of funding which has allowed a long-held policy ambition to be realised for many older people. One particular quote summarises the benefits mentioned in a large number of submissions as it addresses benefits to the client, their family and the State, and also covers the social and common medical benefits that accrue to the client in particular, as follows:

'Home Care Packages provide:

- Vulnerable adults with supervision and support,
- Reduce individual and carer stress,
- Reduce anxiety for those who live alone or are alone for long periods during the day,
- Provide monitoring for individuals regarding non-compliance with taking medication,
- Assist individuals who have difficulty swallowing when eating or taking medication,
- Assist individuals with all aspects of personal care and nutritional needs,
- Allow individuals remain at home at reduced cost to Health Service Executive,
- Provide supervision of hydration for individuals at risk of dehydration which can lead to Urinary Tract Infections causing confusion in some older adults,
- Monitor adults who are medically at risk; e.g. diabetics,
- Offer individuals who have none or limited family support with the opportunity to remain at home,
- Provide individuals with social and emotional support, and
- Provide a better quality of life to individuals, maintaining them in their own communities and close to family and friends.' HSE Social Worker
- 4.3 The significance of the HCP for both individuals receiving the care, and their family members, is also well evident in the submissions. One individual outlined his experience of a HCP:

'I have MS and I am totally dependent on others. I live at home with my wife... In the morning my wife, with the help of the Personal Assistant, gets me washed and dressed and gives me my breakfast. My wife then goes to work and I can call on the Personal Assistant by telephone if I need help. At lunchtime my home help comes in and gives me my lunch and helps to tidy up the house... The advantage of all the help I get is that it lessens the burden on my wife in looking after me. Without assistive technology and my care package I would probably have to be in full-time care.'

4.4 • The benefit of HCPs for those caring for a dependent family member was particularly evident. The HCP allows them to continue to play a part in the care of a loved one but with necessary support. In some cases it has allowed the family to remain in paid employment, where otherwise at least one family member would have had to surrender their job and their own financial independence.

Appropriate home care that allows their relative to maintain their dignity is important not only for the older person themselves, but also for family members who have found themselves in an uncomfortable position in administering personal care in particular. The following quotes illustrate these benefits:

'My wife (who has Alzheimer's Disease) gets a home care package of three hours a day which gives me respite to get out of the house and have some sort of life. The home carer showers my wife twice a week which is of great assistance to me as I cannot manage her on my own in the shower (I am 83 years old). We are tremendously grateful for the home care that we receive and has made a great difference to our lives.' Family Carer

'My mother got a home care package after she was discharged from hospital and the package is administered by a private company. This package has made a huge difference to her life ... the carer is trained in personal care and assists my mother with toileting and washing ... my mother also has a home care plan with this company and the members of the family decide what is the best type of care for my mother with the company. Our family can highly recommend home care packages and my mother has not been back to hospital since.' Family Carer

4.5 The quotes from the submissions, as well as the work that went into piloting HCPs, designing the policy for them, and designing guidelines for how they should operate, indicates the many people who are committed to making HCPs work, and who put significant amounts of effort into this. HCPs represent a very significant increase in the amount of care available for older people and others in the home, and improve quality of life for many. Nonetheless, it became clear in this study that implementation of the HCP policy is very variable, and this gives rise to inconsistencies, confusion, and inequities in service provided in different LHOs. The reasons why these arise will be discussed in more detail in Chapter five, but in this current Chapter the local variations in implementation will be outlined.

Provision for services in the community, and for older people, in each LHO

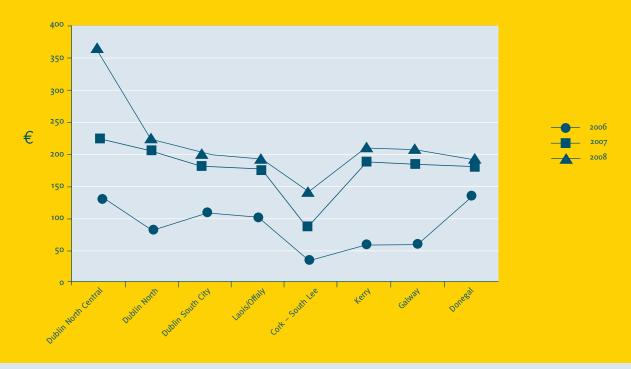
- **4.6** First, different amounts of funding are available for HCPs in different LHOs across the country.
- 4.7 At regional level, data from the HSE shows that, from 2006, funding for HCPs was allocated to four HSE regions on the basis of the proportion of older people in that region, with higher allocations given to the Dublin North East area due to service pressures there¹⁶. See table 4.1.

Table 4.1 Comparison of proportion of total HCP funding allocated, andproportion of national population over 65, per HSE region

| Area | % of population over 65, 2006 | % of total H 2006 | CP fund allocated t 2007 | o the area in: 2008 |
|---------------------|----------------------------------|----------------------|-----------------------------|------------------------|
| Dublin Mid Leinster | 28 | 26.25 | 25.01 | 26.26 |
| Dublin North East | 19 | 21.25 | 25.40 | 24.89 |
| West | 26 | 26.25 | 24.79 | 22.04 |
| South | 27 | 26.25 | 24.81 | 26.81 |

4.8 • Within each HSE region, HCP funding then goes to different LHOs. As an example of the HCP funding per LHO, the following graph 4.1 outlines the amount of HCP funding available per person over 65, in the eight LHOs which are being studied as part of the Dept of Health and Children evaluation of HCPs¹⁷.

Graph 4.1 Amount of HCP funding (€) available per person over 65, per year, in eight LHOs, 2006-2008



*Note These figures were calculated by dividing the funding for home care packages available in a LHO by the population over 65 of that LHO. The figures do not represent the actual value of the HCPs given to individual persons over 65 in the LHO.

¹⁷ This data was included in the Scope of Service document which accompanied the Request for Tender for Evaluation of Home Care Packages, advertised by the Department for Health and Children in July 2008.

- 4.9 This shows that the Dublin North Central area has a much higher proportion of funding per person over 65, possibly due to the service pressures there which were referred to in the HSE document cited earlier. However, the graph also shows that the amount of funding available per person over 65 is not standard across the other LHOs.
- **4.10** The Team was provided with a variety of views as to why these variations existed. As pressure on services was a reason for allocating more HCP funding to Dublin North East, the Team therefore looked at some existing services for older people to see if there was a link between the amount available and the number of HCPs provided. Table 4.2 outlines some data on the amount of home help hours and the budget for HCPs available per population over 65 in each LHO.
- 4.11 Table 4.2 shows that the LHOs in Dublin North East (Louth, Cavan/ Monaghan, Meath, Dublin North West, Dublin North and Dublin North Central) do have higher than the national average budget for HCPs per person aged over 65. Four of the six also have higher than the national average number of home help hours per person aged over 65. Meanwhile some LHOs have lower than the national average proportions of both home help hours and HCP budgets per person over 65 (e.g. Carlow Kilkenny), while some LHOs have higher than average proportions of both home help hours and HCP budget per person over 65 (e.g. Dublin West).
- **4.12** Some of those met during the course of this work suggested that healthcare funding was not always allocated according to the needs of the population in each LHO, but was also influenced by historical and political allocations. However, the Project Team does not have data to show exactly how or why different allocations of funding or staff that affect home care for older people are made to LHOs. But the data that it was able to access does show, that although at a regional level the provision of HCP funding was done in accordance with population, there are variations by LHO in the amount of funding and staff available to provide community care to older people.

Table 4.2Home help hours, HCP budgets and populationover 65 in different LHOs

| National average 24.4 228.33 Carlow Kilkenny 16 209.31 Cavan Monaghan 35.8 237.16 Clare 17.4 199.11 Cork North 43.1 229.97 Cork North Lee 37.4 216.15 Cork South Lee 26.7 187.50 Cork West 35.9 228.47 Donegal 34.3 191.81 Dublin North Central 31.8 502.76 Dublin North Central 31.8 502.76 Dublin North West 15.6 337.00 Dublin South City 12.6 246.57 Dublin South East 8.7 223.80 Dublin South West 10.4 234.22 Dublin South West 10.4 234.22 Dublin South West 24.9 338.67 Dublin South West 24.9 338.67 Dublin South West 24.9 338.67 Dublin South Mest 24.9 329.54 Kildare West Wicklow 29 253.21 | LHO (Local health office) | Approx no of Home Help hours (2008) available per person 65+* | Approx HCP budget (2008) available per person 65+* |
|--|--------------------------------|---|--|
| Cavan Monaghan 35.8 237.16 Clare 17.4 199.11 Cork North 43.1 229.97 Cork North Lee 37.4 216.15 Cork North Lee 26.7 187.50 Cork South Lee 26.7 187.50 Cork West 35.9 228.47 Donegal 34.3 191.81 Dublin North 23.4 (est) 280.30 Dublin North Central 31.8 502.76 Dublin North West 15.6 337.70 Dublin South City 12.6 246.57 Dublin South Kest 10.4 234.22 Dublin South Kest 10.4 234.22 Dublin South West 10.4 234.22 Dublin West 24.9 338.67 Dublin South (Dun Laoghaire) no data 142.34 Galway 17.5 218.93 Kerry 40.3 329.54 Kildare West Wicklow 29 253.21 Laois Offaly 19.1 93.52 L | National average | 24.4 | 228.33 |
| Clare 17.4 199.11 Cork North 43.1 229.97 Cork North Lee 37.4 216.15 Cork South Lee 26.7 187.50 Cork West 35.9 228.47 Donegal 34.3 191.81 Dublin North 23.4 (est) 280.30 Dublin North Central 31.8 502.76 Dublin North Kest 15.6 337.70 Dublin South City 12.6 246.57 Dublin South Kest 10.4 234.22 Dublin South Kest 10.4 234.22 Dublin South West 10.4 234.22 Dublin South (Dun Laoghaire) no data 142.34 Galway 17.5 218.93 Kerry 40.3 329.54 Kildare West Wicklow 29 253.21 Laois Offaly 19.1 93.52 Limerick 24.1 201.66 Longford Westmeath 21.9 111.71 Louth 32.5 246.79 | Carlow Kilkenny | 16 | 209.31 |
| Cork North 43.1 229.97 Cork North Lee 37.4 216.15 Cork South Lee 26.7 187.50 Cork West 35.9 228.47 Donegal 34.3 191.81 Dublin North 23.4 (est) 280.30 Dublin North Central 31.8 502.76 Dublin North West 15.6 337.70 Dublin South City 12.6 246.57 Dublin South East 8.7 223.80 Dublin South East 8.7 234.22 Dublin South West 10.4 234.22 Dublin South West 10.4 234.22 Dublin South Clun Laoghaire) no data 142.34 Galway 17.5 218.93 Kerry 40.3 329.54 Kildare West Wicklow 29 253.21 Laois Offaly 19.1 93.52 Limerick 24.1 201.66 Longford Westmeath 21.9 111.71 Louth 32.5 246.79 <tr< td=""><td>Cavan Monaghan</td><td>35.8</td><td>237.16</td></tr<> | Cavan Monaghan | 35.8 | 237.16 |
| Instruct Instruct Instruct Cork North Lee 37.4 216.15 Cork South Lee 26.7 187.50 Cork West 35.9 228.47 Donegal 34.3 191.81 Dublin North 23.4 (est) 280.30 Dublin North Central 31.8 502.76 Dublin North West 15.6 337.70 Dublin South City 12.6 246.57 Dublin South East 8.7 223.80 Dublin South East 8.7 223.80 Dublin South West 10.4 234.22 Dublin South West 10.4 234.22 Dublin South (Dun Laoghaire) no data 142.34 Galway 17.5 218.93 Kerry 40.3 329.54 Kildare West Wicklow 29 253.21 Laois Offaly 19.1 93.52 Limerick 24.1 201.66 Longford Westmeath 21.9 111.71 Louth 32.5 246.79 | Clare | 17.4 | 199.11 |
| Strik Strik <th< td=""><td>Cork North</td><td>43.1</td><td>229.97</td></th<> | Cork North | 43.1 | 229.97 |
| Cork West 35.9 228.47 Donegal 34.3 191.81 Dublin North 23.4 (est) 280.30 Dublin North Central 31.8 502.76 Dublin North West 15.6 337.70 Dublin South City 12.6 246.57 Dublin South City 12.6 246.57 Dublin South Kest 10.4 234.22 Dublin South West 10.4 234.22 Dublin South West 10.4 234.22 Dublin South West 10.4 234.22 Dublin South (Dun Laoghaire) no data 142.34 Galway 17.5 218.93 Kerry 40.3 329.54 Kildare West Wicklow 29 253.21 Laois Offaly 19.1 93.52 Limerick 24.1 201.66 Longford Westmeath 21.9 111.71 Louth 32.5 246.79 Mayo 25.3 236.06 Meath 28.3 228.27 | Cork North Lee | 37.4 | 216.15 |
| Donegal 34.3 191.81 Dublin North 23.4 (est) 280.30 Dublin North Central 31.8 502.76 Dublin North West 15.6 337.70 Dublin South City 12.6 246.57 Dublin South City 12.6 246.57 Dublin South East 8.7 223.80 Dublin South West 10.4 234.22 Dublin South West 10.4 234.22 Dublin South (Dun Laoghaire) no data 142.34 Galway 17.5 218.93 Kerry 40.3 329.54 Kildare West Wicklow 29 253.21 Laois Offaly 19.1 93.52 Limerick 24.1 20.166 Longford Westmeath 21.9 111.71 Louth 32.5 246.79 Mayo 25.3 236.06 Meath 28.3 228.27 Roscommon 19 204.71 Sligo Leitrim West Cavan 39.8 190.75 | Cork South Lee | 26.7 | 187.50 |
| Dublin North 23.4 (est) 280.30 Dublin North Central 31.8 502.76 Dublin North West 15.6 337.70 Dublin South City 12.6 246.57 Dublin South East 8.7 223.80 Dublin South West 10.4 234.22 Dublin South West 24.9 338.67 Dublin South (Dun Laoghaire) no data 142.34 Galway 17.5 218.93 Kerry 40.3 329.54 Kildare West Wicklow 29 253.21 Laois Offaly 19.1 93.52 Limerick 24.1 201.66 Longford Westmeath 21.9 111.71 Louth 32.5 246.79 Mayo 25.3 236.06 Meath 28.3 228.27 Roscommon 19 204.71 Sligo Leitrim West Cavan 39.8 190.75 Tipperary North – East Limerick 27.4 221.88 Tipperary South 36 229.55 | Cork West | 35.9 | 228.47 |
| Dublin North 23.4 (est) 280.30 Dublin North Central 31.8 502.76 Dublin North West 15.6 337.70 Dublin South City 12.6 246.57 Dublin South East 8.7 223.80 Dublin South West 10.4 234.22 Dublin South West 24.9 338.67 Dublin South (Dun Laoghaire) no data 142.34 Galway 17.5 218.93 Kerry 40.3 329.54 Kildare West Wicklow 29 253.21 Laois Offaly 19.1 93.52 Limerick 24.1 201.66 Longford Westmeath 21.9 111.71 Louth 32.5 246.79 Mayo 25.3 236.06 Meath 28.3 228.27 Roscommon 19 204.71 Sligo Leitrim West Cavan 39.8 190.75 Tipperary North – East Limerick 27.4 221.88 Tipperary South 36 229.55 | Donegal | 34.3 | 191.81 |
| Dublin North West 15.6 337.70 Dublin South City 12.6 246.57 Dublin South East 8.7 223.80 Dublin South West 10.4 234.22 Dublin South West 24.9 338.67 Dublin South (Dun Laoghaire) no data 142.34 Galway 17.5 218.93 Kerry 40.3 329.54 Kildare West Wicklow 29 253.21 Laois Offaly 19.1 93.52 Limerick 24.1 201.66 Longford Westmeath 21.9 111.71 Louth 32.5 246.79 Mayo 25.3 236.06 Meath 28.3 228.27 Roscommon 19 204.71 Sligo Leitrim West Cavan 39.8 190.75 Tipperary North – East Limerick 27.4 221.88 Tipperary South 36 229.55 Waterford 14.6 189.58 Wexford 16.3 196.55 | Dublin North | | 280.30 |
| Dublin South City 12.6 246.57 Dublin South East 8.7 223.80 Dublin South West 10.4 234.22 Dublin South West 24.9 338.67 Dublin South (Dun Laoghaire) no data 142.34 Galway 17.5 218.93 Kerry 40.3 329.54 Kildare West Wicklow 29 253.21 Laois Offaly 19.1 93.52 Limerick 24.1 201.66 Longford Westmeath 21.9 111.71 Louth 32.5 246.79 Mayo 25.3 236.06 Meath 28.3 228.27 Roscommon 19 204.71 Sligo Leitrim West Cavan 39.8 190.75 Tipperary North – East Limerick 27.4 221.88 Tipperary South 36 229.55 Waterford 14.6 189.58 Wexford 16.3 196.55 Wicklow 25 91.70 | Dublin North Central | 31.8 | 502.76 |
| Dublin South East 8.7 223.80 Dublin South West 10.4 234.22 Dublin West 24.9 338.67 Dublin South (Dun Laoghaire) no data 142.34 Galway 17.5 218.93 Kerry 40.3 329.54 Kildare West Wicklow 29 253.21 Laois Offaly 19.1 93.52 Limerick 24.1 201.66 Longford Westmeath 21.9 111.71 Louth 32.5 246.79 Mayo 25.3 236.06 Meath 28.3 228.27 Roscommon 19 204.71 Sligo Leitrim West Cavan 39.8 190.75 Tipperary North – East Limerick 27.4 221.88 Tipperary South 36 229.55 Waterford 14.6 189.58 Wexford 16.3 196.55 Wicklow 25 91.70 | Dublin North West | 15.6 | 337.70 |
| Dublin South West 10.4 234.22 Dublin South West 24.9 338.67 Dublin South (Dun Laoghaire) no data 142.34 Galway 17.5 218.93 Kerry 40.3 329.54 Kildare West Wicklow 29 253.21 Laois Offaly 19.1 93.52 Limerick 24.1 201.66 Longford Westmeath 21.9 111.71 Louth 32.5 246.79 Mayo 25.3 236.06 Meath 28.3 228.27 Roscommon 19 204.71 Sligo Leitrim West Cavan 39.8 190.75 Tipperary North – East Limerick 27.4 21.88 Tipperary South 36 229.55 Waterford 14.6 189.58 Wexford 16.3 196.55 Wicklow 25 91.70 | Dublin South City | 12.6 | 246.57 |
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| Mayo 25.3 236.06 Meath 28.3 228.27 Roscommon 19 204.71 Sligo Leitrim West Cavan 39.8 190.75 Tipperary North – East Limerick 27.4 221.88 Tipperary South 36 229.55 Waterford 14.6 189.58 Wexford 16.3 196.55 Wicklow 25 91.70 | Longford Westmeath | 21.9 | 111.71 |
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| Tipperary South 36 229.55 Waterford 14.6 189.58 Wexford 16.3 196.55 Wicklow 25 91.70 | Sligo Leitrim West Cavan | 39.8 | 190.75 |
| Waterford 14.6 189.58 Wexford 16.3 196.55 Wicklow 25 91.70 | Tipperary North – East Limeric | k 27.4 | 221.88 |
| Wexford 16.3 196.55 Wicklow 25 91.70 | Tipperary South | 36 | 229.55 |
| Wicklow 25 91.70 | Waterford | 14.6 | 189.58 |
| | Wexford | 16.3 | 196.55 |
| National average 24.4 228.33 | Wicklow | 25 | 91.70 |
| | National average | 24.4 | 228.33 |

Sources: Census 2006 figures from HSE website (http://www.hse.ie/eng/HSE_FactFile/FactFile_PDFs/Census_2006_65_plus/ Census_2006_for_65_plus_age_groups.pdf); Home help hour figures for Sept 2008 provided by HSE Employment Census section; HCP figures for 2008 provided by the HSE

*Note: These figures are calculated by dividing the home care package budget and home help hours available in a LHO by the population over 65 of that LHO. The figures do not represent the actual HCP funding or home help hours given to individual persons over 65 in the LHO.

Variations in how HCPs are implemented, by LHO

- **4.13** To gain more precise data on differences in implementation of HCPs in different LHOs, the Project Team decided to survey a small number of LHOs on how they implement HCP policy as outlined in the LTC report. This data was collected through questionnaires devised by the NESF and sent to eight LHOs¹⁸, asking them how they organised HCP implementation in terms of;
 - eligibility criteria to receive a HCP,
 - average amounts paid per HCP,
 - how/who delivers HCPs,
 - the existence of a preferred providers list,
 - co-ordination among HCP providers and managers, and
 - review of HCPs.

The completed questionnaires showed local variation in many of the above. These variations will be outlined in the following sections, along with material from the submissions showing how these variations are experienced in practice. Here, it should be borne in mind that what is expressed in the submissions is individual experience and opinion, and that this does not always necessarily reflect widespread or common practice. However, in many cases the experience was common to a number of individuals or organisations.

- 4.14 One of the benefits of variations in local interpretation and implementation of HCPs is that it allows for greater flexibility in service provision, and the LTC report indicated that the provision of HCPs was to be delivered in a flexible manner. Indeed this was one of the aims of HCPs, including allowing people to organise their own care, another practice becoming more evident internationally (OECD, 2005).
- **4.15** However, as one submission noted 'the obvious downside of this is a difficulty in delivering a standardised service in each part of the country in accordance with identified need.' Comparing the variations in local implementation with the experiences of those receiving, and indeed organising HCPs in different areas, indicates that local variation in implementation can be problematic.

¹⁸ These eight are Kerry, Galway, Donegal, Dublin South Central, North Dublin, Dublin North Central and Cork South Lee. They are the same eight LHOs on which the evaluation commissioned by the Dept of Health and Children will focus. The Dept of Health and Children evaluation will take the 8 LHOs as case studies, and analyse the efficiency and effectiveness of HCPs in detail, by analysing over 100 case files in each of the LHOs. The NESF would like to thank the HSE for their assistance with this questionnaire.

First of all, the questionnaire results showed that the eligibility criteria by which HCPs were allocated varied by LHO. There were some commonalities – not surprisingly, in all 8 LHOs, the criteria used to allocate HCPs included medical needs and family support. It seems that some LHOs who were involved in delivery of HCP pilots prior to 2005 (e.g. those in Dublin-Mid Leinster) now use the same eligibility criteria. However, of the eight LHOs studied, not all assessed income, and only half assessed savings, when allocating HCPs, as Table 4.3 shows.

Table 4.3 Mechanisms used to allocate HCPs in different LHOs

| % |
|-----|
| 100 |
| 100 |
| 75 |
| 50 |
| |

4.17 • This is an issue which came up in the submissions, as the following quotes testify:

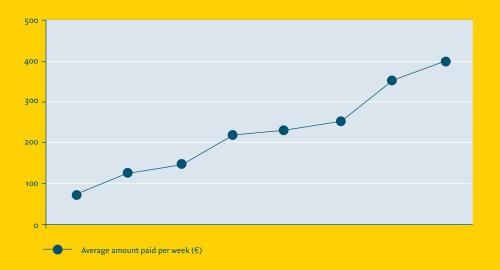
'There is no uniformity in how the packages are allocated and in the numbers in receipt of them. The individual areas are not clear on their criteria and we therefore find the system very inequitable. There is a disparity between what different people receive even though they may have similar levels of need and are on similar income levels'. Hospital Social Worker

'A means test is due to occur but our feedback tells us that is not applied consistently either throughout the country.' Charitable Organisation

- **4.18** Clearly, this variation leads to considerable inconsistency in how the HCPs are implemented, and is also inequitable.
- **4.19** As well as the problems which older people face accessing HCPs, it was also noted that it was not completely clear who else was eligible to access HCPs. To what extent are people with disabilities eligible to access them? Can they be used to provide care for ill children or younger adults? The LTC report stated that the packages should be focused on 'older people currently in residential or hospital care, who have the capacity to return to their homes, and at people in the community who are considered to be at risk of requiring residential care in the absence of such intervention' (5.21).

In line with this, the funding for HCPs comes from the HSE budget for Services for Older People, and in December 2008, 93% of those in receipt of a HCP were aged over 65 (HSE, 2009c). However earlier pilot home care package schemes in the Dublin area were given to people with disabilities. Some people with terminal illnesses also receive the equivalent of a HCP, although this is paid for out of a hospice budget rather than a HCP budget. A number of submissions asked for greater clarity on who exactly is entitled to access a HCP.

- **4.20** The issue of how long people should be eligible to continue receiving a HCP was also raised. In some countries (e.g. Canada), the amount of State funding given to provide care for an individual at home cannot exceed the cost of providing care in a residential setting. It would be helpful to have a debate in Ireland on when it is appropriate to provide care in the home and when it is more appropriate to provide it in a residential setting.
- **4.21** A second variation evident from the questionnaire results is the average amounts paid under a HCP, ranging from an average of €71 paid per week per HCP in one of the eight LHOs, to €400 paid per week per HCP in another. The following graph indicates the range of variation.



Graph 4.2 Average amount paid per HCP per week

4.22 • The questionnaire results also show that the maximum amounts paid per week under a HCP varied by LHO, as the following table indicates.

| Maximum amount paid | Number of LHOs |
|-----------------------------|----------------|
| €252 | 1 |
| €525 | 2 |
| €570 | 1 |
| €625 | 1 |
| €1500 | 1 |
| Limits set by medical needs | 2 |

4.23 ● There is significant variation again here, from a minimum of €252 paid per week, to €1,500¹⁹. This provides at best inconsistencies, and at worst inequities, in the amount of care which people can access through a HCP. This issue was noted in a number of submissions, as the following quotes show.

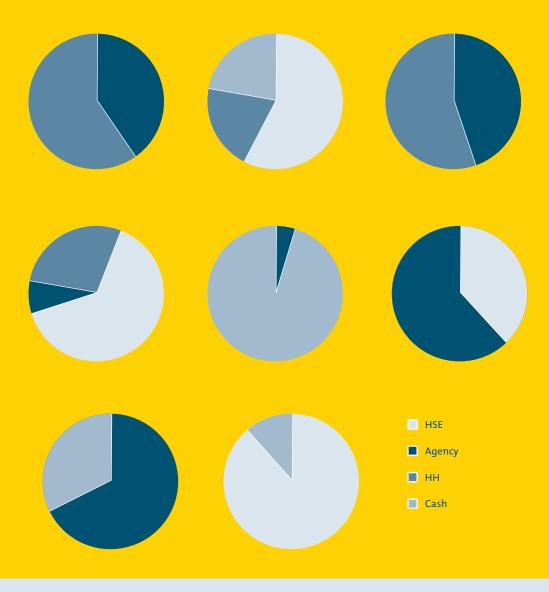
"Our doctor recommended to the public nurse that his home care package hours be increased, a number of times, and all applications for this were refused with no explanation other than "we don't have the money". Family Carer

"My Mother resides in County [X], she suffers from dementia, is wheelchair bound, is doubly incontinent, cannot communicate or eat/move unaided. To take care of her at home she requires full time 24 hour care [and] 15 hours of care [are] provided by the HSE. [In a neighbouring county], a [X] colleague whose Mother also requires care though of a lower level as she is mobile and 'compos mentis' receives a remuneration package in the region of €340 per week to cover the cost of home care and cleaners in the home. This was made available to the family to administer on behalf of the lady in question. I queried this with the Home Care Package providers of the HSE in County [X] but was repeatedly told that no decision had been made on how to administer these funds in that county... I know that it is a difficult financial time economically for everyone and we as a family have made a personal decision to keep our Mother, for as long as possible, in her own home... all we seek is equal access to whatever funding and services are available to us." Family carer

¹⁹ Some LHOs had a pilot HCP scheme in place prior to 2006, and the packages put in place under this earlier scheme often provided high-dependency, and so expensive, care. The HCP costing €1500 per week may date from this earlier scheme.

4.24 • The questionnaire data also showed variations in how HCPs are delivered in each LHO, with different LHOs using a different mix of HCP deliverers, including the HSE, home help organisations, private agencies and cash grants (which allow individuals to organise their own care). These variations are outlined in the following piecharts:

Figure 4.1 Proportion of HCPs provided by different delivery mechanisms, in 8 LHOs



Key: HSE – care is provided directly by HSE staff; Agency – care is provided by a commercial provider; HH – care is provided by a home help organisation; Cash – a cash grant is given to the recipient to organise their own care.

- **4.25** These variations in deliverer can be for good reasons. For example, in an LHO where the HSE has a good infrastructure to provide community services for older people, it makes sense for them to provide HCPs directly. In an LHO where voluntary groups have traditionally delivered home help services, they may provide a good infrastructure to deliver HCPs. Areas without such an infrastructure, or which find the existing infrastructure inadequate, may be more likely to turn to private agencies, which are increasing in number; or to provide cash grants to recipients of HCPs to organise their own care.
- **4.26** However, there can be problems associated with varied means of provision. First, not all providers provide the same hours of care, as outlined in the following quote: *"[Sometimes] the weekday morning hours are allocated to the not-for-profit company whereby the difficult-to-staff evening time and weekend hours are given to a private provider. This situation leads to discontinuity of care and ultimately adversely affects the clients."* Name withheld on request
- **4.27** Secondly, some submissions outlined that the type of care available from providers differed, with some finding that staff from private providers were better trained in providing personal care, such as assistance washing, dressing and toileting. Other problems could be associated with cash grants to organise one's own care. While those with disabilities are in favour of cash grants as they are seen to offer greater choice of service and provider, many older people and their families found the employer responsibilities involved onerous. However, a review of LTC in other OECD countries found that supports can be put in place to ease this. For example, in the US a variety of models operate, with varying levels of consumer responsibility. Under the *direct pay* model, the consumer is the employer and has full hiring, firing, tax and payroll responsibilities. The fiscal intermediary model has a designated agency which deals with payroll and taxes while the consumer selects and manages the care giver; and the supportive intermediary model involves a public agency which can assist in recruitment, background checks and training. There are also various combinations of these supports for those employing their own home care support worker (see OECD, 2005).
- **4.28** In terms of reviewing HCPs, again the questionnaire results showed variations in how often they were reviewed in different LHOs, as the following table outlines.

| How often are HCPs reviewed? | Number of LHOs |
|------------------------------|----------------|
| As necessary | 2 |
| Every month | 2 |
| Every 6 weeks | 1 |
| Every 3 months | 2 |
| On-going | 1 |
| | |

Table 4.5 Monitoring of HCPs in LHOs (N=8)

- **4.29** The questionnaire did not investigate exactly what monitoring consists of, although some of those met during the course of the research reported that they monitored new recipients to check that they are happy with the HCP arrangements. More recently, some HCP co-ordinators reported that they had begun to monitor the HCPs provided, as their budgets were under pressure and they wanted to see if those currently receiving HCPs still needed the level of care originally provided, or if the amount of care being given could be reduced (although some noted that most recipients of HCPs were likely to become more rather than less dependent, and therefore need more rather than less care).
- **4.30** Meanwhile, a number of organisations providing HCPs, as preferred providers, for example, reported that it had never been checked whether or not they were meeting the conditions outlined in the contract which they had with the HSE as a preferred provider. On that issue, it was found that half of the LHOs surveyed used a preferred providers list.
- 4.31 This variation in monitoring, including lack of it in some cases, mirrors international experience. Overall, regulation and assessment of LTC at home is a new development (see OECD, 2005). Where it exists, usually the focus is on input standards, such as provider qualification, the structures of organisations providing care, and the processes by which care is provided. Few standards look at the outcomes of home care for older people, although the UK has developed more comprehensive standards.

- **4.32** Finally, the questionnaire asked about co-ordination of all the organisations providing HCPs. As already mentioned, many different services and individuals are involved in the organisation and provision of HCPs. These include those working in various parts of the HSE (PHNs, HCP case managers, social workers, and other medical workers, such as therapists and geriatricians), voluntary organisations and private providers, and primary care teams²⁰ to co-ordinate all healthcare providers including GPs at local level (where these exist). Regular meetings between these groups can share learning about management and provision of HCPs, as well as helping to plan and co-ordinate the care of individuals who are coming to the attention of various parts of the health services. Six of the LHOs surveyed had such meetings, while two did not. This lack of co-ordination between different groups providing healthcare to older people has also been noted in other OECD countries. A recent review of LTC policy in different OECD countries found that, 'a frequent criticism of these services from users and their families is that, whatever the quality of individual services, there is insufficient communication between them. This may leave users and families having to deal with different services with separate entry criteria and priorities.' (OECD, 2005:34)
- In brief, the results of the questionnaires indicate variations in local implementation of HCPs. A number of other variations in implementation were also identified through the submissions received and those met. Again, many of the experiences are of inconsistencies and confusion. These are both from the point of view of the client, and from a managerial point of view, although there are also crossovers. The variations identified through the submissions and meetings over the course of the project will be outlined in the following sections.

Other variations in implementation – from the viewpoint of clients

Information on and awareness of HCPs

4.34 • The first hurdle faced by many people trying to access HCPs is the lack of readily available information, and general lack of awareness of HCPs among potential beneficiaries and professionals. A number of submissions recounted the experiences of people trying to find out about the service and their possible entitlements to it. Most described a process of being passed around various offices and personnel, with one submission stating that it took 18 telephone calls over a 10 day period to finally find the 'right' person to talk to. Significantly, a number of submissions that highlighted this issue came from professionals within the HSE.

²⁰ Primary Care Teams (PCTs) are healthcare teams at local level, organised around the GP, and including staff such as nurses, therapists and home helps. They can provide better co-ordination of care to individuals. The Primary Care Strategy aims to develop 500 PCTs in Ireland, each serving approximately 5-10,000 people. Approximately 100 are currently in operation.

"Clients trying to access information were not getting the information they were looking for. This frustrated many people who then rang us to enquire on their behalf. Therefore access to information and guidance through the system needs to be spot on. It needs to be accessible to the client at the initial point of use." Advocacy Organisation

"The lack of written information about availability of domiciliary services or a point of contact where one could seek advice about options, was a real drawback. I eventually obtained relevant information from the Manager of Services for Older Persons, following a series of time consuming and often confusing telephone calls with a range of other professionals. If written information regarding policy, eligibility criteria, funding mechanisms and options for service delivery etc. was available it would have saved a great deal of time and energy." Family Carer

4.35 Different LHOs seem to provide different levels of information. Overall, the HSE website does provide general information on HCPs, saying that they can be applied for through the PHN in a person's local LHO. This is correct, but it would seem from the submissions that not many people use this website information, or they may not find it helpful – or even when they do know about home care packages, it is still difficult to access them. The experience of one person, who works in the health service herself, trying to organise a HCP for her mother who had Parkinson's Disease, and a stroke, outlines this well:

"I work in the health service and was somewhat aware of the potential of receiving the home care package scheme. I do not believe this option would ever have been addressed with us only that I queried the availability of same. Home care packages did not appear to be actively prompted... I first rang the PHNs involved in my mother's care who informed me it was not possible for us to care for my mum at home... that there were no resources available to provide home care at any level... Yet I had heard over and over again of the planned community/primary HSE care development and could not understand why I could not progress. I then rang the HSE and literally pleaded and begged with someone to advise me on where I could get some real information on what my entitlements were. Eventually when I spoke with a kind and helpful employee of the HSE, having been moved from Billy to Jack for a period of 30 minutes and at least 4 telephone calls later, I was directed to my local area officer in Dublin 15, who was able to inform me of the minimum requirements that I could possibly get. With this information in hand, I re-contacted the PHNs in my mother's district and asked for contact details of the community area manager. On discussion with the community area manager, who had some information of possible packages available but had great reluctance to commit, she with no hesitation advised me that the services available in [other areas of] Dublin were totally different to her area ... I found myself nearly begging this person to help me in setting up the home care for my mother as the hospital were planning her discharge. She said she would look into my case and would get back to me.

She didn't, but I did get a call from a PHN stating that [I] had been granted the home care package, but they had no persons to provide the care. I said I would source the persons required and set the wheels in motion to find home care persons, without knowing how many hours would be sanctioned... With no formal plan in place one week later, I again rang the Community care manager. I told her how frustrating it all was and the efforts I had made to find a carer for my mother. She then told me that I should not have been asked to look for a carer as she saw it to be the role of the PHN to organise same... I then got the call that was winning the lotto, a carer had been found (a name) but there was still negotiating to be done regarding the number of hours of home care and home help to be sanctioned. [Eventually 25 hours were sanctioned.]" Family carer

- **4.36** The fact that people often start to look for information on home care and HCPs only when an older relative is hospitalised, and thus at a time of stress, probably does not ease the process of accessing information.
- 4.37 Internationally, it has also been found that 'users and families [have] to deal with different services with separate entry criteria and priorities' (OECD, 2005:34). This has been tackled in some countries by employing case managers who are able to provide one contact point for information on care for older people.
- 4.38 Awareness of the existence of HCPs also seems low. Even among those met during the course of this work, from organisations where members were seeking care for older people, few knew exactly what HCPs were. One reason is that in some areas availability seems to be very low. Another reason is that many people seem to confuse HCPs with home help services. A number of factors contribute to this confusion.
- **4.39** First, while HCPs are innovative in that they provide medical and other therapeutic care in the home, they do also provide home help services. The LTC report outlines that HCPs were not intended to replace existing HSE services such as home help (section 5.14), although they could include home help services (section 5.19). In terms of implementation, the description of HCPs now on the HSE website²¹ outlines that HCPs can include home help and personal care. And in practice, figure 4.1 above shows that in 4 of 8 LHOs surveyed, home help organisations delivered HCPs. It is not surprising therefore that there is confusion about the differences between HCPs and home help.
- **4.40** In fact, some of those met during the course of this research considered that it was home help and personal care (such as assistance washing, dressing, toileting and preparing food), rather than more intensive medical therapy, which kept most low-dependency older people living at home. There were conflicting views on this, with some others considering that HCP services should be more medical, and more focused on those with higher medical needs. For example, one submission stated that:

²¹ See http://www.hse.ie/eng/Find_a_Service/Older_People_Services/Benefits_and_Entitlements/Home_Care_Packages.html

"It is our recommendation that HCPs should only be used to provide 'top up' care for people with high needs, to add to the care they receive from core community services." HSE social worker

4.41 • Meanwhile some were of the view that HCP budgets were funding inadequate community services, for example:

"There would be less need for HCPs if there was further investment in core community services, such as Home Help and care assistant services... further investment would allow core community services to be responsive and flexible in terms of duration of visits, tasks carried out and hours worked." Social Worker

4.42 However, overall, the research for this report indicated an overlap between HCPs and home helps²², and certainly, for those seeking care in the home, the issue of whether or not this care is paid from the home help, home care package, or another budget line is of little relevance. Some HCP providers and organisers also wondered how useful it was to have separate budgets for different types of community care for older people, rather than just one funding stream covering all of it.

Management and training of home care support workers

- **4.43** Many submissions praised both the HCP services they were receiving and the individual home care support workers involved. These referred to home care support workers who called at weekends and over holidays, when they were not paid to do so, out of concern for those they cared for; with one woman referring to her home care support worker as 'like a daughter'.
- **4.44** However, for some, problems were experienced with those providing the care. A number of issues arose here, including the time keeping and work carried out by home care support workers, their training (particularly for special needs such as dementia), the vetting of these home care support workers, and the hours worked.
- **4.45** Some submissions pointed to difficulties around home care support workers' lack of punctuality, irregular attendance and unwillingness to undertake some tasks that are needed by the client, as the following quotes outline:

"Rostering appeared to be a problem, for example, at times care staff would fail to turn up or two would arrive at the same time. The unreliability of service delivery had an adverse impact on my mother's confidence and well being as she needed assistance with all aspects of daily living." Family Carer

²² The evaluation of HCPs being carried out for the Dept of Health and Children is examining up to 950 HCP case files in detail, and will provide more information on the breakdown between medical and home help care which is provided in HCPs.

"... [I] was told that the home help was not allowed to do any lifting neither was she allowed to clean any glass or go up any steps or clean out any cupboards.It looks as if I have to perform the heavy work myself and leave the light work (which a child of 12 could do) only for the home help." Name withheld on request, aged 80

4.46 While this difficulty is experienced with the home care support workers, a number of home care support workers themselves pointed to problems with their management which did not assist them to carry out their work.

"I am a home carer with a private company and I do care for some people who have a home care package. I used to be in the Home Help Service with the HSE but I left this because it was so badly run and I never knew where I stood with them. The company I work for now goes into people's homes and does an assessment and draws up a care plan for the client which I follow. I find it great that I have a plan that I stick to and provide care for the older people." Carer employed by private company

"I used to work as a carer in the UK, for 27 years, and I am now doing home help work in Ireland, but the standards are very low in Ireland... I keep a record myself of all the people I care for – the days, times, how they were, what happened. In the UK we always had one, and we would fill in every day when we arrived to someone, how they were, what had happened etc. It is a log, and it is not done here except in private agencies." Carer employed by the HSE

4.47 • Another problem is too many home care support workers coming into the older person's home to provide different types of care. As one submission outlined,

"In some HSE Areas home helps perform both household duties and personal care for clients – this is desirable... the converse happens where home helps perform household duties; in some cases 5/6 individuals (home helps and carers) from different agencies maybe enlisted to provide care." HCP Co-ordinator

4.48 Other submissions refer to the lack of training and qualifications of some home care support workers delivering the services in the home. Training is seen to be vital but minimal.

".....there is no training for new staff. All they get is one manual handling training course per year." HSE Carer

4.49 Furthermore, while Care in the Home courses are run by the HSE or voluntary agencies funded by the HSE, there is no clarity as to who should undertake these courses. There is also no obligation on many of those providing HCP services to ensure their staff are appropriately trained, although in some LHOs those who are on a Preferred Providers list have an obligation to train their staff. One submission makes it clear that while home care support workers may be expected to support clinical programmes they are not trained or supported to do so.

"Because of the complex nature of need of service users, this should be reflected in the quality and expertise of home support workers to support clinical intervention; however, home support workers (in general) are poorly paid, poorly trained and poorly managed." HSE Social Worker

- **4.50** A number of submissions also point out that specialised and appropriate training becomes necessary when providing care to groups with particular medical problems, such as dementia, Parkinson's disease or schizophrenia, as well as caring for those who are in need of palliative care.
- 4.51 Another problem cited by some is that there is no clear requirement for Garda vetting of home care support workers. Organisations which have signed a preferred providers' contract to provide HCPs do have to vet their staff, but in areas where preferred providers contracts are not used, it is not clear to what extent vetting of staff is carried out. Some of those met during the work also pointed out difficulties in Garda vetting of staff it can take several months, during which potential workers may find other jobs; and it can be particularly difficult to vet staff from other countries; for example. This issue, as well as that around training of home care support workers, does have potential to lead to elder abuse, another concern raised in some submissions.

Hours of care

- 4.52 Clients also reported problems with coverage provided by HCPs. One of the benefits of HCPs is that their flexibility allows for out-of-hours care to be provided, which was rare before they were introduced. However, although some providers provide weekend and evening care, not all providers do²³. Some of the quotes given earlier in this Chapter show how family carers were providing night and weekend care on a constant basis, and would welcome extra hours to cover these and holidays, in cases where the older person did not want to go into a respite home. Although HCPs are able to provide out-of-hours care, one drawback is that it is much more expensive than care provided during 9-5 working hours, so less hours of care can be provided with the same funding.
- **4.53** When home care workers were ill, some submissions reported that sometimes no alternative care was provided. For example,

"My mother's carer has been absent due to illness for the last 3 weeks. Now into the third week, we found it necessary to contact the Public Health Nurse and request help in covering some of the shifts. Of the 20 hours previously given by a carer, we have now only 4 hours, done by a home help. The assumption was that we would provide cover ourselves indefinitely with no consultation." Family carer

²³ There was considerable debate among different providers as to who provided night and weekend care hours. Some of those met claimed that really only private providers did so, but people were also met from voluntary organisations who provided such care. It seems that in the past, home help hours were not available at weekends and at night, and that the entry of new service providers into the market has helped spur both new and existing service providers to make more night and weekend care available.

One HSE carer said: "There is also no back-up service.... If I am sick, then there is no-one else who will do it. So I don't want to take a day off, as I know the effects on the people I care for."

- **4.54** According to the HSE, in some cases because of the type of care being provided it is possible that a decision is made not to replace a home care support worker on leave, whereas in other cases, based on the assessed needs of the patient, the worker is replaced.
- 4.55 Another common complaint was that the number of hours' care given was too low. Some of those who stated this were organising a small number of family members to look after severely disabled relatives, such as those with acquired brain injury, with dementia, with Parkinson's Disease etc, who needed 24 hour care 7 days a week. These carers were obviously under severe stress in trying to provide this care. Others, fortunately in less stressed situations, also found it difficult to access adequate care. This can be related to the relatively low amount of funding provided in some areas. The recent declines in budget referred to in some submissions, may also be leading to cutbacks (see next section). As one carer noted:

"Most of the older people I care for under the home care package scheme need more hours but can't get them from the public nurse. In fact, in a number of cases they have taken away hours from my clients (and also from me) when these people are getting older and more frail." Carer employed by private company

Stress of family carers

4.56 • The final issue which came up in many submissions is the stress which family carers are under in trying to provide adequate care for dependent family members. Although this stress cannot be related easily to individual aspects of HCP implementation, it was so striking that it is important to focus on in some detail. Many family carers are looking after relatives that have a range of illnesses and frailties, where outside help is valued but minimal, and where the majority of the caring is borne by them. Their somewhat contradictory position is summed up in one submission as follows:

"For many people caring is a rewarding act borne out of love. However, many carers feel lonely, overburdened, ill-prepared and unrecognised for the care they provide." National Voluntary Organisation

4.57 One submission cites research by the Care Alliance Ireland (O'Sullivan, 2008) on the impact of caring on the carer's own health and well-being. This involved a survey of 1,411 randomly selected carers in receipt of a caring-related payment from the State.

"Family Carers presented a considerably less positive picture of quality of life in comparison to the general population. Carers also reported comparatively high levels of depression, back pain and anxiety. Negative aspects associated with family caring included restricted leisure hours and a high risk of being exposed to stress, emotional strain and social isolation. The extent of limitation posed by caring on leisure/ recreation appeared to be a key factor both in likelihood of health suffering due to caring and likelihood of low quality of life for carers." Family Carer's Support Organisation

4.58 • The particular high stress of those providing care to people with dementia, and to those who needed 24 hour care, have been outlined already in a number of quotes in this Chapter. However, one submission summed up well how stressful such caring can be and the importance of HCP supports for that:

"There is no actual cash figure that can equate the real value the availability of home care package has meant to us as a family. It has meant we can keep our mum in her own home where she is loved and happy. If our home care package of 25 hours per week is taken from us, I hope my mum dies soon as I could not bear to think what will happen to her." Family carer

- 4.59 Meanwhile, the 2006 Census found that over 160,000 people were providing "regular unpaid personal help for a family member with a long-term illness, health problem or disability, including problems which are due to old age and providing help with basic tasks such as feeding or dressing." About 11% of these carers were over 65 years of age. This care can be difficult and stressful, so HCPs play a important role in supporting them.
- **4.60** This mirrors experiences in other countries. An OECD review of LTC supports (OECD, 2005) found that many countries first focused care on older people living alone without co-resident carers, or on the most disabled, as it was considered that this care was most likely to prevent them from entering residential care. However, as countries develop more experience of home care services, they are more likely to put in place supports for informal carers, as knowledge of several facts grows. First, there is no evidence that families withdraw from caring when formal care is supplied. Secondly, schemes aiming to keep more severely dependent older people at home in fact rely heavily on informal carers in order to be successful. Finally, there is growing evidence that carers can burn out without support, so the arguments for directing services towards them grows.

Other variations in implementation – from the viewpoint of HCP providers and organisers

4.61 • A number of more 'strategic' or 'management' issues leading to inconsistency and confusion in implementation – some of which also impact on clients – also came up in the submissions and meetings held as part of this Project. These are in relation to – funding, budget lines, double assessments, co-ordination of various HCP providers, and data collection arrangements.

Funding

- 4.62 On funding, a general theme of submissions is that there is not enough funding for all those who need HCPs. This has led to the existence of waiting lists in a number of areas. In other LHOs, applicants are told there are no further HCPs available for the time being, and to try later that year or the next year, when there might be more funding available²⁴.
- 4.63 Submissions also report what seem to be cutbacks in the HCP budget since 2008. For example, one submission outlines:

"[Social workers] who work with older persons have reported on the steady erosion of this service in many Health Board areas. Currently, from an audit conducted by [X] in 2008, it is clear that there are widespread cutbacks in many local health areas because of budgetary constraints. However, there has been no consistency in the imposition of these current cutbacks. They range from an outright halt to the allocation of any [HCP] grant ... to a reduction in the maximum amount of [HCP] grant that will be allocated." Social worker

- **4.64** Information collected by the Irish Association of Social Workers in summer 2008 found that in some Dublin LHOs new clients could only access a HCP when an existing client stopped using it (a practice known as recycling), while in some others no further HCPs were being allocated, and in one the number of HCPs was being reduced.
- **4.65** Material sent to the NESF from the HSE notes that, after significant additional funding for home care support between 2003 and 2007, the level of increase for these services diminished significantly in 2008, and no new funding was provided in 2009. There is also greater focus and requirement on LHOs to live within their budgets. As a number of LHOs overspent their HCP budget in the early part of 2008, they were then required to return the service provided to the budget level. Therefore, although the HSE has not reduced funding for either HCPs or home helps in particular, it seems that it is more difficult for LHOs to provide all the care sought with the available resources.

²⁴ The HSE reports that it has not reduced its allocation for HCPs since 2008, and for both 2008 and 2009, the allocation was €120m. However social workers report that when they seek HCPs for clients, they are told in some LHOs that budgets are cut and less hours are available.

- **4.66** Similar pressures have been experienced in other countries. With an increase in the ageing population, the costs of long-term care are likely to get higher, with corresponding pressure on public funding. Policy makers in many countries are concerned about the costs of LTC, but the responses vary by country. In some countries, more funding to meet the costs is sought, e.g. through higher payments by older people for care; while in others there are attempts to limit expenditure by increasing targeting or by raising payments by users (OECD, 2005).
- 4.67 In Ireland, the result of a budget which (although high) does not meet all needs for home care, and a lack of standardised eligibility criteria, is that each LHO has to ration the HCP budget which it does have available even more. This is likely to lead to even more inconsistency in implementation and in the effects on older people and their families.

Duplication of work

- **4.68** A number of HCP providers also noted that having different budget lines for HCPs and other types of community care doubles their level of administrative work. One organisation had to run one set of accounts for care provided through a general care budget, and a different set of accounts for care provided through HCPs even though both budgets were allocated by the HSE, and clients of the organisation could be recipients of either type of care. It is also possible that the different budget lines doubles administrative work for HSE staff also, and on that, one submission wondered why an expensively trained professional (a PHN recruited as a HCP co-ordinator) was carrying out administrative work.
- **4.69** Double or triple assessment of the care needs of an older person also occurs. For example:

"The current assessment process for application and approval of a Home Care Package does not always work efficiently in terms of meeting a patient's needs. In many areas, the current system in place is that the Hospital Social Worker submits a Home Care Package application and care plan, following which a Case Manager visits the patient while in hospital to carry out a needs assessment. The Home Care Package application already includes a needs assessment which has been completed by the Hospital Multidisciplinary Team and therefore there is often duplication of assessments which have already taken place." Social worker

- **4.70** In some cases the organisation then asked to provide the HCP care does another assessment of needs! As well as not meeting a patient's needs, and giving rise to conflicting care recommendations, this is clearly a waste of time for both older people and healthcare staff.
- 4.71 Ouble or triple means tests of an older person can also occur. One HSE staff member outlined how an older person could be subject to three different means tests, e.g. for home help services, for a HCP, and for a medical card, often all within a short space of time if they had become suddenly ill. Not only was this extra stress for a patient, but also all three means tests were being carried out by and for the same organisation, the HSE.

4.72 On this issue, a number of submissions noted that inconsistencies between the funding and mean tests for HCPs and nursing home care still favoured nursing home care, even though policy on care of older people aims to maintain as many as possible at home. For example:

"The amount that a patient can apply for (680 euro minus weekly income) to fund support at home is far less than the amount of funding granted for admission to long-term care through the Delayed Discharge Initiative funding or through Enhanced Nursing Home Subventions or what would be provided through the Fair Deal in the future. This highlights that there is still a bias toward the funding of residential placements over supporting people at home in the community." Social Worker

- **4.73** This poor co-ordination of delivery and funding processes around LTC has also occurred in other countries. The OECD review of LTC policies in its member countries (OECD, 2005) found that often older people can face numerous assessments carried out by different personnel, resulting in unnecessary duplication and/or gaps in information. This has been tackled by a variety of means, including agreement on standardised needs assessment, as well as integration of the provision of different healthcare budgets locally.
- **4.74** The above examples indicate again that co-ordination of processes, procedures, organisations and parts of organisations involved in HCPs is poor. In some LHOs HCP co-ordinators made efforts to try and regularly bring together the many different organisations involved in delivering HCPs. However, in gathering information for this report, it was striking that the various groups involved in HCPs seemed to be wary of each other. Different LHOs in the HSE were wary of each other's practices, as were different staff groups within the HSE; while private providers, voluntary groups and the HSE were wary of each other as well. Many were quite defensive about the value of their own work practices compared to those of other groups. This ties in well to similar observations made on the organisational culture of the UK healthcare sector, where different groups working in healthcare could also be defensive (see Mosse, 1994; see also Chapter 2 of this report). It also echoes findings of the Deloitte and Touche (2001:7) review of the Irish health sector, which found that, too often, competition rather than cohesion characterised working relationships between different health sector organisations.

Data on HCPs

- 4.75 In terms of data, it was found that the information collected on LHOs is not adequate for outcomes-oriented policy management. The dataset which is currently collected monthly for each LHO is the number of HCPs being provided (as well as new and 'ceased' cases), the number of recipients, their age, where recipients are referred from, and pay and non-pay costs. Data is not reported on the level of dependency of the older person (which would be assisted by a standardised needs assessment form, if it existed), or on the type of care which they receive. Some LHOs collect more data, and LHOs collate the data which they collect in different ways. Some recorded the data in Excel spreadsheets, which would be easy to collate at national level. However staff in LHOs where this practice was carried out reported that they were not asked for the data. The result is that little data is collated at national level to assist the centre to manage HCPs effectively, either strategically or in terms of client experience.
- 4.76 Data which could be used to assess the quality of life outcomes of those being cared for is not systematically collected either. However this is again quite common internationally. Although the level of satisfaction of those cared for at home is very high, there is very little evidence on the quality of care given in the home. Even the research done in this area usually measures satisfaction and unmet need, and not quality of care in a stricter sense (OECD, 2005).

Conclusion

- **4.77** In summary, this Chapter highlights that HCPs provide much needed care which improves the quality of life of both recipients and their families. Many individuals and their families are very positive about the care which they have received through the significant funding allocated to HCPs over the past few years. However, there are a number of problems in how the policy is implemented on the ground. There are local differences in eligibility criteria; care needs assessment; monitoring; hours when care is available; standards of care; home care worker management; levels of funding and staff available, and co-ordination of key procedures and organisations involved. There is also significant duplication of work, such as care needs assessment, means testing, and accounts administration.
- 4.78 So what accounts for these variations and problems in implementation? The next Chapter will assess why some of these have arisen.

CHAPTER 5

Reasons for local variation in HCP implementation

Introduction

- 5.1 To assess why there are local variations in HCP implementation, as well as other problems in their implementation, this Chapter will compare how HCP policy was developed and implemented with the framework for outcomes-oriented policy implementation identified from the OECD review of the Irish public service (OECD, 2008), the Developmental Welfare State (NESC, 2005) and Improving Delivery of Quality Public Services (NESF, 2006), as outlined in Chapters 1 and 2. Overall, the development and subsequent implementation of HCP policy will be compared first to the five key issues identified from these reports as relevant to an outcomesfocused approach to policy implementation. These are:
 - Strategy plans with agreed outcomes,
 - Measurement of inputs, outputs and outcomes, and monitoring and evaluation using these measurements,
 - Linking budgets to performance,
 - Effective accountability and incentive structures, and
 - Focus on delivery to the client, particularly:
 - equity in provision,
 - delivery plans,
 - · standards for delivery, and review of these,
 - client involvement in shaping of services, and
 - innovative means of delivery (e.g. facilitating access to information, use of private and other service providers, and use of IT).

Following this, reasons for the variations in implementation will be outlined, which will take into account organisational culture.

Strategy plans with agreed outcomes

- **5.2** First of all, did the HCP policy include agreed outcomes and strategy plans?
- 5.3 Overall, the LTC report (Working Group on Long-Term Care, 2005), which as outlined in Chapter three provides the policy basis for HCPs, outlined a comprehensive co-ordinated strategy for care of dependent older people. The report was agreed by a working group, whose membership was drawn from the Departments of An Taoiseach, Health and Children, Finance, and Social and Family Affairs. It recommended a range of supports for long-term care for older people, including HCPs, other community based services, residential care, respite care, housing, support for informal carers, and a variety of means to fund this care.
- 5.4 In relation to HCPs, the report recommended that they be introduced, and this built on a range of pre-existing policy on care in the home for older people. The LTC report also agreed a number of steps to be put in place to allow the HCP strategy to be implemented. Significant funding was then provided in the Budget for 2006, to begin roll out of HCPs at local level. All of these aspects of the strategy development, planning and funding, were very positive.
- 5.5 However on agreed outcomes, the extent to which the LTC report provided these is less clear. It did not agree a specific number of HCPs to be provided, either now or at any time. In some ways the number of people which are expected to need care in the community could be estimated from the report's suggested target residential occupancy rate of 4% of those aged over 65, which means 96% of older people would live in the community although it is not clear how many of that 96% might need HCPs.
- 5.6 It is also not clear what status the 4% figure has as a target. The report clearly states that the Working Group on long-term care 'suggests' a target of 4% of those aged over 65 in residential care. It also outlines that 'a target residential occupancy rate of 4% *may* be achievable in the medium term, if the correct policy mix is implemented' (emphasis added p.11), without stating whether or not the 4% was definitely a target to be achieved, nor what date 'medium-term' would constitute. The report also provided costings and other data in relation to residential occupancy rates of 4.6% and 5.4%. This could suggest that 4% was a target the group would like to achieve, rather than one which they were planning to or were sure would be achieved.
- 5.7 The LTC report noted that data to see what proportion of older people would need HCP care did not exist at the time of writing, and instead referred to estimates of need for HCPs. One estimate was based on the numbers of people in receipt of HCPs in Scotland, and suggested that 12,322 to 15,808 people would need a HCP in Ireland (see p.32)²⁵.

²⁵ This figure was calculated by the National Council for Ageing and Older People at the request of the Department of Health and Children. See NCAOP, 2006.

However, the LTC report did not include this as a target for HCP provision, instead stating that figures for range, distribution and costs of HCPs should be available following evaluation of the initial rollout of HCPs. Meanwhile, some of those met in the HSE by the NESF Secretariat said that the figure of 15,800 HCPs was now an 'informal target' for HCP provision, to be supplied by 2015. However, this is not a target agreed by all involved in financing and providing HCPs, so does not have significant weight, particularly in the current economic downturn. So overall, the LTC report suggested targets and outcomes in relation to HCPs, but these were not clearly stated, and not formally adopted as official policy.

5.8 • Meanwhile, the actions agreed in the LTC report in relation to HCPs are more often inputs, structures and processes to be provided, rather than outcomes. For example, the summary of the key actions arising from the report are mostly about providing funding; developing frameworks, protocols, consultation mechanisms; setting up teams; and providing data of one type or another. See Table 6.1 below.

| Action | Responsibility | Timescale |
|---|---|-----------------------------------|
| Provision of additional increment of home support packages | HSE | During 2006 and 2007 |
| Formal evaluation of this additional increment of packages | Steering Committee, led by D/H&C, to be established. | To be completed by mid 2007 |
| Development of national standardised care needs assessment framework | HSE | Mid 2006 |
| Development of national standard financial assessment framework | D/H&C, D/SFA and D/Finance | Mid 2006 |
| Development of formal protocols for case management and delivery of home support packages on a national basis | HSE | Mid 2006 |
| Development of structured consultation, on a cross-departmental basis with carer representative organisations | D/H&C, D/SFA, D/EHLG and other Departments as appropriate | Beginning in 2006 |
| Planning exercise on staffing requirements | Inter-agency project team led by D/H&C | End 2006 |
| Design and costing exercise to operationalise principles on co-payment | D/H&C, D/SFA and D/Finance | 2006 |

Table 5.1 Key actions relevant to HCPs, arising from proposals in the LTC report

- **5.9** Progress has been made on these actions and there is no doubt that these are useful and key actions to undertake to provide for good implementation of HCP policy. However, they are not actually outcomes to be progressed. The OECD review would consider that these actions are mechanisms to allow policy outcomes to be achieved, rather than outcomes in themselves. This means that the policy is more focused on setting these actions up, rather than on meeting the planned outcomes (e.g. to care for a certain proportion of older people at home).
- 5.10 It is also important that the LTC report states on p.2 in 'Note in relation to publication of the Report of the Long-Term Care Working Group', that, 'while the report's proposals were not formally endorsed by Government, its analysis and recommendations have informed subsequent decisions'. Again this means a lack of clarity around the report and its aims it is used as the policy framework for LTC, but at the same time is not fully agreed by Government.
- 5.11 'Agreed outcomes' in terms of HCPs would also include issues such as agreed national eligibility, copayment and means testing criteria, as they influence the outcomes of the policy i.e. how many people, and which people, can have a HCP. Conditions in relation to these were asked for in the LTC report and subsequently outlined in the PCCC Working Group guidelines on implementation of HCPs (see Working Group on Home Care Packages, 2006). However, these guidelines are not yet in operation. In the interim, with over 8,000 people receiving HCPs at any one time at most, about half of the 15,800 people estimated to need HCPs and no agreement to provide the number of HCPs which is suggested might be needed, a result is that LHOs must come up with local solutions to ration their HCP allocations, and this leads to many of the variations and inconsistencies noted in local implementation.
- **5.12** Overall, a strategy for HCPs was agreed, and funding for this provided. The strategy did not however agree the exact outcomes which it would provide. Instead, to some extent an experimental approach was adopted, and it was planned that an evaluation of the initial rollout of HCPs would be used as a basis to determine the range of community care needed.

Delivery plans

5.13 The LTC report asked for basic delivery plans to be drawn up - 'formal protocols for case management and delivery of home support packages on a national basis'. In line with this, the HSE drew up the PCCC guidelines covering key issues which provide a background for standardised delivery. However these guidelines are still not operational. The history of the guidelines is complicated. The HSE completed them in April 2006, and forwarded them to the Department of Health and Children for approval.

The Department wrote to the HSE in May 2007 stating that the HSE could roll out the guidelines, although not that on co-payment. The Department had sought legal advice on whether or not co-payment was legal, and was advised in late 2008 that it was not. It wrote again to the HSE, advising them once more that they could roll out the guidelines, with the exception of that on co-payment. Currently, the HSE says that roll out of the guidelines is still a matter of discussion between the HSE and the Department of Health and Children. It is difficult to disentangle which organisation is responsible for agreeing the guidelines, but what is clear is that the guidelines are not operational.

- 5.14 Two other issues which are to have a national standardised approach, which are a) care needs assessment, and b) schedules of service and care plans, were being agreed by different groups to the PCCC Working Group on HCPs. However they have not yet been agreed either.
- **5.15** In terms of implementation the fact that these national standardised guidelines are not operational is a key outstanding issue. It is leading to local variance in implementation, as each LHO is developing their own implementation practices (except for a few LHOs such as those which were part of the old Dublin-Mid Leinster health board, which use the same forms, eligibility criteria etc). This leads to the variations and inconsistencies experienced by clients in terms of eligibility criteria, needs assessment, and means testing, HCP reviews and monitoring. At the same time staff in different LHOs are duplicating work, as each area sets its own eligibility criteria, needs assessment, and means testing.
- 5.16 Some of these issues were identified as problematic in an earlier evaluation of pilot home care packages (see Timonen, 2004). The LTC report notes that the Timonen evaluation was taken into account in developing the larger tranche of HCPs. Indeed, the Timonen evaluation called for a dedicated home care package budget to cover unmet need, and such a budget was put in place following the LTC report. And other problematic issues noted in the Timonen evaluation - no standard means testing or care needs assessment, lack of standard reviews, and a need for staff to support HCPs - are identified for action in the LTC report. The PCCC guidelines developed a standard means test and outlined the parameters of regular HCP reviews, and work is planned on a standard care needs assessment. However, some other problems identified in the Timonen evaluation (such as poor co-ordination, poor public access to information about HCPs, lack of standard computerised records) were not addressed in the LTC report or in the PCCC guidelines. In short, some key issues remain problematic and difficult to tackle. This contributes to these implementation problems continuing into the current policy.

Measurement of inputs, outputs and outcomes; monitoring and evaluation

- 5.17 The LTC report noted that data was required to assess the need for community care services for older people, and outlined data which should be collected (see Chapter 3). It is not completely clear whether or not that data was to be collected prior to the evaluation of HCPs, or through the evaluation process itself. In any case, such data is not yet available as the evaluation is not yet completed.
- 5.18 Meanwhile, data is also needed on the outputs of the HCPs provided, and such data was asked for in the PCCC Working Group guidelines (see Chapter 3). In practice, Chapter four shows that little of this is actually being collected. Instead the data collected monthly for each LHO are the number of HCPs being provided (as well as new and 'ceased' cases), the number of recipients, their age, where recipients are referred from, and pay and non-pay costs. But this is only information on inputs to HCPs.
- **5.19** While this is useful and necessary data to collect, on its own it does not provide enough information on outputs or outcomes, and when inputs and outputs and outcomes cannot be compared, then the efficiency and effectiveness of the monies being spent cannot be assessed. While the Department of Health and Children evaluation of HCPs should help assess efficiency and effectiveness, the input focus of the data routinely collected does not promote on-going central management knowledge of HCP operation. It is not possible to identify areas which are operating well or badly from this, and to then spread good implementation practices. It is particularly important to regularly review rollout of a new policy, such as HCPs, where an experimental approach has been adopted which starts rollout as soon as possible, aiming to learn from and adapt the policy based on that early rollout.
- 5.20 Evaluation of HCPs was asked for in the LTC report, and this is now being carried out at the moment. This is a very useful exercise, in that it should pinpoint many outcomes of the HCP policy, and help identify areas of good practice. So overall, although the strategy for data collection on outputs and outcomes was good, in practice collection and collation is poor. Meanwhile, the focus on evaluation is welcome.

Link performance to budget

5.21 • The LTC report asks for more data to allow budgets and performance to be better linked, but such data is still not available. At a macro level, the HSE Service Plan for 2009 contains Key Performance Indicators, but these are not linked at all to budgets. In the appendices of the Service Plan, the capital costs of specific new infrastructure (e.g. a hospital extension) are provided, but the costs of service provision are not outlined. No links are made between the number of HCPs to be provided, and their costs (see HSE, 2009a).

In the Performance Reports on this Service Plan (e.g. for Feb 2009 – see HSE 2009b) data is provided on the number of HCPs and the number of people receiving them (input and output data), but with no data on outcomes, and no links to budget.

- **5.22** At a more micro-level, the (mostly input and some output) data collected by LHOs on HCPs does include pay and non-pay costs. The average costs of a HCP can be calculated, but more in-depth links between performance and budget, such as the costs of different types of HCP deliverers for various types of care provision, is not available as standard. Having such data would allow better management of HCP budgets and outcomes. For example it could allow the most efficient ways to manage and implement HCPs to be identified, which could help promote use of such more effective work practices within and across LHOs.
- **5.23** On performance and budget, it also appears that staff are not allocated according to needs²⁶. The staff planning exercise called for in the LTC report, which would have been relevant to provision of all care for older people, has not been done. Not having enough staff to manage and monitor HCPs is likely to have some links to inconsistent monitoring, for example.

Accountability

- 5.24 There is little on accountability in the various policy documents or guidelines. The actions that are to be undertaken are outlined, and sometimes by when, but who should do what is not always outlined, nor are the consequences if an action is not completed on time. This seems to occur at many levels. First, as outlined earlier, the LTC report was 'not formally endorsed' by Government. And although it includes a list of actions and times by which (or in which?) they were to be done, few of these were done by the time proposed (see Table 6.1 earlier). This does not seem to have triggered any particular sanctions, or supports to get back on track.
- **5.25** At the next level, the guidelines developed to standardise HCP implementation again have been written, but are not operational. As outlined earlier, whether or not the PCCC Working Group guidelines are agreed for implementation cannot be agreed between the Department of Health and Children and the HSE. The former says that the guidelines can be implemented by the HSE, with the exception of co-payment. The HSE says that implementation of the guidelines is still subject to discussion between the two organisations. This shows that lines of responsibility and accountability on this key issue are not clear.

²⁶ Interestingly, the HSE Performance Report for February 2009 calls the LHOs which have less staff in place than the staff ceiling which they are allowed, as 'LHOs with Most Significant *Favourable* HR Variances' (emphasis added). LHOs which have more staff than allowed are listed as having 'significant *adverse* HR variances'. There is no data provided in the report on how the staff allocations link to the number of staff which might be needed for the population of an LHO. See HSE, 2009b:9.

- 5.26 At LHO level, better data and monitoring is needed to assess what is being delivered, and by whom. If accountability mechanisms were more developed (e.g. with definite dates, personnel responsible, and consequences for not delivering on time), then it is likely that some of the standardised guidelines which would prevent inconsistencies and inequities arising through local implementation of HCPs, would have been operational more quickly.
- **5.27** Overall, although accountability was an issue examined in this research as it is stressed in the OECD outcomes approach, so little information was found on it that little could be said apart from the fact that accountability lines, incentives and sanctions in relation to HCP implementation are very unclear.

Focus on delivery

- **5.28** In the following sections, how the HCP policy fares regarding a number of issues relevant to delivery will be outlined. The issues covered will be equity in provision, co-ordination, standards for delivery and review of these, client involvement in shaping of services, and innovative delivery through a range of service providers.
- **5.29 Equity** is an issue which is not explicitly discussed in the LTC report, but it does request the development of a standardised national framework, with co-payment based on an individual's financial means, which would ensure greater equity in provision of HCPs. A suggested framework on this was proposed in the PCCC Working Group guidelines. But these guidelines are yet not operational, and legal advice has ruled that co-payment (charging) for HCPs is illegal. Without national guidance on how to assess financial eligibility for HCPs, LHOs have devised their own eligibility criteria, which is one of the main issues leading to inequity and inconsistency in implementation of this policy.
- **5.30** A HCP facilitates **coordination** in the delivery of different services to a client, and so is an innovative co-ordinating policy. In practice however, implementation problems arise from poor co-ordination in aspects of HCP management. However, as outlined in Chapters three and four, there is no common needs assessment, means test, or case management approach, yet. Co-ordination would cut down on duplication in these areas, which is waste of both client and HSE time. Meanwhile, separate budget lines for HCPs, for home helps, and for other community services provided by voluntary and other organisations leads to parallel budgeting and accounts administration for both the HSE and HCP providers. Time spent on this duplication could be better spent on other aspects of HCP implementation currently receiving less attention, such as monitoring. For HCP recipients, different budget lines and administrative systems for different services means they have to find out about and access several services, and provide the same personal information to them, instead of providing the information once to one point of contact which could then inform them of all services available.

- **5.31** On co-ordination of the different HCP providers, although the LTC report mentions links between a client, their family, and different providers, no detail was given on how this would operate. The PCCC Working Group guidelines do not cover this either. This may be a factor leading to clients receiving unco-ordinated services from a range of different community care services, which causes problems for them. Greater co-ordination would cut down on some of these implementation problems.
- **5.32** Links to Primary Care Teams (PCTs) are mentioned in the 2008 EAG standards guidelines. A diagrammatic model is provided of how integrated services should work under a primary care team, and it is outlined that home care support providers would be part of primary care teams as part of the reconfiguration of existing services (p.5). This would have some relevance to co-ordination of the home care support aspects of HCPs. However, it is estimated that only 20% of primary care teams are currently in operation.
- **5.33** Overall, the focus on co-ordination at delivery level is weak. Although co-ordination of procedures such as care needs assessment was planned, it has not happened. Similarly co-ordination of deliverers is very weak. PCTs, which would provide a good mechanism of co-ordinating different healthcare providers at local level, are not yet operational in most areas. And in terms of the whole strategy for providing long-term care, although the NESF research did not assess the extent to which the whole LTC report was being implemented, a number of those involved in management of HCPs said that it was difficult for HCPs to operate as originally planned, while other aspects of that strategy were not in place. The fact that other co-ordinated supports planned for LTC (e.g. more respite care, sheltered housing etc) were not in place meant that more people sought a HCP.
- **5.34** Standards in relation to the provision of home care were asked for in the LTC report (p.29), and this did figure in the key actions to be progressed, which were summarised in the final section of the report (p.54). To date the EAG Working Group has agreed standards in relation to home care, which would cover some aspects of HCPs, although not all. However, theses guidelines still need to be approved by a number of decision-making levels in the HSE and the Department of Health and Children, before they could be implemented. This means there are no standardised conditions in operation in relation to home care support worker training, coverage and rostering, HCP reviews and monitoring etc. Agreeing, passing and monitoring these common standards would help to resolve many of the problems experienced by clients, as well as saving HSE staff time.
- **5.35** The need to **review** packages was not outlined in the LTC report, but was asked for in the PCCC Working Group guidelines, which focused on the monitoring of individual packages to ensure that the care being provided was adequate. These guidelines were weak on specifics, and in practice, the NESF questionnaire on LHO practices showed that review of HCPs takes place at varying intervals in different LHOs, and it is also not clear what exactly is monitored.

- **5.36** Another aspect of review is the monitoring of home care staff, and this issue is covered in the EAG guidelines on home care standards, although these are not yet operational and would not apply to all aspects of HCPs. So overall, it is hard to know what care people are getting, if it is adequate, and if there are problems with it. From a more strategic point of view, it is hard to know which provider, LHO etc, is doing what well. None of this helps develop more efficient or effective implementation; and contributes to local variation in practices.
- 5.37 Client involvement in the shaping of services includes tailored universalism, which means designing services around a user's capabilities. At a strategic level the whole concept of a HCP is to provide the mix of services an individual needs. The ethos of linking HCP provision with informal care, as outlined in the LTC report, also fits with the idea of tailored univeralism, which stresses how the solutions provided to an individual through such a tailored service should take into account the capabilities of the individual, their family and community. And in line with this, the PCCC Working Group guidelines call for a schedule of services/ care plan, agreed with individual and family. The cash grants also allow for tailored universalism, as they allow a person to choose their own care.
- 5.38 The reality is more mixed. Some people reported that home care support workers do not carry out the work which clients would like them to do, and it is also not clear to what extent services and care plans are being agreed with individuals and their families. Meanwhile, 28% of new HCP recipients received a cash grant to organise their own care in December 2008 (HSE, 2009c); and in some areas, but not all, HCP recipients can choose which of the preferred provider organisations will provide them with care. Where people can choose a preferred provider organisation, or where they can choose whatever care provider they wish through a cash grant, it seems that people would welcome more support in choosing a care provider. In the case of cash grants, some older people found the responsibility of being an employer too much. More support on this might help implementation of HCPs for individuals.
- **5.39** It also seems that cash grants are being phased out in many LHOs, which reduces the choice and input of care recipients. Even though the responsibility of being an employer which came with this level of choice is not something which many recipients will miss, many would, however, welcome the possibility to decide what type of care they would receive, from who, at what hours etc, and this would ease the burden of caring.
- 5.40 Innovative forms of delivery can be developed through competition among service providers, and this is allowed for in the LTC report, which is an innovative aspect of HCP policy which has been translated into practice. HCPs can be and are delivered by private providers, which provides competition with voluntary organisations and HSE providers.

Some private providers seem to have very good management systems (in terms of staff management ratios, home care support worker training, home care support worker monitoring, home care support worker handover practices, existence of logs recording client care, complaints procedures etc), and some voluntary organisations met over the course of this project are also improving their management systems, possibly in response to this competition. A range of better management systems could improve HCP implementation on the ground, particularly if the higher standards now available from some providers become the norm, and are required from all deliverers.

- 5.41 On the other hand, better monitoring is needed of these alternative models and options of delivery. It is not clear that all deliverers are providing good quality services. The PCCC Guidelines refer to monitoring by the HSE of different HCP providers. They recommended that service level agreements (SLAs) be in place with these providers, specifying monitoring arrangements, among other things. However, although SLAs are in place in many cases, it is reported that monitoring of these agreements does not happen in practice. The preferred providers' contract also exists in some LHOs, but again monitoring of the extent to which providers meet its provisions is poor.
- 5.42 Better provision of information is also a means of improving delivery of services to clients. However, the submissions sent to the NESF showed the difficulties which many people faced in trying to find out what HCP supports were available, from who, and if they were eligible for them or not. And although Information Technology can improve access to information, it is not well used in relation to HCPs, with the HSE website providing only limited information on what a HCP is, along with contact details for LHOs. IT could be used to provide detailed information on eligibility criteria, application forms, and means test forms, for example, all in one place for clients. It could also be used to store management information for use by the HSE, such as the monitoring information collected, average costs of HCPs etc. However this does not occur as standard in LHOs.

Discussion

5.43 This review of how HCP policy was designed and implemented shows that the strategy development followed best practice in many ways. A comprehensive and co-ordinated strategy document (the LTC report) was developed and agreed, drawing on international experience in the area of LTC, as well as a number of Irish strategies on the care of older people. These had stressed the desire of older people to remain in their own homes as long as possible, and that policy wished to support this.

The report also outlined how HCPs would fit into a range of supports to care for older people. In the LTC report, key aspects of delivery were also identified (such as eligibility, means testing, common assessment tools and evaluation), along with a timetable for agreement and rollout of these issues. A Working Group was set up to agree how to implement these key aspects of delivery. At the same time, significant funding was allocated to HCPs, allowing a much greater number of older people to be cared for in their homes. Rollout of the packages also occurred despite the stresses of organisational change, as the HSE was being set up at the same time.

5.44 • However, some issues such as fully agreed policy outcomes, links between budget and performance, and clear accountability mechanisms, were not as well outlined in the policy development. Meanwhile, local implementation of HCPs has been quite variable. The following table summarises progress to date.

Table 5.2 How HCP policy design and implementation matches outcomes-oriented best practice

| The theory – Key issues to be covered in best practice outcomes-oriented policy design and implementation | The practice – How these key issues were taken into account in HCP design and implementation |
|--|--|
| Strategy plans with agreed outcomes | Strategy – yes; Agreed outcomes – to some extent. |
| Measurement of inputs, outputs and outcomes, and monitoring and evaluation using these | Measurement of inputs – yes; Measurement of outputs – some; Measurement of outcomes – no; Evaluation – under way. |
| Linking budgets to performance | This is weak |
| Effective accountability and incentive structures | This is very weak |
| Focus on delivery to the client, particularly:equity in provision | A strategy was designed, but is not yet operational |
| delivery plans | Plans designed, but not yet operational |
| • co-ordination | This is weak |
| • standards for delivery, and review of these | Standards for some aspects of HCP designed, not yet operational; Review of HCPs is variable. |
| client involvement in shaping of services, and | Some HCPs allow recipients to choose and/or organise their own care; This does not apply in all LHOs. |
| innovative means of delivery (e.g. facilitating access to information, use of private and other service providers, and use of IT). | A range of service providers deliver HCPs; Information provision is poor; Use of IT is poor. |

5.45 • What reasons are there for good practice in some aspects of HCP design and delivery, and weaker practice in some other aspects? This will be discussed in the following sections.

Similar experiences in other countries

- **5.46** First of all, although Irish HCP implementation may seem poor, this is not an isolated experience. A review of experiences in many other OECD countries when introducing LTC in the home also indicates many problems with e.g. local variations in provision of LTC, conflicting approaches to needs assessment and eligibility, poor monitoring when home care supports are first implemented, very little data on their progress, few or no standards developed for home care, problems developing an equitable charging system, and poor co-ordination with other forms of care for older people (see OECD, 2005). That OECD LTC report also showed that it is common for policy on home care to be lagging behind that on residential care internationally. This is now the case in Ireland also, where for example agreement on eligibility and charging for nursing homes is being reached, where there is more data on care in nursing homes, and standards on residential care are more advanced.
- 5.47 The Irish experience of HCP implementation also ties in with the very comprehensive review of implementation processes carried out by Fixsen et al (2005), outlined in Chapter two. The overview of HCPs in Ireland indicate that the HCP policy is in what Fixsen et al would call Stage 3 of policy implementation - i.e. initial implementation, the stage of change, which is at the core of implementation. At this stage change is required in skill levels, organisational capacity, and culture. Fear of change and inertia are important in this stage, and it is a time when new practices may end, overwhelmed by the change process. This also gives hope of a move to Stage 4, full operation, for HCP policy implementation in future, when the new learning is integrated into practitioner, organisational and community practices and procedures. This stage is characterised by full staffing complements, full client loads and referrals flowing according to agreed-upon inclusion criteria. Typically, it takes two to four years to reach this stage of implementation, which is near the length of time in which HCPs have been operational. The Project Team hopes that this NESF report, and the Department of Health and Children evaluation of the HCPs, will provide the basis to move to Stage 4 implementation.
- 5.48 What other factors might explain the variable progress on different aspects of HCP design and implementation? Some particular issues relevant to organisational culture which help explain this are outlined below.

Reasons for slow progress towards full implementation

Delays

- 5.49 A key reason for problems in implementation is delays. One of the biggest delays evident is getting both the guidelines for HCP implementation, and the standards for quality home care, into operation. These delays have serious repercussions in terms of equity for clients and effective use of time by staff. Why have they occurred?
- **5.50** First, a decision was made to focus first on developing and implementing new legislation and standards in relation to residential care. This is common in other countries also (see OECD, 2005), and while disappointing for those involved in HCPs, is necessary if there are not enough staff to develop both residential and home care legislation and standards at the same time.
- **5.51** Another possible reason is that timelines for action are often very short, and may be unrealistic. For example the LTC report asks for a standardised needs assessment framework, a standard financial assessment framework and formal protocols for case management and delivery of HCPs by mid 2006, and three years later none of these are agreed. In areas where new legislation is required (e.g. for charging) it also takes a significant amount of time to draft and pass this. Perhaps setting a longer timetable might have been more realistic.
- **5.52** Another reason for delays, this time in relation to standards of care, is that some of the organisations currently providing care may find it hard to meet new standards (an issue noted internationally, see OECD, 2005), and fears round this are likely to increase the time spent agreeing standards.
- 5.53 However some more systemic reasons for delays are evident. A key issue is the number of organisations involved in agreeing standards for implementation. For example, in relation to the quality home care standards, it was decided to broker agreement between the HSE, voluntary home help organisations, private care providers, groups representing older people and carers, on these standards. This has the benefit of ensuring buy-in from all those who will implement the standards, but it does take time to get such a large grouping together, and more time for them to agree a common approach. They now have agreed guidelines, but these guidelines have then to be passed by the EAG on Services for Older People, then by the HSE Governance Group on Services for Older People, then by the HSE PCCC Management Team, then by the HSE Board, and then by the Department of Health and Children. Once passed by these groups, some aspects of such standards would need to be put in legislative form, which would involve a costing exercise, an RIA (regulatory impact assessment), and drafting of legislation. Some of the structures which are to pass the standards have been changed in the HSE reorganisations, which again slows down the process.

5.54 Many of the delays in decision-making are filled with dialogue among a large number of groups. This suggests that dialogue is favoured over decision-making. Interestingly, those who were actually delivering the HCPs were usually not only absent from this dialogue, but often did not even know what had been agreed through it – even though they would be involved in delivering it. Overall, there is too much dialogue among decision-makers, and too little between decision-makers and implementers, and among different implementers. Dialogue with users, also important, is notable by its absence. Information flow is also poor. Clear lines of communication between decision-makers (at national level) and implementers (at local level) are not seen as important. Again information flow to service users is weak.

Costs of care

- **5.55** A reason for delays regarding equity and eligibility in allocation of HCPs, is that there is no legal provision to charge for HCP care. Without such legislative support, a co-payment system cannot be agreed. A timetable for legislation to deal with this would therefore be useful. At the moment, it is reported that the Eligibility Review Group in the Department of Health and Children is the most appropriate body to look at this issue. However there is no date for this group to report, and apparently it may never report. A reason may be that issues around eligibility and charging for health care are not politically popular.
- **5.56** Similar factors may also be a reason for not agreeing the exact number of HCPS to be provided. Although the LTC report gives a lack of strategic data as a reason, closer examination of this suggests that it may not have been necessary to have precise data to agree outcomes. At the time, the LTC report included an estimate, based on Scottish data, that approximately 15,800 people would need a HCP, planning to have a clearer idea of how many HCPs were needed following the evaluation of HCPs after two years of rollout. At the moment, approximately 8,000 people receive a HCP at any one time, which is at most half of the figure of 15,800 which might be needed. With such a gap between the numbers being provided with a HCP and the number estimated to need one, exact data on needs is not really necessary to agree an outcome for the time being. It is likely that unwillingness to commit to providing full funding for all the HCPs which could be needed may be relevant. LTC is expensive to provide and many countries have difficulties funding it and have made decisions to limit and target it, rather than to make it universally available (see OECD, 2005). This is a politically difficult issue to tackle, as shown by the debate around introduction of the Fair Deal scheme to fund residential care.
- **5.57** Difficulties agreeing funding and eligibility for the policy may be linked to the lack of clarity on HCP targets and eligibility. In fact a lack of clear information is evident at many levels in this policy. During the course of this research, it was extremely difficult to access information on HCPs. Very little information is centrally published or available. Some data which was published at central level later turned out to be incorrect.

These difficulties mirror the experience of members of the public trying to find out information on HCPs. The lack of clarity around accountability is also quite striking. It is not clear where the responsibilities of one group end and another begin, or how the handover in between should be handled. The results of lack of clarity include inequity, duplication of work and inefficiency. As they continue to exist, this suggests that they are viewed as less problematic than being clear about what is available and to whom, and prioritising a national standardised approach over local variations. Overall it seems that on some level, lack of clarity is preferred over specifics.

Loyalty to local group, rather than to national strategy

- 5.58 Another important issue which has an impact on implementation is the focus on local rather than national implementation. The national plans that were made to ensure delivery (the PCCC guidelines) are not yet operational. They are also not very detailed in terms of delivery, with no discussion of processes which will be used to deliver HCPs on the ground. Meanwhile, best practice in local implementation has not been tracked at national level. The HCP evaluation will do that, but it would have been better for implementation of HCPs if best practice had been identified, and disseminated nationally, much earlier.
- **5.59** Leadership was not looked at in detail in this research, but it is interesting that the post of National Care Group Manager of Services for Older People in the HSE has been filled three times in three years, and is currently just one element of a person's job description. The result is that national co-ordination of services for older people in the HSE has received less priority over time.
- **5.60** The various groups involved in design and delivery of HCPs all work very separately from each other. There is very little drawing together of the diverse people working on HCPs, and their experiences. For example, one HCP co-ordinator, an employee of the HSE, asked the NESF for a list of all other HSE HCP co-ordinators. Outside the HSE, some of the different groups delivering HCPs (e.g. private agencies, voluntary groups) were curious about each other, for example asking the NESF how did the other groups work, and was it true that their work approach was as rumoured etc. However more often the groups were wary of each other, and tended to attribute poor working practices to other groups. Overall the research showed that different groups are isolated from each other, and loyalty seems to be to the professional group within which one works, or to the geographical region in which one works (e.g. one's own LHO), rather than to the national HCP strategy.

Mechanisms in place to ensure delivery

- 5.61 There are a range of mechanisms in place which aim to ensure and to monitor delivery of the HCP strategy. These include delivery plans, data on inputs and outputs, and on costs, data on targets, and accountability mechanisms.
- 5.62 On delivery plans, as outlined already, the national plans made to ensure delivery (the PCCC guidelines) are not yet operational, and are also not very detailed, with no discussion of processes which will be used to deliver HCPs on the ground.
- 5.63 On data, very little standardised data on HCPs is collected. One problem is that the PCCC Working Group guidelines outlining the comprehensive data to be collected are not yet operational. However agreement has been reached for all LHOs to collect some more basic data, on HCP inputs and some outputs. Despite a lack of administrative staff and comprehensive IT to record the data, some LHOs report collecting and collating this and other data on Excel data sheets. However they also report that they are asked for little of this data by anyone outside the LHO. It seems that a key problem may be that even when data is collected, it is not collated and used for management at national level.
- 5.64 Without a range of data on inputs and outputs, it is very difficult to link performance and budget. While some information was provided on how HCP budgets are allocated, it is quite difficult, based on the HSE Service Plan for example, to see the links between budget and performance. Again, this is not limited to HCPs only. As Deloitte and Touche (2001:44) pointed out in their earlier Value for Money review of the Irish health sector, 'the health system ... was singularly deficient in the application of comprehensive measurement systems across the sector to enable an informed assessment of value for money to be undertaken'. The OECD review found that the Department of Finance does not seem to use performance data to allocate budgets (OECD, 2008: 160). So there is little motivation for staff to link the two.
- **5.65** The connection between HCPs and strategic targets around long-term care policy is also weak. An example is the indicator set regarding the proportion of older people in long-term residential care in the HSE Service Plan 2009. This is the 'percentage % of the population aged 75 years and over in residential care continuing care settings, i.e. HSE Area and other residential continuing care settings, including private and voluntary, as a percentage of the total population aged 75 years and over', which is to be less than 10% in 2009 (see HSE, 2009a). This does not link to the LTC report, which discusses a target of between 4 and 5.4% of those aged over 65 (not 75) being in residential care, so is not helpful in assessing to what extent the strategic targets around long-term care are being met.

- 5.66 Accountability has already been outlined, and it is not always clear what exactly has to be done, by when and by who, in order to deliver the LTC strategy. In this situation, it is not surprising that deadlines for delivery are missed. In fact, there is no effective monitoring of whether or not the steps planned to put HCPs in place are being met; and as there are no precise targets set for HCPs, this is also not being measured. Collection and use of such information does not seem to be a priority.
- **5.67** The constant delays in agreeing guidelines, needs assessment criteria etc, also seem to be accepted rather than seen as problematic; as does the duplication of work. Instead budget procedures seem more important than strategic planning procedures. The timeframes and targets which are not missed are those around annual spending on HCPs in each LHO. This suggests that spending or saving costs on an annual basis in an LHO is rewarded more than meeting strategic HCP targets. This is the case even though the strategic targets have been developed to meet needs while at the same time containing long-term costs.
- **5.68** Some of the issues identified in the evaluation of earlier pilots (see Timonen, 2004) are still problematic for delivery of HCPs, such as the need for standard eligibility criteria, equitable means testing, standard needs assessment etc. As mechanisms to address some of these were outlined in the LTC report, this indicates that these problems were recognised and there was a desire to deal with them in new strategy. However they still are not operating effectively on the ground. Why is this?

Disconnect between strategy and working practices?

- 5.69 This all suggests a disconnect between the strategic planning for HCPs and the reality of what is rewarded in the system for implementing them. HCPs form part of a well thought-out strategy to meet an agreed need for long-term care, and aim to do so in an equitable and efficient way. However implementation of this national strategy does not seem to be rewarded, and no sanctions are evident where it is not implemented. Current working practices are strongly structured around annual budgets; local work practices; weak accountability; a lack of connection between policy makers and policy implementers, and between different policy implementers; unclear eligibility for the service; and weak review of whether or not the strategy is being implemented.
- **5.70** Altogether, these all underpin the lack of agreed outcomes and targeting which means that it is difficult to target the HCPs which are available at those who need them most; and the lack of agreed national implementation procedures. It is these factors which lead to the inconsistencies and inequities in services delivered, and to the ineffective use of staff time.

Summary

- **5.71** To summarise, analysis of how HCPs were designed and implemented suggests a number of organisational culture issues which underpin the lack of targeting, and inconsistencies in delivery. These are:
 - Decisions are not being taken at national level on how to target limited funding in a policy area with high costs.
 - This links to a preference for lack of clarity over specifics.
 - Dialogue and communication seem favoured over decision-making.
 - This dialogue has too many layers of policy makers, with too few policy deliverers and service users involved.
 - There is a focus on annual budgets over strategic process.
 - This is one reason for data not being collected and not being used to improve management of implementation.
 - It is also linked to the lack of consequences when strategy targets are not met within set timelines.
 - And it links to the poor delivery plans for reaching agreed national strategic outcomes.
 - The last four are also linked to loyalty to local group, rather than to national strategy.
- **5.72** All of these suggest that the connection between strategy, decision-making and working practices is poor.
- **5.73** The next and final chapter will make recommendations in relation to implementation of HCPs, as well as drawing out learning from this study of policy implementation for that issue overall.

CHAPTER 6

Recommendations

Introduction

- 6.1 The analysis in this latest NESF report confirms the validity and usefulness of focussing on the issue of implementation as part of the policy-making loop, as the tendency up to now has been to focus more on policy analysis and strategy statements and frameworks. Not enough attention has been given to why targets and objectives were not being realised, with results that were quite different in many cases to what was originally planned when the policy in question was first introduced.
- 6.2 This new approach in the policy design process also reflects and is in keeping with developments and initiatives that have been introduced in a number of other OECD countries. These have a strengthened focus on improving service outcomes in policy-making, giving greater recognition to equity and fairness in the provision of services, and adapting public services to better meet people's different needs and be more responsive to the challenges in our rapidly changing societies.
- 6.3 In this final Chapter of the report, a number of key recommendations first on Home Care Packages, and second on policy implementation overall are brought together. These draw on the analysis and findings in earlier Chapters of the report. Those on HCPs are designed to be complementary to the HCP evaluation commissioned by the Department of Health and Children. Meanwhile, those on policy implementation overall will test in a real policy context the advice on implementation given to the Government in earlier OECD, NESC and NESF reports.

Recommendations for Implementation of HCPs

- 6.4 As outlined earlier, the provision of HCPs represents a significant increase in funding for care in the community for older people. This provision was based on a comprehensive strategy for care of older people outlined in the 2005 Long-Term Care report, which built on previous policies in that area. However although the strategy was well planned, in the absence of agreed outcomes and operational guidelines for standardised national implementation of HCP policy, inconsistencies and inequities have arisen at local level. High demand for care for older people is likely to continue, and indeed to grow, and realistically, it will be hard to meet all demands for that. Nonetheless, more consistent and equitable implementation of HCP policy could be gained through the following recommendations, which should be seen in the context of an overall strategy for older people.
- 6.5 These recommendations involve all stakeholders and are not confined solely to the Government and State agencies, most notably the HSE. They will not in themselves involve any major additional costs for the Exchequer. On the contrary, these are designed to achieve better and more effective and efficient results from present expenditure levels. To the extent that decisions are taken to increase the number of HCPs and narrow the gap between present levels of provision and unfilled needs this would, of course, involve extra public expenditure but these are political issues and ones ultimately for decision by the Government.
- **6.6** The recommendations are as follows:
- 6.7 Agree exact outcomes
 - First, the number of HCPs which is needed, and which will be supplied, needs to be agreed, and the time frame in which this is to be achieved. The budget and staff resources to support this also need to be agreed. This agreement should be between all involved – policy makers, implementers and politicians.
 - At this stage, any issues impacting on the number of HCPs needed, such as eligibility criteria, means assessment, and needs assessment, need to be agreed.
 - These actions should be co-ordinated with other relevant strategies.

6.8 • Focus on delivery

In terms of delivery, a number of recommendations are made.

- Detailed delivery plans need to be devised, outlining at national and local level the actions to be taken, who is responsible in each organisation, and the follow-through from one step to the next. Practices should be codified, and presented in a set of instructions²⁷. The delivery plans particularly need to take into account how links between national organisations designing policy, and local bodies implementing it, will work.
- Much greater co-ordination of services is also needed. For example, greater co-ordination of information, of needs assessment, of budgets for home care, and of different providers of homecare.
- Standards for delivery need to be agreed and passed. These would cover issues such as user access and information points, care plans, hours during which care is available, standards required of home care support workers, staff handover procedures, vetting of staff, training of staff, type of care to be given to those with particular requirements (those with disabilities, with terminal diseases, dementia, etc).
- Monitoring also needs to be carried out, of individual HCPs, and of LHOs, as well as of providers (including their staff), to see if they all meet the standards of care agreed. The results should be published and the corrective actions outlined where quality standards for services delivery are not met.
- An **appeals and complaints procedure** should also be introduced.
- From the client point of view, guidance is needed on how a person should select a provider, where this option is available; and support in terms of being an employer should also be available. A variety of options have been put in place in other countries, ranging from organisations which advise on payroll and employer responsibilities, to others which provide payroll facilities (see OECD, 2005).
- Information Technology (IT) should be used more to record and collate outcome data; and to improve delivery to clients on the ground. For the latter, IT can be used to provide clear information on eligibility, on-line application forms, and information on exactly who the contact person for HCPs is in each LHO. It can also be used to put all client records on-line, accessible for all relevant HSE staff through a password, which would reduce duplication for staff and clients.

²⁷ Such detailed instructions are used in Logorno, Spain, where the city council has operating system guidelines covering all types of care in the home. The four steps to be taken to move from a situation where a need for home care is identified, to having it in place, are outlined. Under each step the action to be taken is identified(e.g. identify care needs); followed by who is responsible (e.g. social worker); any other necessary steps (e.g. completion of documentation); and follow through to other staff.

6.9 • Tie outcomes to budget allocations

- The agreed budget for HCPs should link to the number, needs and resources of older people in an LHO (or as a start, mechanisms to allow this to happen need to be set up).
- Staff allocation should also be linked to outcomes, for both service delivery and service management.

6.10 • Measurement, monitoring and evaluation

- Two types of data need to be collected regularly both strategic development data, and delivery data. For strategic development, data should be collected on:
 - the health and care needs of older people in general,
 - · the likely availability of informal caregivers,
 - the needs of other groups who also need care in the home (e.g. those with disabilities),
 - longer term outcomes, such as delayed discharges from hospital, and satisfaction with level of and type of care, by recipients and carers, and
 - the characteristics of those receiving HCPs.
- Since the LTC report was finished in late 2005, some more data has become available which could be used to help decisions to be taken on the level of need of older people for HCPs. These sources are outlined in Annex 4.
- Delivery data should also be collected on
 - Finance, including how much it costs for each type of service provider to provide a given standard of care, to allow the relative costs of e.g. private, voluntary and HSE provision to be assessed; and
 - Issues such as the most effective staff-client ratios, staffmanagement ratios, staff training and evaluation processes, management of private providers etc.
- The data collected should be in the same format in every LHO, and be recorded on a computer package (e.g. Excel). It should be used for periodic evaluation of how the outcomes of the policy are being reached, and the processes whereby these are reached. These evaluations should be used to make whatever adjustments are needed to practices that are not delivering the results that were planned.
- Regular review of policy implementation should also be undertaken, particularly where an experimental approach to implementation has been adopted, to rollout a policy before all plans for its implementation are in place. In this case regular review is necessary to see what aspects are working well and what aspects need to be changed.

6.11 • Accountability

- To develop this, there needs to be clear and explicit outlines of the responsibility of each organisation and individuals within them, to meet the agreed outcomes.
- Individuals should be provided with the resources they need to meet the targets set.
- A form of incentive and/or sanction needs to be introduced to help ensure that outcomes are reached. Incentives could be provided for a period of time, to help organisations and individuals to meet the outcomes set. In the case where outcomes are consistently not being met, sanctions may be more appropriate.

6.12 • Types of HCPs

- The submissions show that those whose relatives are very dependent are very stressed, and may benefit from stronger HCP supports. In Australia, Community Aged Care Packages (CACPs) provide home care to those who are eligible for low-level residential care. In addition, Extended Aged Care at Home (EACH) packages deliver care at home which is equivalent to high-level residential care. They make up about 8% of all Australian home care packages. More recently the Australian Government introduced EACH Dementia packages, to provide high-level residential care in the home to those with symptoms associated with dementia. These make up 3% of all Australian home care packages (see AIHW, 2008). It may be useful to consider providing such varied level of HCPs in Ireland also.
- Similarly, the particular needs of those who need care in relation to disabilities, ill children, and the terminally ill, may also need more attention in the form of particularly targeted HCPs.

6.13 • Drivers for Implementation

- Finally, follow-up action across the whole area of HCPs needs to be given greater priority, focus and direction from the Centre, at both political and Departmental levels.
- For this purpose, a Steering Committee should be established to drive forward and put into effect the above policy recommendations. The Chair of the Committee should be the Minister of State at the Department of Health and Children, with responsibility for older people, to provide the necessary political leadership and momentum. The membership should comprise representatives of all the main stakeholder interests
- The Committee should prepare a Work Programme to serve as a framework for its work, and assist it in setting priorities and timescales for the different components to its remit. The Committee should also prepare periodic reports on progress achieved and obstacles encountered and these should be published for public information and debate. The focus should be on delivery, at both national and local level, and the links between them.

 It is essential that this work includes consideration of the organisational culture issues which influence implementation of HCP policy.

What relevance does study of this particular policy have for implementation overall?

- **6.14** This study of HCP implementation suggests that the OECD (2008) outcomes approach provides a very good basis for strategy development and planning. This includes
 - agreement on policy outcomes,
 - measurement and evaluation of these,
 - tying performance to budget allocation,
 - better accountability, and
 - more innovative ways to deliver services.
- 6.15 However, this study of HCP implementation suggests that the approaches outlined in the Developmental Welfare State (DWS) (NESC, 2005) and in Improving the Delivery of Quality Public Services (QPS) (NESF, 2006) are also needed in policy implementation, to strengthen the focus on delivery to clients. While there are some overlaps between these two reports and the issues covered in the OECD report, a number of issues are particularly highlighted in the DWS and QPS in relation to client delivery, which include the following:
 - equity in provision,
 - plans for delivery, including national-local linkages,
 - standards for delivery, and monitoring of these,
 - client involvement in shaping of services, and
 - innovative means of delivery (e.g. facilitating access to information, use of private and other service providers, and use of IT).
- 6.16 Finally, examination of organisational culture issues in relation to HCPs identified how important these are, particularly to understand why some 'intransigent' issues remain problematic in policy implementation over time. The organisational issues influencing implementation of HCPs include the following:
 - Decisions are not being taken at national level on how to target limited funding in a policy area with high costs.
 - This links to a preference for lack of clarity over specifics.
 - Dialogue and communication seem favoured over decision-making.
 - This dialogue has too many layers of policy makers, with too few policy deliverers and service users involved.

- There is a focus on annual budgets over strategic process.
- This is one reason for data not being collected and not being used to improve design and implementation.
- It is also linked to the lack of consequences when strategy targets are not met within set timelines.
- And it links to the poor implementation plans for reaching agreed national strategic outcomes.
- The last four are also linked to loyalty to local group, rather than to national strategy.
- 6.17 This suggests a disconnect between the strategy designed, and the decision-making and working practices which are in place to implement this, with the result that a well-planned strategy is not being consistently implemented. Such a disconnect may not be confined to the healthcare sector only, although more research would be needed to confirm this.
- **6.18** To summarise, this study of HCP implementation suggests six key issues which are important to take into account in designing and implementing all outcomes-oriented policies. These are:
 - Strategy plans with agreed outcomes;
 - Measurement of inputs, outputs and outcomes, and use of this data for monitoring and evaluation;
 - Links between budgets and outcomes;
 - Good accountability and incentive structure;
 - A focus on delivery; and
 - Organisational culture.
- **6.19** Some of these issues are already well developed in many areas of Irish policy design and implementation, particularly strategy plans with agreed outcomes. However, analysis of HCP implementation shows that delivery to clients is a particularly important issue to consider, and that it is not adequately focused on in Irish policy implementation. A focus on client delivery is key, as well as a focus on more effective links between the different bodies charged with developing policy and with implementing policy, which is where the interface between policy and client is located.
- 6.20 A range of suggestions have been made in this report on how better delivery could be developed. For each policy, a detailed roadmap of how delivery will be achieved needs to be made and put into practice. This should cover the stages of implementation, the core components of a policy which have to be in place so that it is implemented, and the key drivers to be put in place to ensure that it is implemented (see Fixsen *et al*, 2005, in Chapter two). To ensure that such roadmaps are put in place, dialogue between national policy makers and local policy implementers needs to be developed, as well as communication between different groups of policy implementers.

- 6.21 Regular review of a policy's implementation is also needed, to ensure that it is delivering what is planned, and to identify the most effective means of doing so. The role of policy mentors is key in this, as they are able to identify key aspects of a policy, to monitor how it is being implemented in different sites, and to advise implementers in other sites on the best mechanisms to use to avoid problems and to promote sustainable implementation.
- 6.22 Finally, this report also affirms the importance of ensuring that all aspects of working practices and reward systems are aligned to achieve the same policy outcomes. The current arrangements suggest some ambivalence around an outcomes-oriented approach to national policy design and implementation. Although strategies are designed with planned outcomes, pre-existing decision-making and working practices impede implementation of the strategy to reach the planned outcomes. These are part of existing organisational culture, and are often not adequately taken into account when planning policy implementation. Sustainable implementation of outcomes-oriented policy will only occur when all aspects of work practices necessary for outcomes-oriented policy design and implementation are in place and aligned. This means that a focus on organisational culture is as important as that on strategy design and delivery.



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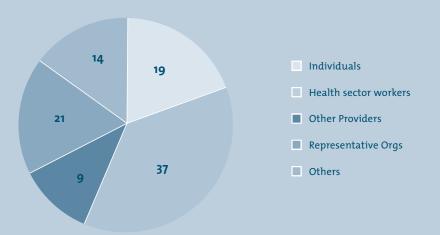
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Annex I Summary of Submissions Received

Introduction

In January 2009, the NESF placed a call for written submissions on the Home Care Package Initiative (HCPI) in the national newspapers and on their own website. In total, 100 submissions were received. Some of these submissions were from people who were themselves in receipt of care under the HCPI. Others were received from family members who are, or had been the primary care provider to a beneficiary of the Initiative. Organisations that made submissions were comprised of representative and advocacy groups concerned with older people, people with disabilities, adults and children with long-term or terminal illnesses, and carers. A number of submissions also came from those employed to manage and provide care services and their representative organisations and trade unions. In the public sector these included submissions from individuals and groups of HSE social workers, occupational therapists and Public Health Nurses (PHNs). In the private sector submissions were primarily from private care providers.

The NESF highlighted their desire to hear about people's experiences of the HCPI. This, in conjunction with the diversity of both individuals and organisations that made submissions, provides for a wide range of experiences and opinions being expressed and has provided the very rich material on which this summary draws. Table and Graph A 1 below outline the groups and individuals from whom the data was received.



Graph A1 Who sent submissions? (n=100)

| Individuals | In receipt of a HCP | 16 | 19 |
|------------------------------|------------------------------|----|----|
| | Not stated | 3 | |
| Health Sector Workers | Care workers | 3 | 37 |
| | Social Workers | 14 | |
| | Therapists | 5 | |
| | HCP Managers/Co-ordinators | 7 | |
| | Other health sector managers | 8 | |
| Other Providers | Voluntary | 3 | 9 |
| | Private | 6 | |
| Representative Organisations | Older People Organisations | 7 | 21 |
| | Disability Organisations | 6 | |
| | Carer Organisations | 4 | |
| | Other Organisations | 4 | |
| Other | | | 14 |

Table A1 Detailed breakdown of who sent a submission

Notwithstanding the variety of groups and individuals who sent in submissions, it should be borne in mind that much of what is expressed in the submissions is opinion and individual experience, and that this does not always necessarily reflect widespread or common practice.

In its call for submissions, the NESF indicated that it was interested in the implementation of the HCPI, more commonly referred to as Home Care Packages (HCPs), in access to it, its management, its benefits and drawbacks. Many of the submissions directly addressed these four broad areas, but in the process also raised a number of other issues that are summarised below. These include the profile of carers and those cared for, changes in the nature of the caring relationship, the policy context and recommendations for the future development of the HCPI.

Reflecting the focus of the HCPI, the vast majority of submissions related to HCPs for older people. However, a small number relate to the need for and provision of HCPs for people with disabilities who may or may not be over 65 years of age, and children with complex and ongoing medical conditions. In addition, a small number raised the issue of HCPs for people in need of palliative care.

What are HCPs?

A number of the submissions drew attention in the first instance to the focus and objectives of the HCPI itself. It was stressed that the focus of the Initiative is older people over the age of 65 who are either at risk of entering or being discharged from acute hospital beds and who could, with appropriate support, reside and be cared for in their own home. HCPs are primarily targeted at people with medium to high dependency needs. Although they may be made available to support other clients, where the person is aged under 65 years the Initiative has proven particularly difficult to access.

A number of submissions refer to the following five underpinning reasons for the introduction of HCPs:

- To facilitate timely discharge of older people from acute hospitals,
- To reduce inappropriate admissions,
- To reduce pressure on A&E Departments,
- To support older people to continue to live in their own community, and
- To support carers so that they might be able to continue providing care.

A number of submissions citing these objectives go on to question whether these indicate a service that is led by the needs of the health system or available funding rather than by the needs of the older people and others they serve. This issue is returned to below.

The Need for the HCPI

Many submissions drew attention to a number of changes that make the development of the HCPI desirable and, in some cases, essential. These changes are seen to have occurred in three key areas: demography, the labour market and increased awareness of the wishes of older people.

An Ageing Population

Changes to the age profile of the population and demographic projections mean that the age structure of our population will change substantially over the coming decades.

"The numbers of people aged over 65 will more than treble from a current level of 464,000 to 1,500,000 in 50 years time. At present there are more than four workers contributing to the support of every pensioner. This will fall to 2.7 in 2026 and to less than 1.5 workers per pensioner in 50 years time." A Carers' Organisation

Labour Market, Family Structures and Decreasing Number of Family Carers

Increases in our older population come at a time of dramatic changes in the structure and size of families and increased labour market participation, particularly among women. These changes result in the much reduced availability of family carers.

"The lack of availability of family members is a major factor in the growth in demand for community & private services. Family networks of support & care are often fractured or non-existent. Where family members do undertake the carer role, they are often poorly supported, leading to carer burn-out and to increased demands for long-term care." HSE Social Worker

Consequently, there is a need for greater support for those undertaking the caring role.

"Family units, generally, have become smaller and more women are entering the paid workforce so there may be less carers available to look after those that need care. Therefore it is even more important now than ever that the carers' role is nurtured, promoted and supported in terms of their pivotal role in the care of people who have become dependent." HSE Development Manager of Services for Carers

In addition to supporting the family carers who are available, a number of submissions drew attention to the need for the State to accept that a heavy reliance on family carers is no longer a realistic prospect.

A number of submissions point out that these demographic and employment changes also came about at a time when there was a general consensus about the preferences of older people to remain in their homes and communities for as long as possible, and contributed also to a need for the broader development of community care.

The Starting Point of the HCPI

Some concern about the starting point of the scheme was expressed: was this essentially to free up hospital beds and secure revenue savings, or was it as a means of promoting and developing community care and meeting the wishes of many patients? At least one submission sees a reconciliation of these two objectives:

"The Home Care Package Scheme appeared to begin with the end point (freeing up beds) as its starter, as opposed to identifying what is the best way of delivering community support for community needs, so that people do not enter acute hospitals or long-term care. The Home Care Package Scheme developed over time into focussing more on the prevention of the person entering acute care or long-term care prematurely, which in effect addressed community needs better." Voluntary Organisation

The Policy Context

Irish Policy Commitments

Many submissions referred to the policy context that surrounds and supports the development of HCPs. In the Irish context these include the now 21-year old policy document, *The Years Ahead: A Policy for the Elderly*, which clearly states that the aim of Government policy has been "to enable older people to remain living at home in dignity and independence for as long as is possible or practical." Further policy commitments to such an approach are to be found in the National Health Strategy, *Quality and Fairness* (2001) and the more recent national partnership agreement *Towards 2016*. In the area of disability, commitments to supporting independent living are more recent and are contained in the *National Disability Strategy* and *Towards 2016*. The latter document states that people with disabilities will have the opportunity to live full lives with their families and communities, free from discrimination.

EU Obligations

One submission drew attention to EU level policy as set out in the Tallinn Charter, which was signed by the Irish Minister for Health and Children in 2008. Among other concerns, the Charter highlights the need for coordination among a variety of health care providers, institutions and settings, including primary care, acute and extended care facilities and people's homes. Effective primary care is seen as providing an essential platform for the interface of health services with communities and families. Under the Charter due attention must be paid to the needs of vulnerable groups such as older people.

People with Disabilities

With regard to people with disabilities, one submission reminds us of Ireland's obligations under both international agreements and domestic legislation. The Council of Europe *Disability Action Plan 2006 – 2015* requires that member States "promote schemes which will allow disabled people to employ personal assistants of their choice." The UN *Convention on the Rights of Persons with Disabilities*, which is to be ratified by the Irish Government, includes the right to the "personal assistance necessary to support living and inclusion in the community". Finally, Part 2 of the Disability Act 2005 entitles people with disabilities to an independent assessment of need in relation to their health and education.

Disparity between Policy and Practice

While a number of submissions refer to the policy context within which the HCPI operates, some also point to the disparity that exists between stated policy and actual implementation or practice on the ground.

".....the policy rhetoric relating to personal social services for older people has not been matched by the reality on the ground. The current state of affairs has given rise to situations where many older people and their carers live in great distress." Organisation representing welfare professionals

Profile of Carers and those Cared for

Profile of Carers

Many submissions framed their experience, views and recommendations in the context of a profile of both those who care and those who are cared for. The most commonly cited statistics relate to the numbers, age profile and hours of care provided to and by people. Much of this has already been presented in the main body of this report. A brief reminder of this profile is set out clearly in one submission, which draws on the 2006 Census.

"The Census [2006] asked people to tick the box if somebody provided "regular unpaid personal help for a family member with a long-term illness, health problem or disability, including problems which are due to old age and providing help with basic tasks such as feeding or dressing."

The figure of 161,000 [carers] represents:

- nearly 5% of all people over 15 years of age in Ireland,
- over 100,000 women
- over 60,000 men
- 60% of all carers reported that they provided between 1 and 14 hours of unpaid caring per week,
- 25% reported that they provided 43 or more hours a week.
- 56% of all carers (90,544) indicated that their principal economic status was "at work"
- 16,000 were aged over 65 years of age, representing about 11% of all carers.
- Older carers are most likely to be caring for people of all ages and in a range of circumstances.

"Young carers - in the region of 5,400 people aged between 15 years and 19 years gave unpaid personal help to a family member or relative each week, just over 1,000 of these young carers said they devoted in excess of 15 hours a week to caring, while almost 500 young people between 15 and 19 gave 43 or more hours a week to looking after family members. In international terms it is estimated that between 1.6% and 4% of children are carers." HSE Community Services

However, another submission points to two important considerations in the counting of carers by means of Census data.

"According to the Census of Population 2006 there are 160,917 family carers in Ireland, representing 4.8% of the total population. This figure is understood by us to be an underestimation as the question on the Census form excluded young carers aged less than 15 years and did not clarify whether receipt of the Carer's Allowance was included or excluded from the category of "unpaid personal help." Voluntary Organisation for Family Carers Although a basic demographic picture of carers can be drawn, a number of submissions point out that we know relatively little about the impact of caring on family carers. However, one submission cites research by the Care Alliance Ireland²⁸ on the impact of caring on the carer's own health and well-being. This involved a survey of 1,411 randomly selected carers in receipt of a caring-related payment from the State.

"Family carers presented a considerably less positive picture of quality of life in comparison to the general population. Carers also reported comparatively high levels of depression, back pain and anxiety. Negative aspects associated with family caring included restricted leisure hours and a high risk of being exposed to stress, emotional strain and social isolation. The extent of limitation posed by caring on leisure/recreation appeared to be a key factor both in likelihood of health suffering due to caring and likelihood of low quality of life for carers." Family Carer's Support Organisation

The Difficult Reality of Caring

The difficult situation faced by many family carers is articulated in the submissions. Many family carers are looking after older relatives that have a range of illnesses and frailties, where outside help is valued but minimal, and where the majority of the caring is borne by them.

"My wife gets a home care package of three hours a day which gives me respite to get out of the house and have some sort of life. The home carer showers my wife twice a week which is of great assistance to me as I cannot manage her on my own in the shower. I am 83 years of age and I don't know what we will do and I don't know what I will do when I get to the age that I need care myself." Family Carer

"....my Mother she suffers from dementia, is wheelchair bound, is doubly incontinent, cannot communicate or eat/move unaided. To take care of her at home she requires full time 24 hour care which amounts to 168 hours of care per week. This is provided by me and two siblings with the exception of 15 hours of care provided by the HSE home help service; and only during week mornings; there is no evening or weekend assistance available." Family Carer

The perspective of family carers and the impact that caring responsibilities have on their lives was presented in a number of submissions by both individuals and organisations. Many carers try to balance a range of work and personal responsibilities alongside their caring role and the emotional aspects of this. The somewhat contradictory position of family carers is summed up in one submission as follows:

"For many people caring is a rewarding act borne out of love. However, many carers feel lonely, overburdened, ill-prepared and unrecognised for the care they provide." National Voluntary Organisation

²⁸ O'Sullivan, Liam (2008) Health and Well-being of Family Carers in Ireland: Results of a survey of recipients of the Carer's Allowance, Research Working Paper 2008/11, Dublin: Care Alliance Ireland

While acknowledging their emotional commitment to their spouse, partner, mother, father etc., some carers point out that they are not physically capable of undertaking some necessary care duties, and even if they are able to do so now, they will not be able to do so in the longer term. This reflects the fact that many family carers are themselves older people. They worry about what will happen to both themselves and their loved one when they are no longer able to provide care.

Profile of those Receiving Care

The profile of those cared for received somewhat less attention in the submissions, possibly due to the focus of the HCPI to date on older people. It appears from the submissions that the majority of people in receipt of HCPs or other home- and community-based care services are older people in their 70s, 80s and 90s. Many of these have medical conditions such as Alzheimer's, Parkinson's disease or heart disease in addition to the more general functional difficulties that come with advancing age. A small number of submissions concerned younger people with disabilities, including those with acquired disabilities as a result of illness or accident. Children with complex medical conditions and people of various ages who have terminal illnesses and who are in need of palliative care were the focus of a small number of submissions.

The Nature of Provision under the HCPI

A number of the submissions provided brief outlines of the services the HCPI is intended to provide and the mechanisms for doing so. Essentially, HCPs can be comprised of a combination of any of the following services: home help, nurse services, home care attendant, physiotherapy, occupational therapy, speech and language therapy and other community-based services. The provision of specialist equipment such as pressure mattresses, hospital beds, breathing apparatus etc. may also be part of the HCP.

A Complex System

The complexity of the HCP system can be garnered from a number of submissions that pointed to the range of mechanisms through which such elements of care are provided. Services may be provided directly by the HSE, may be delivered through voluntary or private sector organisations on behalf of the HSE, or the HSE may provide patients and their family with cash grants to purchase such services as are necessary. Several submissions also suggest that HCPs may comprise a combination of these mechanisms, such as a cash grant and HSE services.

The submissions consistently raised a number of problems with this complex system of provision. Where services are being provided by different organisations the number of people involved in providing care increases. This, in turn, can lead to reduced privacy and increased distress and confusion among those in receipt of the services and their family. "A classic example of this situation is where the weekday morning hours are allocated to the not-for-profit company whereby the difficult-to-staff evening time and weekend hours are given to a private provider. This situation leads to discontinuity of care and ultimately adversely affects the clients." Name withheld on request

Cash Payments

A considerable number of submissions raised issues in relation to the practice of providing cash payments to clients for the direct purchase of services. It is noteworthy here that those making submissions from the perspective of older people and those making submissions from the perspectives of people with disabilities reside at opposite ends of a spectrum, as will be outlined below.

Cash Payments and Older People

Submissions relating to older people by-and-large oppose cash payments for the purchase of services. This is because it places the onus of finding and managing the service provider and the service on the client or their family. In addition, it requires the older person or their family to become a registered employer and all that this entails. This has significant legal implications for older people of which they may not be aware or be reluctant to undertake.

"In these [cash grants] cases, the client becomes the employer and is required to abide by and adhere to all legal requirements as an employer including PRSI, PAYE and insurances. Abiding by labour legislation is also a requirement by employers, and the client, who employs a private carer through the cash grant provision, bears all responsibilities governing the statutory rights and entitlements of the employee." Trade Union

While a very small number of submissions pointed to the benefits of cash grants, including the freedom and control they can give in providing and directing the services they purchase, these appear to be out-weighed by the perceived and actual reluctance of older people and their families to accept what can be an onerous role as employer.

Cash Payments and People with Disabilities

Submissions relating to people with disabilities are in favour of cash grants as they are seen to offer greater choice of service and provider. The perceived benefits of this are clearly set out by one submission as follows:

"....individualised funding gives the person with a disability an alternative option for funding their service. The person establishes his/her needs and utilizes the resulting service plan to secure funding for the service. Then he/she chooses who supports them in the implementation of the plan and how the plan should be implemented. The person directs the service that is required, where it will be delivered and how it will be received. The individualised funding option ensures that traditional models of service delivery do not have to be mandatory to the receiver although it does not exclude them. It gives the person and all their family the option of being more involved in directing the services that will best support their needs. Coupled with other necessary best practices and parameters it can significantly enhance the quality of life of a person with a disability." National Voluntary Organisation According to another submission, "direct cash payments:

- enhance the individual's self esteem and self confidence,
- allow and encourage the development of more innovative, flexible and personalised support systems and services,
- alleviate the pressure on family members and other 'informal carers' who are often held responsible for supporting individuals with disabilities in the community, and
- provide the individual with more opportunities to participate fully in the economic and social life in the community." National Disability Organisation

In almost all of the submissions relating to people with disabilities the direct payment schemes in other countries, most specifically the UK, are cited as possible examples of how such payments can work. One submission describes the direct payment scheme, which is established in law in the UK, as follows:

"A direct payment is money given by social services in the UK to an individual to buy the services they have been assessed as needing and in lieu of the services available to them. The money provided can be used to pay for day-to-day needs including:

- personal services dressing, bathing etc.,
- domestic services cleaning, cooking etc.,
- social activities visiting friends, leisure, recreation and entertainment activities, and
- support with employment, training and education." National Disability Organisation

Another aspect of the UK model that is recommended is the introduction of a Carer's Assessment, whereby family carers are regularly provided with an opportunity to discuss what they need to help them in their caring role as well as an assessment of their own health and well-being needs.

Benefits of the HCP

Overall, the majority of submissions were positive about the introduction of HCPs and their potential to improve the lives of older people. One submissions sums up this broad sentiment as follows:

"This service has the potential to deliver cost effective, sensitive and flexible support to people in their own communities, enabling people to maintain their independence and stay in their own homes as long as is possible." HSE Social Worker The significance of such provision in the lives of family members is also well recognised in the submissions. Such packages allow them to continue to play a part in the care of a loved one but with necessary support. In some cases it has allowed the family to remain in paid employment where otherwise at least one family member would have had to surrender their job and their own financial independence. Appropriate home care that allows their mother, father, spouse etc. to maintain their dignity is important not only for the older person themselves, but also for family members who have found themselves in an uncomfortable position in administering personal care in particular.

"The home care package scheme is fantastic. My father (79) was in hospital for three months and although he was able to go home he needed some home care. He received a home care package 2 years ago and has not been back in hospital since. The package has made a tremendous difference to his life, our lives as his children, and the relationships between us." Family Carer

"The advantage of all the help I get is that it lessens the burden on my wife in looking after me." Family Carer

The specific benefits mentioned differ between submissions, largely on the basis of the role of the individual/organisations in home- and community-based care, the local management approach to the HCPI and the services available. However, the following quote summarises the benefits mentioned in a large number of submissions as it addresses benefits to the client, their family and the State, and also covers the social and common medical benefits that accrue to the client in particular.

"Home Care Packages provide:

- vulnerable adults with supervision and support,
- reduce individual and carer stress,
- reduce anxiety for those who live alone or are alone for long periods during the day,
- provide monitoring for individuals regarding non-compliance with taking medication,
- assist individuals who have difficulty swallowing when eating or taking medication,
- assist individuals with all aspects of personal care and nutritional needs,
- allow individuals to remain at home at reduced cost to Health Service Executive,
- provide supervision of hydration for individuals at risk of dehydration which can lead to Urinary Tract Infections causing confusion in some older adults,
- monitor adults who are medically at risk, e.g. diabetics,
- offer individuals who have none or limited family support with opportunity to remain at home,

- provide individuals with social and emotional support, and
- provide a better quality of life to individuals maintaining them in their own communities and close to family and friends." HSE Social Worker

Weaknesses in the Current System

With few exceptions, submissions drew attention to some of the weaknesses in the current HCPI and the care packages delivered under it. These are summarised here. Overall however, the foremost weakness is inconsistency in access to, and management and delivery of the services.

Access to Services: Information

The first hurdle faced by many people trying to access services under the HCPI is the lack of readily available information and general lack of awareness of the Initiative among potential beneficiaries and professionals. A number of submissions recounted the experiences of people trying to find out about the service and their possible entitlements under it. Most described a process of being passed around various offices and personnel, with one submission stating that it took 18 telephone calls over a 10 day period to finally find the 'right' person to talk to. Significantly, a number of submissions that highlighted this issue came from professionals within the HSE.

"Clients trying to access information were not getting the information they were looking for. This frustrated many people who then rang us to enquire on their behalf. Therefore access to information and guidance through the system needs to be spot on. It needs to be accessible to the client at the initial point of use." Advocacy Organisation

"The lack of written information about availability of domiciliary services or a point of contact where one could seek advice about options, was a real drawback. I eventually obtained relevant information from the Manager of Services for Older Persons, following a series of time consuming and often confusing telephone calls with a range of other professionals. If written information regarding policy, eligibility criteria, funding mechanisms and options for service delivery etc. was available it would have saved a great deal of time and energy." Family Carer

Given this situation, first-line care providers play an essential role in providing accurate information.

"..... it is important from the onset, for the community health care services, for example the Clients General Practitioner or their Public Health Nurse, to advise clients and their families of the availability of the Home Care Package." Professional Carer's Organisation

Access to Services: Eligibility

Inconsistency in access to HCPs was cited by submissions as a real obstacle faced by people and their families looking for support. Inconsistency in eligibility criteria, needs assessment and means testing is common and many submissions point to the need for a standardised approach to these. "There is no uniformity in how the packages are allocated and in the numbers in receipt of them. The individual areas are not clear on their criteria and we therefore find the system very inequitable. There is a disparity between what different people receive even though they may have similar levels of need and are on similar income levels." Hospital Social Worker

One voluntary organisations further points to disparities in access by stating that:

"Referral is due to be based on need, but no standardised needs assessment occurs throughout the country. Equally, a means test is due to occur but our feedback tells us that is not applied consistently either throughout the country." Charitable Organisation

Access to Services: Assessment of Need

Of particular concern in the submissions is the lack of a standardised approach to the assessment of need. Reflecting the priority given to older people leaving acute hospitals, the possibility of having a number of assessments and the potential impacts of this were highlighted.

"There can often be a dual assessment process required to access HCPs in some areas. Assessments are undertaken in both the community and hospital which can lead to the duplication of roles and tasks. As a result of this duplication, there can be conflicting recommendations in relation to care needs and care plans." Hospital Social Worker

Access to Services: Links with Existing Services

A further issue on access to emerge in the submissions was that of the connection with existing services. A number of submissions stated that older people could only access HCPs if they were already in receipt of a service, particularly Home Help, or if they were in an acute hospital. This, it was felt, made access to the Initiative very difficult for older people who are not in fact ill or in need of hospital care but who are in need of home-based supports.

"...it appears that priority is given to older people who are about to be admitted to, or who are already in acute hospitals – the result is that older people who need care at home but do not need hospital care are not having their needs met." Family Carer's Support Organisation

Implementation of HCPs

A significant proportion of the submissions made reference to a number of issues relating to the implementation of HCPs including inconsistent provision, training and quality of staff, funding and lack of quality standards.

Inconsistent Implementation

Inconsistency in the implementation or delivery of HCPs was a common concern. At least some of this inconsistency stems from the fact that each HSE Local Health Office (LHO) is responsible for the administration of the Initiative in their area, coupled with the absence of agreed national guidelines on delivery. Therefore any one LHO can use any of the available delivery mechanisms (direct provision of services, use of private or voluntary care providers, cash grants) or a combination of these. In addition, it appears that each HSE Area and many LHOs can and do apply a variety of eligibility criteria and methods of means testing. That each HSE area differs leads to inconsistency in provision and confusion among care providers, family carers and those being cared for.

"There is no uniformity in how HSE areas administer home care packages. Some provide a personal budget to each person and let that person then choose a provider to provide the care. Others provide a centralised system whereby a case manager assesses need and chooses a provider for the person. Others provide a cash grant to families and expect the families to source care themselves. This situation creates uncertainty and distress for families as they are sometimes faced with a myriad of different systems." Name withheld on request

Quality of Home Care Support Workers

Many submissions praised both the HCP services they were receiving and the individual carers involved. However, a number of submissions pointed to difficulties with carers including their lack of punctuality, irregular attendance, and unwillingness to undertake some tasks that are needed by the client.

"Rostering appeared to be a problem, for example, at times care staff would fail to turn up or two would arrive at the same time. The unreliability of service delivery had an adverse impact on my mother's confidence and well being as she needed assistance with all aspects of daily living." Family Carer

"...and [I] was told that the home help was not allowed to do any lifting; neither was she allowed to clean any glass or go up any steps or clean out any cupboards.It looks as if I have to perform the heavy work myself and leave the light work (which a child of 12 could do) only for the home help." Name withheld on request

A number of submissions refer to issues relating to the lack of training and qualifications of home care support workers delivering the services in the home. Training is seen to be vital but minimal.

".....there is no training for new staff. All they get is one manual handling training course per year." HSE Carer

Furthermore, while Care in the Home courses are run by the HSE or voluntary agencies funded by the HSE, there is no clarity as to who should undertake these courses. As significantly, there is no obligation on many of those providing HCP services to ensure their staff are appropriately trained. In some LHOs those who are on a Preferred Providers list²⁹ have an obligation to train their staff. However, it is not clear whether such obligations are monitored and therefore it is impossible to know the degree to which such obligations are maintained over time. In addition, this obligation does not apply in all LHOs. One submission makes it clear that while carers may be expected to support clinical programmes they are not trained or supported to do so.

"Because of the complex nature of need of service users, this should be reflected in the quality and expertise of home support workers to support clinical intervention; however, home support workers (in general) are poorly paid, poorly trained and poorly managed." HSE Social Worker

A number of submissions also point out that specialised and appropriate training becomes necessary when providing care to groups with particular medical problems, such as dementia, Parkinson's disease or schizophrenia, as well as caring for those who are in need of palliative care.

Supplementing Other Services

Even where a comprehensive care plan is designed to meet the various needs of clients, this does not mean that the services will be available to them. Often, the HCP will need to draw on existing community services that are already stretched to capacity (even though HCPs are intended to provide more intensive services that are additional to or supplement existing community services). The unavailability of such services results in family members or others having to fill the gaps that are left.

"While the expectation is that clinical teams (individual professionals) will work with the service user in their own home the reality is that community therapists are already over stretched, with long waiting lists and often their intervention is once off or low maintenance, with the understanding that family, loved ones and /or home support workers will continue with interventions." HSE Social Worker

Submissions also referred to the need for HCPs to be flexible and to change over time with the changing needs of the clients. However, in the absence of regular reviews of existing HCPs, changing the type and amount of care provided can be difficult.

Insufficient Hours of Care

The lack of sufficient hours of care was frequently raised. A number of submissions also referred to the implied threat that if they complained about the insufficiency of hours that these would be further reduced.

"Our doctor recommended that her home care package hours be increased to 20 hours per week and the private provider made this application to the HSE but not only was it turned down they indicated that they might reduce her hours from 12 to 10 hours." Family Carer

²⁹ Preferred providers are those agencies, both voluntary and private, which have tendered to the HSE to provide HCP services. They agree to apply required standards when providing HCPs, such as standards relating to the recruitment of staff, their training and supervision. They are subject to review by the HSE. Preferred providers lists exist in some HSE areas, such as Dublin/Mid Leinster, but are not used in all HSE areas.

".....There was the subliminal message of 'consider yourself lucky in what you are getting and be forever grateful'. This message is reiterated time over time by healthcare professionals as a constant reminder of the threat of care withdrawal and the implications." Family Carer

In addition, the lack of 24 hour care services, home-based and institutional respite care and cover for holidays and illness of both paid and family carers arose time and again in the submissions

"Provide fulltime cover to allow one person carer family to go on occasional holidays / weekends off. The elderly person might not wish to leave their home environment to go to respite / hospital which is understandable and which might be detrimental to their long-term health." Family Carer

"I applied for some night-time home care package hours as my wife has Alzheimer's but I was refused. I am 83 years of age..." Family Carer

Funding

Funding is clearly a problem that impacts on the number of HCPs that can be offered and the quality and timing of putting a package in place. Insufficient funding affects the potential of HCPs to supplement rather than replace existing community-based services, even though such replacement is not their intended use. This leads to inconsistent provision across different HSE areas.

"Not all areas get funding therefore some people don't get the option of going home from hospital but are transferred to other institutions. In recent times community services are limited due to budgetary restrictions hence the HCP is often a substitute for community services rather than an addition to these services." Hospital Social Worker

"Within the current Home Care Package (HCP) scheme there are variations in the availability of HCP funding both within the greater Dublin area and also nationally. This results in inconsistencies within the HCP scheme and ultimately in the existence of inherent inequalities for those trying to access home care packages." Hospital Social Work Department

However, some submissions drew attention to what they see as the inadequate funding of the HCPI, while the more expensive option of subvention of nursing home places continues to be pursued.

"The weekly salary scale of a home help worker according to HSE salary scales (March, 2008, updated Sept 2008) is \in 556.77 based on a 39 hours working week. This is equal to \notin 28,952.04 per annum. In addition the estimated cost of nursing home care is in the region of \notin 800- \notin 1,000 per week, whilst the cost of acute hospital care is in the region of \notin 5,000 per week³⁰. These weekly figures amount to \notin 41,600- \notin 52,000 per annum for nursing home care and c \notin 260,000 per annum for acute hospital care. Both nursing home and acute hospital care are care options which have often become the default provision as opposed to the appropriate provision due to the lack of capacity within community care." Family Carer's Support Organisation

30 A Fair Deal on Long-Term Nursing Home Care' – Speech by Mary Harney, T.D., Minister for Health, 12 December 2006 www.dohc.ie/ press/speeches/2006/20061211.html Also Nursing Home Ireland, Radio Comment, April 2008

Management of HCPs

As in a number of areas outlined above, the primary issue to emerge in relation to the HCPI is the lack of consistency and standardisation of approach.

Inconsistency in Management Approaches

Inconsistency in the management of HCPs also emerged in the submissions as a major source of concern, with a number drawing attention to the different approaches. In some areas it appears that responsibility for the Initiative has been given to specific staff such as social workers or co-ordinators of services. In some areas case managers have been appointed to liaise with other staff and providers in the creation of a care package, while in yet others the PHN (Public Health Nurse) acts as first point of contact and case manager. This leads to inconsistencies and lack of clarity in the roles of various organisations and staff.

"Different HSE areas have adopted different models for dealing with home care package applications. In some cases a case manager has been appointed who oversees assessment and authorisation and review of care packages. In other areas the public health nurses are responsible for care plan assessment while authorisation of monies is dealt with in a different centralised section. Such differences in treatment create difficulties for providers of care in that different HSE areas can adopt different treatment for similar cases." Name withheld on request

However, it would appear that in many cases, and in line with the original HCPI proposal, the PHN is in fact operating as a case manager in many areas. One submission, citing a research study by Delaney *et al* (2001)³¹ argues for the development of a clear and consistent case management approach and against this being seen as an add-on to the role of the PHNs.

"The case manager is essential to the operation of a successful integrated Care and Case Management service. In the model proposed by Delaney et al (2001), the case manager is envisaged as a separate staff member, with specific core skills and training. Case management is not seen as an add-on to an existing role (e.g. to the Public Health Nurse role). Key core skills include targeting, screening, assessment, goal-setting and care planning, implementation, monitoring, management and inter-personal skills. The study also recommended that proactive steps be taken to ensure adequate numbers of qualified professionals are available to staff a comprehensive Care and Case Management programme." Research Organisation

Furthermore, the lack of clear and consistent management of finance, cases and services can have a direct impact on family carers and the client.

"Lack of management of HCPs can result in individuals and families being left to manage complex packages of care on their own, at a difficult transitional phase in their lives, without support." Hospital Social Worker

³¹ Delaney, S., Garavan, R., McGee, H.M. and Tynan, A. (2001). Care and Case Management for Older People in Ireland: an outline of current status and a best practice model for service development. Report No. 66. Dublin: National Council on Ageing and Older People.

Lack of Standardisation and Geographical Differences

It could be argued that allowing for local interpretation and implementation of the HCPI could lead to greater flexibility in service provision.

"One of the strengths of the Scheme is its flexibility......Schemes vary in different parts of the country depending on the local population, individual needs, the personnel available to deliver services and demand."

However, this submission goes on to state that:

"The obvious downside of this is a difficulty in delivering a standardised service in each part of the country in accordance with identified need." Information and Advocacy Organisation

In the absence of such standardisation, it is not surprising that a number of submissions draw attention to the inconsistency in the operation of the HCPI in different areas of the country. A number of submissions drew attention to this and stated that geographical location should not determine either access to HCPs or the services provided.

"...... the decision to support an individual in their home or place them in residential care is often taken not on individual need but on the basis of geographic location. This scheme should be clearly defined, be placed on a national footing and should be available to all who require it without reference to geographic location." Rehabilitation Organisation

The Need for a Quality Framework

A repeatedly cited weakness in current approaches to managing the quality of HCPs is the lack of a quality framework for services, although it should be noted that a draft framework has been prepared by the HSE but not yet approved. The need to involve the Health Information and Quality Authority (HIQA) in setting appropriate and enforceable standards was stressed. Particular reference was made in a number of submissions to the need for standards equivalent to those that operate in relation to residential care for older people.

".....is concerned with the lack of standards being applied to the delivery of HCP, it is surely important that HIQA prioritises enforceable standards for such a valuable service which supports some of the most vulnerable and often isolated members of our society. All supports must be monitored regularly in line with policies that protect vulnerable adults." Disability Organisation

Lack of Integration of Services

A further frequently cited weakness in the current management of HCPs is their poor integration with other services, both hospital services and services based in the community. This can lead to a high number of personnel involved in the assessment and compilation of a HCP, with one submission stating that four different services and staff were involved in putting together a package for one client. The duplication of assessment that can arise due to lack of integration of services is also cited as a waste of valuable resources and contrary to the client's best interests. "In many areas, the current system in place is that the Hospital Social Worker submits a Home Care Package application and care plan, following which a Case Manager visits the patient while in hospital to carry out a needs assessment. The Home Care Package application already includes a needs assessment which has been completed by the Hospital Multidisciplinary Team and therefore there is often duplication of assessments which have already taken place, and/or adjustments to assessments without consultation about aspects of the care plan. Good inter-agency working and information sharing is essential in these circumstances, but sometimes arrangements are not in place to facilitate this." Hospital Social Work Department

Lack of integration between traditional Home Help services and service providers under a HCP was the subject of particular note in a number of submissions.

"Feedback we have received from various quarters points to some difficulties in the low level of integration between traditional home help services and the more recently introduced Home Care Packages scheme. Whilst the evidence for this contention is limited and anecdotal, nonetheless we feel that this merits further reflection and analysis." Family Carers' Support Organisation

The Relationship between Providers of Care

The tension between statutory and voluntary providers of services on the one hand and private providers or care agencies on the other is notable in a number of submissions. Overall, the main thrust of the management issues raised in this regard relate to ensuring that all agencies, statutory, voluntary or private, should be subject to the same rigorous standards that need to be put in place before they are allowed to provide care services to vulnerable people.

As indicated above, the relationship between existing services, and Home Help services in particular, was raised in a number of the submissions received. A number of perspectives on this are recurrent. For example, one voluntary organisation stated that they were delivering Home Help services as part of a Service Level Agreement and accepted all of the administration work that this entailed. When they applied to deliver HCP services, they had to take on the administration of this scheme separately, thereby significantly increasing their administration responsibilities. This was viewed as a means of passing the administrative burden of implementing the HCPI from the HSE to the voluntary providers involved.

An alternative perspective, articulated particularly by private care providers, is one that sees this tendency to use Home Help service providers to deliver HCPs as reducing both competition and choice. One submission expressed the view that the use of the Preferred Provider list was seen to bring about the same limited choice as well as greater inflexibility and costly provision.

"The practice of a preferred provider list reduces competitiveness. It would be helpful if lower rates could be negotiated with the preferred provider care agencies.Care agencies are also inflexible to individuals' care needs and are not client centred." Hospital Social Worker One submission points to a potential solution to the tensions that currently appear to exist between home help service providers and the HCPI.

"When home help organisations can provide home helps who have also been trained as carers it reduces the number of people visiting clients' homes." HSE HCP Case Managers

Not only could this relieve the pressure on home help organisations to provide additional caring support through untrained personnel, and the tension between the home help services and the HCPI, but it would also be more cost effective.

Other Management Weaknesses

Other frequently cited weaknesses in the current approach to the management of the HCPI include:

- the lack of a clear and consistent monitoring of the services and service providers,
- poor supervision of staff,
- lack of a consistent and monitored requirement for Garda vetting of carers by all organisations providing care,
- lack of a standardised approach to training and the qualification required of home help or care attendant staff in particular,
- poor transparency and accountability in assessment and entitlements,
- lengthy waiting periods between assessment and implementation of a HCP and
- the operation of waiting lists.

Elder Abuse

The issue of elder abuse and the potential for this to occur where there is little training, supervision and review of staff and services was clearly articulated in a number of submissions. One submission points out that elder abuse can occur through lack of systems of prevention, detection and management of such abuse, the inability of older people to assume and carry out the role of employer in relation to direct cash grants for care, lack of a consistent requirement for Garda vetting of all carers, lack of training for staff on elder abuse, poor care standards and lack of quality control, diversion of resources and the use of non-registered nurses.

"Another issue is whether or not the care provided is sufficiently sophisticated to avoid the charge of a more diffuse version of institutional abuse, i.e., "institutional abuse can occur which may comprise of poor care standards, lack of a positive response to complex needs, rigid regimes, inadequate staffing and an insufficient knowledge base within the service." It would be helpful if the NESF review would clarify that procedures are in place to prevent and monitor this – the role of HIQA in quality assurance should be considered." National Implementation Group Family carers may also be guilty of elder abuse and not, in many cases, be aware of their abusive behaviours, particularly when trying to manage the care of people with various forms of dementia, where support, and training on how to care, is particularly necessary.

While guidelines on the reporting of elder abuse have been issued by the HSE, a number of submissions point out that prevention is better than cure.

"It is not clear that the Department of Health and Children (DoHC) and/or Health Service Executive (HSE) has considered the systems for prevention, detection and management of elder abuse within the provision of Home Care Packages." National Implementation Group

The Way Forward: Recommendations from the Submissions

As expected, the recommendations made in the submissions reflect the main issues of concern highlighted above and range from the very specific to those of a broader nature.

The Need for Information

Many submissions made reference to the need for improved information and communication on the HCPI so that people can access the service more easily. While a widely available and accessible information leaflet would represent a start in this area, the need for a more comprehensive information system was also suggested.

"..... recommends the development of a publicly accessible information system regarding the Home Care Package Initiative. Models of such systems are available internationally." Advocacy Alliance

The Need for Improved Consistency: Needs Assessment

One of the principle and cross-cutting issues raised in relation to the HCPI is the lack of consistency in a number of areas: assessment, eligibility, means tests, available services and management approach. Recommendations in relation to such inconsistencies are frequent in the submissions but primary among these is the need for a common needs assessment tool that is person-centred and that can be applied equally across the country.

"A standard care needs assessment tool urgently needs to be put in place to ensure that older persons' and care recipient's needs are measured objectively. In the absence of such a national framework on assessment, disparities in patient needs and the level of services designated will continue." Carers' Organisation

"A model of needs assessment must be patient focused taking into account the person's general health, their disability, the physical environment of their home and the support networks that surround them;" Medical Organisation

The Need for Improved Consistency: Eligibility

In the area of eligibility and access, a number of submissions recommend that the HCPI be placed on a legislative as opposed to administrative footing to address the issue of inconsistencies and to promote equity.

"It is urgent that the Home Care Support Scheme as a community based model of social care is underpinned by legislation." Local Voluntary Association for People with Intellectual Disabilities

Further to this, some submissions recommend that the eligibility criteria of the scheme be extended to cover more clients who are under 65 years of age, and that access for these clients should be simplified. Access to the HCPI should be based on need and not on chronological age or tight financial eligibility rules. Also, in LHO areas where eligibility is based on having prior contact with specific services, such as home help, this criterion should be removed as this excludes people who experience serious and sudden illness.

In relation to financial eligibility, a number of submissions recommended that these be equalised, with the same eligibility criteria and means tests that apply in other schemes and services.

"Financial eligibility assessment for both the home help service and the HCP funding should be on par - in some HSE Areas the household income is taken into consideration when assessing an individual's financial eligibility for the home help service but **not** for HCP funding (individually assessed)." Assistant Director of Public Health Nursing

At a minimum, inconsistency in access to the HCPI should be addressed by processes that are standardised and transparent.

".....the development of systems of access to essential home-care benefits that are clear, consistent and equitable for all older citizens, irrespective of where they live or in what circumstances." Advisory Agency

The Development of Quality Standards

The development of quality standards that would encompass a wide range of issues was also commonly cited as a recommendation. The areas to be covered by such standards included access and eligibility procedures, assessment of need, quality of staff, review and monitoring of HCPs and the HCPI itself, and standards of care.

"New quality standards and performance monitoring protocols must be introduced and should apply equally to all providers, regardless of whether these are public, non-profit or private." Carer's Organisation

Some submissions acknowledged the development of guidelines by the HSE in relation to home care services. However, as these are not formalised, the involvement of HIQA in establishing standards that are open to formal inspection was recommended. "The Health Service Executive has taken steps to develop National Quality Guidelines for Home Care Support Services but these are not formal standards and are not subject to inspection. These guidelines should now be considered by HIQA as the basis of a process to develop independent, statutory standards with appropriate inspection provisions." Rehabilitation Organisation

Clearly linked to the issue of quality standards, a number of submissions highlighted the need for national performance and monitoring systems to be put in place to ensure ongoing quality services and to improve our knowledge of the demand for HCPs and their individual components. The regular review of packages, the hours and subventions provided, and an assessment and flexible means of responding to clients' changing needs were also recommended in the context of quality standards.

"All Home Care Packages should be reviewed regularly and modulated to meet changing need, thus making the service as effective, supportive and cost efficient as possible." HSE Social Worker

Quality and Conduct of Staff

While the above national standards, if introduced, would cover the quality and conduct of staff involved in HCPs, this is an area that received considerable attention and a number of recommendations were made in relation to it. It is clear in the submissions that the following recommendations apply to all carers, irrespective of whether their employer is the HSE, a voluntary agency or a private company. In summary, these issues are:

- All carers should be subject to appropriate recruitment strategies and to Garda vetting;
- Carers, including those providing respite care, should be trained and hold FETAC Level 5 Certificate in Community Care at a minimum;
- Where carers are providing services to people with specific needs, such as palliative care, special modules on these should be undertaken as part of their training;
- All carers should have training in the identification, prevention and reporting of elder abuse;
- Carers who provide services directly to the client and care agencies should meet the minimum standards required in respect of tax clearance, health and safety procedures and appropriate insurance;
- Carers should be flexible in relation to the work they do this should be needs-based and play a role in the medical and social well-being;
- Carers should be properly supervised to ensure appropriate conduct and to prevent elder abuse;
- Care agencies should not be permitted to use unregistered nursing staff;
- Care workers should receive adequate levels of payment.

The Need for Adequate Funding

Funding emerged as a common theme of the recommendations. These focussed on the need for adequate funding to be made available for the delivery of HCPs and the employment of sufficient numbers of the various carers, medical staff and therapists. In addition, some submissions recommended that dedicated funds be provided to support the HCPI and related community services.

"...the following recommendations.....the designation of home help services, meals services, day care, respite care (inside and outside the home) and allied medical services as 'essential services' and the underpinning of these services by dedicated funding." Advisory Agency

Improved Integration of Services

A number of recommendations related to the integration of HCPs with other services, in particular the home help services, and Primary Care Teams where these have been established.

HCPs should work with all such services in order to ensure that the client's needs are met, to share valuable information and knowledge and to prevent duplication of assessments. A number of submissions drew attention to the importance of integration with the Primary Care Teams in particular

"Home Care Packages should be integral to and accessible from/ through Primary Care Teams. All members of Primary Care Teams must be able to access Home Care Packages, ensuring the service is as accessible as possible.it would seem that moving towards delivery through Primary Care Teams would facilitate Home Care Packages being as accessible as possible." HSE Social Worker

In addition, the care provider may need to accept responsibility in facilitating people to access other entitlements and services. This may include helping older people get their pension payments or other entitlements such as free fuel or meals-on-wheels that also help support them to remain in their homes and communities.

Client Consultation and Consent

In determining what services should comprise any individual HCP, the client and relevant family members should be consulted. In addition, the client's informed consent to the planned package of care should be secured whenever possible.

"Each service provider should ensure that they have a clear policy and procedure in relation to gaining informed consent from its clients. The service should give consideration to the individual's rights under the proposed Mental Capacity Bill when managing issues in relation to informed consent." Rehabilitation Organisation

A List of Preferred Providers

With regard to the selection of service providers by clients or the awarding of a HCP to a specific provider, a number of submissions recommended that one list of preferred providers should be provided by the HSE. This should include both voluntary and private agencies. In line with the recommendation on national standards above, the HSE should ensure that each provider meets all of the necessary quality standards.

"One nationally accredited List of Service Providers incorporating Home Help Service, Voluntary/Charitable Groups and Private Providers to be made available to all those concerned with Home Care Packages including the client users. This list should be reviewed on a yearly basis, with any non-compliant providers struck off immediately." Professional Carer's Organisation

Need to Extend the Hours Available

A final recommendation from many submissions is the need to extend HCPs so as to provide 24 hours, seven days a week care where necessary, and sufficient respite care for family members. This means that a mix of new services, such as night sitters and in-home respite carers needs to be more extensively available alongside more traditional services such as home help, physiotherapy etc. Flexible delivery of these services will be necessary.

Annex II List of Submissions Received

The names of ten individuals who sent in submissions do not appear, as they wished their names to remain confidential.

| | The National Council on Ageing and Older People |
|-----------------------|--|
| Jennifer Allen | St Vincent's University Hospital |
| Cathy Allen | |
| Brigid Barron | Caring for Carers Ireland |
| Siobhán Barron | National Disability Authority |
| Gillian Boardman | Community Hospital of the Assumption |
| Percy Boland | |
| John Brennan | Irish Association of Social Workers |
| Diana Burgui Murua | The Adelaide & Meath Hospital |
| Triona Burke | HSE, North Tipperary/East Limerick |
| Eileen Byrnes | Bray Area Partnership |
| Irene Byrne | Irish Council for Social Housing |
| Frank Carmody | |
| Lucia Carragher | Dundalk Institute of Technology |
| Maureen Chalmers | HSE |
| Jim Cogan | |
| Patricia Conboy | Older and Bolder |
| Mary Courtney | St Columcille's Hosptial |
| Sharon Cregan | SIPTU |
| Sarah Delaney | Work Research Centre |
| Una Doherty | HSE |
| Gerry Dolan | IMPACT Trade Union |
| Taragh Donohoe | Multiple Sclerosis Ireland |
| James Doyle | Emergency Response Social Monitoring Centre |
| Claire Duffy | The Carers' Association |
| Mary Duffy | The Royal Hospital Donnybrook |
| Fiona Duigan | Inclusion Ireland |
| Tom Duke | Caremark |
| Edel Dunphy | HSE – Laois |
| David Egan | The Centre for Independent Living |
| Anita Ennis | HSE – Dublin North Central |
| Mary Farrell | |
| Frank Farrelly | |
| Valerie Flattery | Association of Occupational Therapists of Ireland |
| Áine Flynn | HSE – Community Re-enablement Unit |
| Alan Garvey | |
| Maria Gates | James Connolly Memorial Hospital |
| Jackie Gibson | HSE West |
| Mark Golden | |
| Alice Gormley | Cavan Monaghan Occupational Therapy Services |
| Siobhán Hayden | Microboard |
| Vannessa Hetherington | Irish Medical Organisation |
| Anne Hickey | HSE – Dublin South City/Dublin West |
| | |

| Eileen Hutchin | KARE Social Services |
|---------------------|---|
| John Inns | |
| Noreen Keane | Mater Misericordiae University Hospital |
| Edwin Kelly | Professional Institute of Care Providers, Ireland |
| Catherine Keogh | The Alzheimer Society of Ireland |
| Leo Kinsella | HSE – Cavan Monagahn |
| Anne Labrosse | MFG-Meitheal Mhúscraí |
| Clodagh Lawler | St James's Hospital |
| John Linehan | HSE |
| Pamela Logan | Irish Pharmacy Union |
| Marie Lynch | The Irish Hospice Foundation |
| Catherine Maher | |
| Theresa Mannion | |
| Tracy Marsden | The Jack & Jill Foundation |
| Cliona McCormack | Rehab Group |
| Rita McCormack | |
| Siobhan McEniff | St John's Hospital |
| Geralyn McGarry | Citizens' Information Board |
| Mary McNutt | Darndale Primary Care |
| Richard Meade | TCP Ltd |
| Niamh Merriman | St James's Hospital |
| Sheelagh Mooney | St Dympna's Hospital |
| Margaret Nally | HSE – Longford Westmeath |
| Elizabeth Nicholson | Private Home Care |
| Lucy Nugent | Temple Street Childrens' University Hospital |
| Joan O'Donnell | Disability Federation of Ireland |
| Mary O'Dwyer | HSE West |
| Toni O'Dwyer | National Council for the Blind, Ireland |
| Angela O'Grady | HSE – Galway University Hospital |
| Anne O'Malley | HSE - Marino Health Centre |
| Michelle O'Rourke | Oak Tree Home Care |
| Liam O'Sullivan | Care Alliance Ireland |
| Mary O'Sullivan | St Columcille's Hospital |
| Rose O'Sullivan | West Cork Carers' Support Group |
| Ray Parkinson | HSE – Meath Disability Services |
| Lauren Quinn Taylor | Irish Senior Citizens' Parliament |
| Jack Reacher | |
| Lorna Roe | Age Action Ireland Ltd |
| Colette Ryan | Community Care Network |
| Hilary Scanlan | HSE South |
| Tony Shaw | |
| Sheila Simmons | Irish Association of Older People |
| Kathy Sinnott | MEP |
| Maria Stanley | Elder Abuse National Implementation Group |
| Peter Taylor | Home Instead |
| Eamonn Teague | Walkinstown Association |
| Moira Tysall | HSE Dublin Mid-Leinster |
| inona iyoan | |

| Annex III | Individuals and organisations consulted |
|-----------|---|
| | by the NESF Secretariat |

| Lerre Dec | |
|--------------------------------------|--|
| Lorna Roe | Age Action |
| Frankie Barrett | Alzheimer's Society |
| Catherine Keogh | Alzheimer's Society |
| Steffani McDonogh | Carers' Association |
| Catherine Cox | Carers' Association |
| Claire Duffy | Carers' Association |
| Ed Murphy | Home Instead |
| Maureen Chalmers | HSE |
| Janet Convery | HSE |
| Jackie Ebbs | HSE |
| Michael Fitzgerald | HSE |
| Brenda Hannon | HSE |
| Adrienne Jordan | HSE |
| Mo Flynn | Our Lady's Hospice, Harold's Cross, Dublin |
| Anne Doyle | Tallaght Home Help Service |
| Helen Toner | Tallaght Home Help Service |
| Mary Nally | Third Age Centre |
| Maria Pierce | Trinity College Dublin |
| Virpi Timonen | Trinity College Dublin |
| Matt Merrigan | SIPTU |
| Noel McGovern | |
| Bill O'Neill | |
| Members of the Irish Senior Citizens | Parliament, Limerick |
| Members of the Irish Senior Citizens | Parliament, Cork |
| Members of the Irish Senior Citizens | Parliament, Dublin |
| Members of the Older Women's Net | work, Dublin |
| | |

Annex IV Data which can be used to assess need for care for older people

As outlined in Chapter 4, Census 2006 data shows that over 160,000 persons were providing "regular unpaid personal help for a family member with a long-term illness, health problem or disability, including problems which are due to old age and providing help with basic tasks such as feeding or dressing." That Census also provides information on the proportion of persons aged over 65 with a disability³², finding that 29.5% (138,257 persons) did have a disability. The proportion with a disability increased with age, as did the number of disabilities a person was likely to have (CSO, 2007).

More detailed analysis of the type of disabilities which older people have is also indicated by the Disability Survey of 2006 (CSO, 2008), which is a sample of 14,516 people (of all ages) selected on a random basis from persons who indicated in the Census that they had a disability or longstanding health condition. It records the level of difficulty experienced in performing everyday tasks. Mobility and dexterity was the most frequently reported disability for older age groups, with 70% of the 65-74 age group and 83% of people aged 75 and over reporting this disability. Linking this data to overall Census figures on the population aged over 65 leads to an estimate of 117,400 people aged 65 and over having a disability, of which 38% (44,700) report being severely limited by their disability. Interestingly, this is very similar to the number of people estimated in the LTC report, based on projections from the figures in the Mercer report on long-term care, to be in need of high or continuous levels of care (i.e. over 21 hours per week). That figure was 48,800 persons in 2002.³³

The above studies have not been used to link the individuals with disabilities and those who care – if possible to do so, this might be a very useful study, particularly as the data would be available by LHO. In the meantime, the SHARE study, a longitudinal study of 1103 older people in Ireland, provides information on both their health status and caring arrangements. Analysis of this data is included in Annex 5 below.

A much larger longitudinal study is also being put in place of older people, the TILDA survey. It will study at least 8,000 Irish people over the age of 50 over a 10 year period, and will also assess the health and care arrangements of these older people. This is another survey which could be used as a basis for deciding the number of HCPs needed by LHO. As it is longitudinal, it can also be used to assess outcomes for older people, such as use of formal care services, the proportion of older people living at home, etc, although the exact questions which will be asked are not yet publicly available³⁴.

³² Disability is indicated as having any of the following long-lasting conditions – a) blindness, deafness or a severe vision or hearing impairment; b) a condition that substantially limits one or more basic physical activities such as walking, climbing stairs, reaching, lifting or carrying; c) a learning or intellectual difficulty; d) a psychological or emotional condition; e) other, including any chronic illness. Or difficulty doing any of the following activities – a) learning, remembering or concentrating; b) dressing, bathing or getting around inside the home; c) going outside the home alone to shop or visit a doctor's surgery; d) working at a job or business or attending school or college; and e) participating in other activities, such as leisure or using transport.

33 Working Group on Long-Term Care, 2005 Report of the Inter-Departmental Group on Long-Term Care, Dublin: Dept of An Taoiseach

34 See http://www.esri.ie/research/research areas/social inclusion/lifecycle social exclusio/TILDA Life cycle Brendan Whelan.pdf

Annex V Analysis of SHARE data

Care of Older People in the Home: Analysis of Survey of Health, Ageing and Retirement in Europe, Ireland



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April 2009

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1. Introduction

Knowledge of the determinants of use of home based services among older people is of particular importance for predicting the need for and cost of home care packages in the future. Coping at home often requires home based care arrangements and services organised by the public sector such as home help services (Blomgren et al. 2008). The policy in Ireland is to support older people at home for as long as possible. An interesting debate in the literature surrounds the idea of substitution and complementarity between formal and informal care. For example, if a person is receiving care informally from family members or friends, their need for formal care services may be low, and hence the term substitution of informal care for formal. On the other hand, informal carers may not have time or resources to provide a full level of care and hence will complement their care with formal care services, where possible. Therefore to explore the demand for formal home care services, we also should consider availability of informal care and support, as well as need for all kinds of care, which can be gauged through knowledge of older people's ability to carry out various activities.

In this short paper, we outline utilisation of home care services in Ireland, using the SHARE (Survey of Health Ageing and Retirement in Europe), a rich source of data on older people in Ireland in terms of health, wealth and health care utilisation. The paper outlines firstly, the health status of older people, secondly, the proportion of older people receiving home care, thirdly, the determinants of use of home based services bearing in mind the availability of informal support.

2. Demographics and care in Ireland

There are about 470,000 in the 65 and over age group and this has increased by almost 8% since 2002, in line with the overall population trend. The proportion of people aged 65 and over has remained quite consistent since 2002 at approximately 11% of the total population. In 2002 there was a ratio of 1.3 females to males in the 65 years and above age group. This ratio has shown a slow decline since and in 2006 was about 1.26. The proportion of people aged 65 and over is expected to increase. In fact, it is expected that by 2031, there will be 1.04 million people aged 65 and above in the population (approximately 19 per cent of total population). The consequences of these changing demographics are very important to the future of formal and informal care provision (Barrett and Bergin, 2006).

Almost 19,500 people were in residential long-term care in Ireland in 2004, representing 4.3% of the older population. At present home help services are the core services in place to support people to remain in the home, at an approximate cost of €120 million for an average of 5 hours per week (Long term care working group, 2005). The care of elderly has been highlighted in the media in recent times, particularly with reference to payments for formal care in residential homes. The Mercer group (2002) believes that the role of the family in providing long-term care is central to the future of older people.

3. SHARE Data

Europe

SHARE is a longitudinal study, following the same group of people over time. It is intended to be biennial; however an interim module on life history, employment and health will be conducted in 2009. Participants were chosen to be a representative sample of the population over 50 years of age in each of the participating countries. Individuals in institutions were not surveyed (except for Denmark). However those involved may move to an institution at a later stage and due to the longitudinal nature of the project these individuals would then be included. All members of a household aged 50 and over are surveyed as are their partners (irrespective of age). In Ireland, 1,103 individuals were surveyed.

Data were collected using face to face computer assisted personal interviews (CAPI). The SHARE questionnaires feature a number of different modules relating to various topics. The modules of interest to this study include health, use of health services, social support.

Ireland

The SHARE study was piloted over a number of stages in Ireland. The test was conducted in November-December 2006 by the Economic and Social Research Institute (ESRI), the purpose of which was to evaluate the fieldwork procedures and reception of the questionnaire by respondents. The full survey was conducted between February 2007 and December 2007, with a 55 per cent response rate at household level and a 85 per cent response rate of individuals within those households.

4. Health

Respondents were asked about their general health and chronic illnesses. Harmon *et al.* (2008) state that one third of individuals aged 50-59 have a long term illness and this increases to over 40 per cent for older age groups. In particular, women aged 70-79 have the highest rate of long-term illness at over 50 per cent.

Individuals are asked about their activities of daily living. The term "activities of daily living," or ADLs, refers to the basic tasks of everyday life, such as eating, bathing, dressing, toileting, and transferring. When people are unable to perform these activities, they need help in order to cope, either from other human beings or mechanical devices or both. Although persons of all ages may have problems performing the ADLs, prevalence rates are much higher for older people.

Measurement of the activities of daily living is critical because they have been found to be significant predictors of admission to a nursing home (Branch and Jette, 1982); use of paid home care (Garber, 1989); use of hospital services (Branch, Jette, and Evashwick, 1981); living arrangements (Bishop, 1986); use of physician services (Wan and Odell, 1981); insurance coverage (Dunlop, Wells, and Wilensky, 1989); and mortality (Manton, 1988), prediction of falls among cancer patients (Overcash, J., 2007), and predictor of long term admission to nursing homes, (Gill, 2006). For research on older people, the ability to perform the ADLs has become a standard variable to include in analyses, just like age, sex, marital status, and income. Instrumental Activities of Daily Living (IADLs) are the activities often performed by a person who is living independently in a community setting during the course of a normal day, such as managing money, shopping, telephone use, travel in community, housekeeping, preparing meals, and taking medications correctly. Increasing inability to perform IADLs may result in the need for care facility placement.

The individuals were also asked about a number of functional limitations and a summary measure of functional limitations is classified into 1-2 limitations, 3-5, and 6-10. The summary measure of ADL is categorised as no difficulties, one to two difficulties, three to four, and five to six. IADL is summarised as no difficulties, one to two, three to four, five to seven.

In the SHARE survey, individuals are asked to exclude difficulties not expected to last more than three months.

Table 1 describes each functional limitation and the proportion of people aged 65 and over that experience each type of such limitation. These are walking 100 metres, sitting for about two hours, getting up from a chair after sitting for long periods, climbing several flights of stairs without resting, climbing one flight of stairs without resting, stooping, kneeling or crouching, reaching or extending arms about shoulder level, pulling or pushing large objects like a living room chair, lifting or carrying weights over 10 pounds/5 kilos – like a heavy bag of groceries, picking up a small coin from a table. The most frequently reported limitations are climbing several flights of stairs and stooping, kneeling or crouching. Fewer individuals have difficulty picking up a small coin, indicating that only a small proportion is quite frail.

Table 1 Percentage of those aged over 65 with a functional limitation

| Type of functional limitation | Age 65 and over |
|------------------------------------|-----------------|
| Walking 100 metres | 16.5 |
| Sitting for about 2 hours | 12.4 |
| Getting up from chair | 24.9 |
| Climbing several flights of stairs | 36.7 |
| Climbing one flight of stairs | 12.4 |
| Stooping, kneeling, crouching | 31.9 |
| Reaching | 14.1 |
| Pulling or pushing large objects | 18.4 |
| Lifting or carrying weights | 25.4 |
| Picking up small coin | 5.2 |
| N | 461 |

We then compile the number of functional limitations for each individual. Table 2 indicates that approximately 60 per cent of people aged 65 and over have at least one functional limitation. Just over 10 per cent have a large number of functional limitations ranging from 6 to 10. The proportions with more limitations increase as people get older.

| | | | | Total Age |
|------|-----------|-----------|---------|-------------|
| | Age 65-75 | Age 75-85 | Age 85+ | 65 and over |
| | | % | | |
| None | 50.7 | 27.2 | 16 | 40.6 |
| 1-2 | 26.3 | 32.1 | 20 | 28.0 |
| 3-5 | 15.7 | 24.7 | 28 | 19.5 |
| 6-10 | 7.3 | 16.0 | 36 | 11.9 |
| N | 274 | 162 | 25 | 461 |

Table 2 Number of functional limitations per individual aged over 65

The type of ADL is described in Table 3. Individuals are asked if they have any difficulty with these because of a physical, mental, emotional or memory problem. These are dressing, including putting on shoes and socks; walking across a room; bathing or showering; eating, such as cutting up food; getting in and out of bed; and using the toilet including getting up or down. Table 3 shows that the most frequently reported ADL is either walking across a room or bathing/ showering. People aged 65 and over also report dressing as an activity they have difficulty with. The other basic activities of getting in and out of bed or using the toilet do not pose the same level of difficulty.

Table 3Percentage of those aged 65 and over
having difficulty with an ADL

| Type of ADL | Age 65 and over | |
|---------------------------|-----------------|--|
| Dressing | 8.9 | |
| Walking across room | 11.3 | |
| Bathing/showering | 10.6 | |
| Eating | 4.1 | |
| Getting in and out of bed | 3.7 | |
| Using toilet | 2.6 | |
| N | 461 | |

The number of difficulties with these activities is shown in Table 6, where we see that among those aged 65 and over, almost 25 per cent have difficulties carrying out at least one IADL. The proportion of people with a high number of difficulties carrying out IADLs is just over 1 per cent. In the age group 65-75, 17 per cent had difficulty with at least one IADL, compared to 32 per cent in the next age group.

| | Age 65-75 | Age 75-85 | Age 85+ | Total Age 65 and over |
|------|-----------|-----------|---------|--------------------------|
| | | % | | |
| None | 89.8 | 77.2 | 56 | 83.5 |
| 1-2 | 8.4 | 17.3 | 28 | 12.6 |
| 3-5 | 1.1 | 3.7 | 8 | 2.4 |
| 6-10 | 0.7 | 1.9 | 8 | 1.5 |
| N | 274 | 162 | 25 | 461 |

Table 4 Proportion of older people who have difficulty with a number of ADLs

Types of IADL are listed in Table 5. These include using a map to figure out how to get around in a strange place, preparing a hot meal, shopping for groceries, making telephone calls, taking medications, doing work around the house or garden, and managing money – such as paying bills, and keeping track of expenses. Many people aged 65 and over require help with preparing meals and managing money.

Table 5 Percentage of older people who have difficulty with an IADL

| Type of IADL | Age 65 and over | |
|----------------------------|-----------------|--|
| Using a map | 2.6 | |
| Preparing a hot meal | 11.7 | |
| Shopping for groceries | 6.3 | |
| Making telephone calls | 10.8 | |
| Taking medication | 3.0 | |
| Doing work in house/garden | 3.9 | |
| Managing money | 12.1 | |
| N | 461 | |

The number of difficulties with these activities is shown in Table 6, where we see that among those aged 65 and over, almost 25 per cent have difficulties carrying out at least one IADL. The proportion of people with a high number of difficulties carrying out IADLs is just over 1 per cent. In the age group 65-75, 17 per cent had difficulty with at least one IADL, compared to 32 per cent in the next age group.

| | Age 65-75 | Age 75-85 | Age 85+ | Total Age 65 and over |
|------|-----------|-----------|---------|--------------------------|
| | | % | | |
| None | 83.2 | 67.9 | 48 | 75.9 |
| 1-2 | 13.9 | 24.1 | 32 | 18.4 |
| 3-5 | 2.6 | 5.6 | 16 | 4.3 |
| 6-10 | 0.4 | 2.5 | 4 | 1.3 |
| N | 274 | 162 | 25 | 461 |

Table 6 Number of functional limitations per individual aged over 65

Use of aids and appliances

If a person has a functional limitation that affects their ADL or IADL, it is possible that they use an aid such as a walking stick, wheel chair, or personal alarm. Individuals were asked if they had the use of such aids, and could give up to 7 answers. The type of aids and appliances are listed in Table 7. Many people, approximately 14 per cent, have the use of a cane or walking stick.

Table 7Type of aids/appliances, and percentageof those over 65 using them

| Type of aid/appliance | Age 65 and over | |
|------------------------|-----------------|--|
| Cane or walking stick | 14.5 | |
| Zimmer frame or walker | 2.3 | |
| Manual wheelchair | 2.1 | |
| Electric wheelchair | 0.4 | |
| Buggy or scooter | 1.1 | |
| Personal alarm | 7.5 | |
| N | 461 | |

The most aids any one individual reported was 5. Table 8 indicates that one fifth of older people have the use of an aid. The proportion with 1 or more aids/ appliances increases significantly among older age groups. About 2.5 per cent of people aged 75-85 use 3-5 aids or appliances.

 Table 8 Number of aids and appliances used by those over 65

| | | | | Total Age |
|------|-----------|-----------|---------|-------------|
| | Age 65-75 | Age 75-85 | Age 85+ | 65 and over |
| | | % | | |
| None | 90.0 | 69.9 | 42.3 | 80.4 |
| 1-2 | 8.9 | 27.6 | 53.8 | 17.9 |
| 3-5 | 1.1 | 2.5 | 3.8 | 1.7 |
| N | 280 | 163 | 26 | 469 |

Help and unmet needs

In terms of ADL and IADL, individuals were asked if they received help with these activities. If they answered yes, they were asked does this help meet their needs, to which they could answer (1) all the time (2) usually (3) sometimes (4) hardly ever.

By combining these answers, we create a variable called 'unmet needs'. In Harmon *et al.* it is shown that of over one third of people aged 70-79 that received help, the help received did not meet their need for care and this increases to almost one half for those in the group aged 80 and over.

Of course, we must bear in mind that this level of unmet needs is self-reported and may be subject to reporting bias. If individuals perceive need for care differently, then the level of unmet needs may be over-or-under reported. Nonetheless, Table 9 gives an average indication of perceived unmet needs and about 13 per cent report that help only meets their needs sometimes or hardly ever. This gives a strong suggestion that people believe current care does not meet expectations of demand.

| Does the help meet your needs? | Of those who receive help % |
|--------------------------------|-----------------------------|
| All the time | 63.3 |
| Usually | 23.9 |
| Sometimes | 10.1 |
| Hardly Ever | 2.8 |
| N | 109 |

Table 9Views of over 65s on whether the help
they receive meets their needs

5. Health Care Utilisation

The magnitude of the impending demographic change requires planning in health services and information on current use of health services. SHARE is an important source in this regard and asks for data on health care utilisation among respondents in the last 12 months. The data will be used to track changes in people's use of health services as they age. Harmon *et al.* showed that over 80 per cent of respondents had visited the GP at least once in the last 12 months and 11 per cent had visited a specialist.

Table 10 shows that 19.2 per cent of people aged 65 and over had some stay in hospital over the previous 12 months. The percentage staying in a nursing home, who then returned home again, was 2.7 per cent. For those in hospital, the average number of nights was 13.

| | % | Average number of nights |
|--------------|------|--------------------------|
| Hospital | 19.2 | 12.8 |
| Nursing home | 2.7 | 4.3 weeks |
| N | 459 | |

Table 10 Health care utilisation among age 65+

Private Care

Individuals were asked if they received any of the care during the last twelve months from private providers that was paid for by the person themselves or through private insurance. The type of care received from a private provider could include (1) surgery (2) care from a GP (3) care from a specialist physician (4) drugs (5) dental care (6) hospital inpatient (rehabilitation) (7) ambulatory (outpatient) rehabilitation (8) aids and appliances (9) care in a nursing home (10) home care (11) paid home help (12) other care. Twelve per cent said they received some sort of care from private providers (Table 11).

Table 11Type of care received by over 65s fromprivate providers during last 12 months

| | % | |
|-----------------|-----|--|
| Home Care | 0.2 | |
| Paid home help | 0.9 | |
| Surgery | 3.7 | |
| GP | 3.1 | |
| Specialist | 4.4 | |
| Drugs | 1.8 | |
| Dental | 2.8 | |
| Hospital | 0.2 | |
| Outpatient | 0.2 | |
| Aids/appliances | 0.4 | |
| Nursing home | 0.7 | |
| Other | 1.1 | |
| N | 457 | |

A number of individuals paid for more than one type of care, so in Table 12 we show that 2.1 per cent pay for two kinds of care and about one per cent pay for 3 and 4 types of care, respectively.

| | Age 65 and ove | |
|------|----------------|--|
| None | 88.3 | |
| 1 | 7.7 | |
| 2 | 2.1 | |
| 3 | 0.9 | |
| 4 | 0.9 | |
| 5 | 0.2 | |
| N | 469 | |

Table 12 Number of private care services received

They were then asked how much they paid out of pocket for inpatient care, outpatient care and day care, nursing home, and home based care, in last 12 months. There was a very low response rate to this question so we do not the provide data in this report.

6. Formal Care Received at Home

Individuals were asked if during the last 12 months they had received in their own home, any of the following types of care (1) professional or paid nursing or personal care (2) professional or paid home help, for domestic tasks that they could not perform themselves due to health problems (3) meals on wheels. Individuals were then asked the number of weeks and hours during which they received each type of care.

In Table 13, we show that 4.6 per cent received professional or paid nursing or personal care, 7.3 per cent received professional or paid home help for domestic tasks and 1.8 per cent received meals on wheels. Timonen (2008) found that 2.4 per cent of older people use meals on wheels, about 11,000 individuals.

| | % |
|----------------------------|-----|
| Personal care | 4.6 |
| Home help (domestic tasks) | 7.3 |
| Meals on wheels | 1.8 |
| Two types of help | 2.2 |
| Three types of help | 0.7 |
| N | 454 |

Table 13 Formal care services received at home

Table 14 shows that the percentage of people receiving care is much higher among older age groups. About 4 per cent of people aged 65-75 get help with domestic tasks compared to 10 per cent of people aged 75-85. In the lower age group, approximately 5 per cent receive some sort of care and this proportion is 14 per cent among those aged 75-85.

| | Age 65-75 | Age 75-85 | Age 85+ | Total Age 65 and over |
|-----------------|-----------|-----------|---------|--------------------------|
| | | % | | |
| Personal care | 2.9 | 5.7 | 16.7 | 4.6 |
| Domestic tasks | 3.7 | 10.1 | 29.2 | 7.3 |
| Meals on wheels | 1.1 | 3.2 | 0.0 | 1.8 |
| No formal care | 94.9 | 86.1 | 58.3 | 89.9 |
| N | 272 | 158 | 24 | 454 |

Table 14 Formal care services at home by age group

Figure 1 describes formal care services used, by age group and by male and female categories. In general, females get more assistance with domestic tasks for those aged 65-75 and age 75-85. For the age 85+ group, more males receive assistance with personal care and domestic tasks – however we should note the sample size here for over 85s is very small and may not be totally representative.



Figure 1 Formal care services received at home by age group and sex (%)

Overall, we see in Figure 2 that formal care services are received more by non-married older people. The exception is among the over 85 age group, but again the sample size here is too small to arrive at any definite conclusion.



Figure 2 Formal care services received at home by age group and marital status (%)

The numbers who report receiving care in the home are very low and hence hinder any statistical analyses of duration of that help. However, in Table 15 we show that for those who did get personal care, this lasted for 19 weeks and for 11 hours per week. The number of hours for home help was on average 17 hours per week. Meals on wheels were delivered on average for 19 weeks, although the numbers in this case are particularly low (8) and so not very statistically reliable.

| | Weeks | Hours | Ν |
|-----------------|-------|-------|----|
| | | % | |
| Personal care | 19.3 | 11.3 | 21 |
| Home help | 39 | 17 | 32 |
| Meals on wheels | 18.6 | N/A | 8 |

Table 15 Duration during which services were received in the home

7. Informal care received at home

Care in Ireland is often given informally by family members and friends outside the household. In the SHARE data, a number of questions are asked in relation to this type of social support. Individuals were asked if they received help from others for (1) personal care e.g. dressing, bathing or showering, eating, getting in or out of bed, using the toilet; (2) practical household help e.g. with home repairs, gardening, transportation, shopping, household chores; (3) help with paperwork, such as filling out forms, settling financial or legal matters. In Table 16, we show that of those aged 65 and over, one fifth receive help. The proportion ranges from 15 per cent among age 65-75, to 23.9 per cent among those aged 75-85.

| | Age 65-75 | Age 75-85 | Age 85+ | Total age 65+ |
|-----|-----------|-----------|---------|---------------|
| | | % | | |
| Yes | 15.4 | 23.9 | 57.7 | 20.7 |
| No | 84.6 | 76.1 | 42.3 | 57.4 |
| N | 280 | 163 | 26 | 469 |

Table 16 Received help from others?

The types of informal care are described further in Table 17. The most common type of informal care is for household chores and domestic tasks. About 17 per cent of people aged 65 and over receive informal assistance with household tasks. As people get older, higher proportions are in receipt of this type of care. The proportion of those aged 65-75 and receiving some care is 15 per cent, compared to 24 per cent among those aged 75-85. About 60 per cent of people aged 85+ receive some informal care, but the small samples may not be representative among the older age group.

Table 17 Informal care – proportion of each age group receiving this care

| Help with: | Age 65-75 | Age 75-85 | Age 85+ | Age 65 and over |
|------------------|-----------|-----------|---------|-----------------|
| | | % | | |
| Personal care | 2.1 | 4.9 | 19.2 | 4.0 |
| Household chores | 13.9 | 17.8 | 50 | 17.3 |
| Paperwork | 1.8 | 5.5 | 30.8 | 4.7 |
| No informal care | 84.6 | 76.1 | 42.3 | 79.3 |
| N | 280 | 163 | 86 | 469 |

Figure 3 illustrates the proportion of males and females getting informal care in each age group. Females are more likely to get all types of care up to age 85. For the age group 85+, men receive more care – again this sample size is quite low.

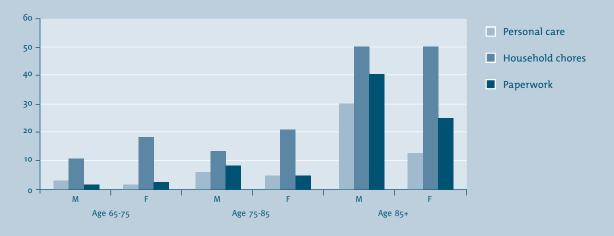


Figure 3 Informal care received in the home by age and sex (%)

Of those who do receive informal help from family and friends, almost one third do so on a daily basis, a similar proportion on a weekly basis, 13 per cent monthly and the remainder less often. In Table 18, we show that the most regular type of care is for household tasks. Five per cent of older people get weekly help from family and friends and 4 per cent get daily help.

| | Personal care | Household | Paperwork |
|--------------------|---------------|-----------|-----------|
| | % of over 65s | | |
| Almost daily | 2.1 | 4.1 | 2.1 |
| Almost every week | 1.3 | 5.3 | 0.6 |
| Almost every month | 0.0 | 2.6 | 0.4 |
| Less often | 0.6 | 5.3 | 1.5 |
| No help | 95.9 | 82.7 | 95.3 |
| N | 469 | 469 | 469 |

Table 18 How often is help received by those aged over 65

Figure 4 details the duration of help among each age group. Overall, the older age groups get more regular help.

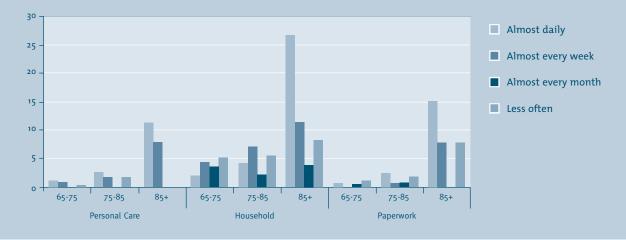


Figure 4 How often informal care received by age group (%)

It is also interesting to note who provides the informal care, outlined in Table 19. Respondents were asked if they received help from a household member and 6.2 per cent of the full sample responded yes. This help was generally from the spouse/ partner (about 60% of the 29 receiving such care).

Table 19 Help from outside family, received from:

| | % | |
|--------------------------------|------|--|
| Family | 13.0 | |
| Extended family | 0.9 | |
| Friend | 4.1 | |
| Neighbour | 2.6 | |
| No help from outside household | 79.5 | |

8. Health Status, Education and Receipt of Care

The relationship between health status and receipt of care is well documented in the literature. Home health care can lower the risk of functional decline and institutionalization (Martin, Oyewole, and Moloney 1994; Fabacher *et al.* 1994; Mayo *et al.* 2000; Hansen, Spedtsberg, and Schroll 1992; Stuck *et al.* 2002). In Table 20, we show the proportion of people with functional limitations that are in receipt of formal or informal care. These figures are highly relevant to the next section of this paper, where we aim to assess the level of unmet need. The general pattern is that there are more recipients of informal care, regardless of functional limitations. For example, of those who have difficulty climbing several flights of stairs, 26.6% receive informal care and 17.7% are in receipt of formal care. The total number of respondents with difficulty climbing several flights of stairs is 169, so overall 45 are in receipt of informal care and 30 are receiving formal care.

| Functional limitation | % receiving informal care | % receiving formal care | N |
|------------------------------------|------------------------------|----------------------------|-----|
| Walking 100 metres | 36.8 | 31.6 | 76 |
| Sitting for about 2 hours | 36.8 | 24.6 | 57 |
| Getting up from chair | 36.5 | 22.1 | 115 |
| Climbing several flights of stairs | 26.6 | 17.7 | 169 |
| Climbing one flight of stairs | 50.9 | 36.8 | 57 |
| Stooping, kneeling, crouching | 33.3 | 20.5 | 147 |
| Reaching | 38.5 | 26.2 | 65 |
| Pulling or pushing large objects | 36.5 | 35.7 | 85 |
| Lifting or carrying weights | 35 | 26.3 | 117 |
| Picking up small coin | 41.7 | 39.1 | 24 |

Table 20 Type of functional limitation and percentage receiving care

In previous literature, income exhibits a U-shaped relationship with home health care, with higher usage among the poorest and wealthiest (Stum, Bauer, and Delaney 1996; Liu, Manton, and Aragon 2000). Education also appears to be related to access, with lower educated seniors less likely to use paid care at home and more likely to report unmet need with respect to home health care use following hospital discharge (Solomon *et al.* 1993; Bowles, Naylor, and Foust 2002).

In Table 21, we note that the less educated are more likely to use formal care and informal care. The sample sizes here are relatively small and should be analysed with caution.

| Type of care received | Third Level | Higher Secondary | Lower Secondary | Primary | None |
|--------------------------|----------------|---------------------|--------------------|---------|------|
| Formal care | 6.6 | 9.0 | 6.3 | 13.4 | 17.6 |
| Informal care | 16.9 | 17.6 | 21.3 | 24.3 | 17.6 |
| N | 77 | 100 | 80 | 180 | 17 |

Table 21 Percentage of those over 65 receiving care, by education level

9. International Comparisons

The SHARE survey was carried out in a range of European countries, allowing us to directly compare usage of care services and differences in health status. Of course, the responses are subjective and this must be taken into account when interpreting the data. In some countries, depending on cultural differences, people may be less inclined to report a limitation. There are some notable differences across countries in levels of functional limitations and use of formal or informal care. For example, in France 42.1 per cent of people aged 65 and over have difficulty climbing several flights of stairs, compared to 27 per cent in Sweden. Likewise, in the Netherlands, 12.8 per cent have difficulty pulling large objects, compared to 22.6 per cent in France.

The usage of formal care is also striking – in Ireland 9 per cent of people receive formal care. This is similar to Austria and Sweden but much lower than in France or Belgium. Informal care is provided to at least one fifth of older people in most countries.

| | Austria | Netherlands | Sweden | France | Belgium | Ireland |
|-------------------------|---------|-------------|--------|--------|---------|---------|
| Difficulty with | | | | | | |
| Walking | 11.5 | 14.7 | 10.5 | 17.8 | 15.8 | 3.9 |
| Sitting | 13.3 | 6.8 | 10.0 | 9.4 | 11.6 | 12.4 |
| Getting up | 25.6 | 18.9 | 23.5 | 20.8 | 19.8 | 24.9 |
| Climbing several stairs | 38.5 | 28.5 | 27.1 | 42.1 | 29.4 | 36.7 |
| Climbing stairs | 18.6 | 14.7 | 10.6 | 16.7 | 15.2 | 12.4 |
| Stooping | 35.3 | 27.3 | 39.6 | 40.1 | 37.4 | 31.9 |
| Reaching | 12.9 | 8.1 | 8.4 | 12.2 | 9.4 | 14.1 |
| Pulling | 16.4 | 12.8 | 11.1 | 22.6 | 20.6 | 18.4 |
| Lifting | 27.8 | 23.9 | 23.0 | 28.8 | 25.4 | 25.4 |
| Picking up coin | 7.5 | 3.0 | 5.0 | 4.6 | 4.5 | 5.2 |
| Receiving formal care | 10.7 | 15.9 | 9.9 | 24.8 | 23.0 | 9.0 |
| nformal care | 23.2 | 19.2 | 19.0 | 20.5 | 22.5 | 23.0 |

Table 22International levels of functional limitations and care, age 65+(SHARE data)

10. Assessing demand for formal care in Ireland

In the SHARE survey, there are no explicit questions asked on need for care among older people. Individuals are asked if they receive formal or informal care but we do not know if people are receiving too much or too little care. We discussed earlier that about 13 per cent report that help only meets their needs sometimes or hardly ever. The proportion is much higher among those aged 75-85, compared to people aged 65-75. This could be taken as a proxy of unmet need, and although the response is subjective, the proportion should not be ignored.

11. Conclusions

This paper assessed the use of formal and informal care services among 1103 older people surveyed by the SHARE survey in Ireland. It found that:

- The proportion receiving formal care is 20.7 per cent and the proportion in receipt of informal care is 10 per cent.
- The older age group of 75+ get higher levels of formal personal care and domestic help.
- Females receive more help with domestic tasks and meals on wheels.

- A high number of functional limitations are associated with more formal care.
- In terms of informal care, household tasks are the main form of help.
- Among those aged 85+, more get help with personal care and paperwork, and a higher proportion of males get help, and get help more frequently (although the sample size is small).
- 5.5% receive both formal and informal care.

Finally, this paper provides accurate analysis of SHARE data. Unfortunately, the sample size does not warrant detailed investigation of care recipients and unmet need. It raises the point, once again, that detailed data on care among older people is required.

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Annex VI NESF Questionnaire sent to Eight HSE Local Health Offices

Introduction

The NESF is a State agency under the Dept of the Taoiseach, which is made up of a Forum of 60 social partners (see www.nesf.ie). In its new work programme the NESF is looking at successful and unsuccessful ways of implementing policies. One policy we are studying is the home care package scheme, to find out what works well about the scheme, and what does not work so well. The study is looking at the points of view of those receiving home care packages (HCPs), as well as those providing them and managing them. As part of this we are gathering information on the processes used in different LHOs to allocate and deliver HCPs.

- 2. What forms are filled in, in order to get a HCP in your LHO? Please tick all that apply, and please attach a copy of each form (where possible)³⁵
- Form filled in by member of the public
- Form filled in by PHN
- Form filled in by case manager
- Form filled in by social worker
- Form filled in by other
 hospital staff
- Other forms please specify

In a typical case, which of the above forms are likely to be filled in by a person applying for a HCP?

Information we are interested in

We would be grateful if you could answer the following questions for your LHO. Please ring Anne-Marie McGauran at o1 814 6365, or email am.mcgauran@nesf. ie, if you have any queries in relation to these questions.

- Who do members of the public need to apply to, to get a HCP in your LHO? Please tick all that are relevant:
- PHN
- Home care package
 case manager
- Hospital social worker
- GP
- Others please specify

3. What eligibility criteria is used to allocate a HCP in your LHO? Please tick all that apply

- Income What level of income?
- Savings What amount of savings?
- Medical need
- Level of family support
- Other, please specify

³⁵ These can also be posted to Anne-Marie McGauran, NESF, 16 Parnell Square, Dublin 1.

4. In 2007

• What was the maximum amount allowed to be paid for a HCP in your LHO?

• What was the average amount paid per HCP in your LHO?

€

5. Who decides if a person gets a HCP? Please tick all that apply

• Case manager

€

- PHN
- Other individual
- A number of people together (please specify who)

6. What information is provided to a member of the public who is looking for information on HCPs in your LHO? Please tick all that apply

- A brochure
 (please attach a copy)
- Information on the internet
 - Can you provide the webpage address______
- Other please specify

- 7. For 2007, can you give an estimate of who delivered the Home Care Package care in your LHO, as follows:
- Approximate percentage of HCPs carried out directly by HSE
- Approximate percentage of HCPs provided by private commercial agencies
- Approximate percentage of HCPs provided by home help or other voluntary organisations
- Approximate percentage of HCPs which were Home Care Grants
- Other, please specify

8. Do you have a preferred providers list in your LHO? Please tick yes or no

- Yes (if yes, please provide a copy)
- No

| 9. | What co-ordination is there with other organisations or individuals about HCP recipients: | 10. Are the HCPs in your LHO reviewed? • Yes No |
|----|---|---|
| • | Are there regular meetings with Primary Care Teams about HCP recipients? | If yes, how often? |
| | Yes No N/A | If yes, by whom? |
| | If yes, how often? | |
| • | Are there regular meetings with social workers about HCP recipients? | 11. Any other information which is relevant, or other comments you have |
| | Yes No N/A | |
| | If yes, how often? | |
| | | |
| • | Are there regular meetings with home help organisers about HCP recipients? | |
| | Yes No N/A | |
| | If yes, how often? | Name of person completing questionnaire: |
| • | Are there regular meetings with private agencies about HCP | Job title: |
| | recipients? | · Job title. |
| | Yes No N/A | |
| | If yes, how often? | Name and address of your Local Health Office: |
| | | |
| • | Are there regular meetings which all groups providing HCPs attend about HCP recipients? | |
| | Yes No N/A | Thank you very much for your help! |
| | If yes, how often? | |
| | | |

Annex VII Terms of Reference and Constitution of the NESF

- 1. The role of the NESF will be:
 - to monitor and analyse the implementation of specific measures and programmes identified in the context of social partnership arrangements, especially those concerned with the achievement of equality and social inclusion; and
 - to facilitate public consultation on policy matters referred to it by the Government from time to time.
- 2. In carrying out this role the NESF will:
 - consider policy issues on its own initiative or at the request of the Government; the work programme to be agreed with the Department of the Taoiseach, taking into account the overall context of the NESDO;
 - consider reports prepared by Teams involving the social partners, with appropriate expertise and representatives of relevant Departments and agencies and its own Secretariat;
 - ensure that the Teams compiling such reports take account of the experience of implementing bodies and customers/clients including regional variations;
 - publish reports with such comments as may be considered appropriate; and
 - convene meetings and other forms of relevant consultations appropriate to the nature of issues referred to it by the Government from time to time.
- 3. The term of office of members of the NESF will be three years. During the term alternates may be nominated. Casual vacancies will be filled by the nominating body or the Government as appropriate; members so appointed will hold office until the expiry of the current term of office of all members. Retiring members will be eligible for re-appointment.
- 4. The Chairperson and Deputy Chairperson of the NESF will be appointed by the Government.
- 5. Membership of the NESF will comprise 15 representatives from each of the following four strands:
 - the Oireachtas;
 - employer, trade union and farm organisations;
 - the voluntary and community sector; and
 - central government, local government and independents.
- 6. The NESF will decide on its own internal structures and working arrangements.

| Annex VIII Membership of the NESF | |
|-----------------------------------|---|
| Independent Chairperson | Dr. Maureen Gaffney |
| Deputy Chairperson | Mary Doyle |
| Strand (i) Oireachtas | |
| Fianna Fáil | Michael McGrath T.D Cyprian Brady T.D Seán Ardagh T.D Senator Brian Ó Domhnaill Senator Geraldine Feeney Senator Marc McSharry Senator Maria Corrigan |
| Fine Gael | Dan Neville T.D Terence Flanagan T.D Senator Paul Coghlan Senator Jerry Buttimer |
| Labour | Seán Sherlock T.D Willie Penrose T.D |
| Green Party | Senator Dan Boyle |
| Independents | Senator Rónán Mullen |

Strand (ii) Employer/Trade Union/Farming Organisations

| a. Employer/Business Organisations | | |
|--|-------------------|--|
| IBEC | Danny McCoy | |
| | Tony Donohoe | |
| Small Firms' Association | Patricia Callan | |
| Construction Industry Federation | Dr Peter Stafford | |
| Chambers of Commerce/ | | |
| Tourist Industry/ Exporters' Association | Seán Murphy | |
| | | |
| Trade Unions | | |
| Technical Engineering & Electrical Union | Eamon Devoy | |
| Civil & Public Service Union | Blair Horan | |
| AMICUS | Jerry Shanahan | |
| SIPTU | Manus O'Riordan | |
| ІСТИ | Esther Lynch | |
| | | |

Agricultural/Farming Organisations

| Irish Farmers' Association | Michael Berkery |
|--|-----------------|
| Irish Creamery Milk Suppliers' Association | Mike Doody |
| Irish Co-Operative Organisation Society | Emer Duffy |
| Macra na Feirme | Michael Gowing |
| Irish Countrywomen's Association | Carmel Dawson |

Strand (iii) Community and Voluntary Sector

| Gender | |
|--|-----------------------|
| National Women's Council of Ireland | Órla O'Connor |
| Housing | |
| Irish Council for Social Housing | Karen Murphy |
| Labour Market | |
| Congress Centres Network | Sylvia Ryan |
| Social Analysis | |
| CORI | Sr Brigid Reynolds SM |
| Poverty | |
| Society of St Vincent de Paul | John Mark McCafferty |
| Youth/Children | |
| NYCI | Marie Claire McAleer |
| Children's Rights Alliance | Jillian van Turnhout |
| Older People | |
| Senior Citizens' Parliament/Age Action | Maireád Hayes |
| Disability/Carers | |
| Disability Federation of Ireland | Joanne McCarthy |
| The Carers' Association | Frank Goodwin |
| Rural | |
| Irish Rural Link | Seámus Boland |
| Voluntary/Networks | |
| Community Platform | Frances Byrne |
| The Wheel | Ivan Cooper |
| Others | |
| National Traveller Women's Forum | Maria Joyce |
| Integrating Ireland | Stavros Stavrou |
| | |

Strand (iv) Central Government, Local Government and Independents

Central Government

Secretary-General, Department of Finance Secretary-General, Department of Enterprise, Trade and Employment Secretary-General, Department of Social and Family Affairs Secretary-General, Department of Community, Rural and Gaeltacht Affairs Secretary-General, Department of the Environment, Heritage and Local Government

Local Government

| Association of County & City Councils | Cllr Ger Barron |
|---------------------------------------|-------------------------|
| | Cllr Constance Hanniffy |
| | Cllr Mattie Ryan |
| Association of Municipal Authorities | Cllr Paddy O'Callaghan |
| Local Authority Members' Association | Cllr William Ireland |

Independents

| Institute for the Study of Social Change, UCD | Prof. Colm Harmon |
|---|------------------------|
| NUI Maynooth | Prof. Mary P. Corcoran |
| Trinity College, Dublin | Prof. Rose Ann Kenny |
| Southside Partnership | Marie Carroll |
| | |

Secretariat

| Director | Seán Óh Éigeartaigh |
|---------------------|------------------------|
| Policy Analysts | Dr Anne Marie McGauran |
| | Dr Jeanne Moore |
| Executive Secretary | Paula Hennelly |

Annex IX NESF Publications

(i) NESF Reports

| Report No. | Title | Date |
|------------|--|------------|
| 1. | Negotiations on a Successor Agreement to the PESP | Nov 1993 |
| 2. | National Development Plan 1994 – 1999 | Nov 1993 |
| 3. | Commission on Social Welfare – Outstanding Recommendations | Jan 1994 |
| 4. | Ending Long-term Unemployment | June 1994 |
| 5. | Income Maintenance Strategies | July 1994 |
| 6. | Quality Delivery of Social Services | Feb 1995 |
| 7. | Jobs Potential of the Services Sector | April 1995 |
| 8. | First Periodic Report on the Work of the Forum | May 1995 |
| 9. | Jobs Potential of Work Sharing | Jan 1996 |
| 10. | Equality Proofing Issues | Feb 1996 |
| 11. | Early School Leavers and Youth Employment | Jan 1997 |
| 12. | Rural Renewal – Combating Social Exclusion | Mar 1997 |
| 13. | Unemployment Statistics | May 1997 |
| 14. | Self-Employment, Enterprise and Social Inclusion | Oct 1997 |
| 15. | Second Periodic Report on the Work of the Forum | Nov 1997 |
| 16. | A Framework for Partnership – Enriching Strategic Consensus through Participation | Dec 1997 |
| 17. | Enhancing the Effectiveness of the Local Employment Service | Mar 2000 |
| 18. | Social and Affordable Housing and Accommodation: Building the Future | Sept 2000 |
| 19. | Alleviating Labour Shortages | Nov 2000 |
| 20. | Lone Parents | July 2001 |
| 21. | Third Periodic Report on the Work of the Forum | Nov 2001 |
| 22. | Re-integration of Prisoners | Jan 2002 |
| 23. | A Strategic Policy Framework for Equality Issues | Mar 2002 |
| 24. | Early School Leavers | Mar 2002 |
| 25. | Equity of Access to Hospital Care | July 2002 |
| 26. | Labour Market Issues for Older Workers | Feb 2003 |
| 27. | Equality Policies for Lesbian, Gay and Bisexual People: Implementation Issues | April 2003 |
| 28. | The Policy Implications of Social Capital | June 2003 |
| 29. | Equality Policies for Older People: Implementation Issues | July 2003 |
| 30. | Fourth Periodic Report on the Work of the NESF | Nov 2004 |
| 31. | Early Childhood Care and Education | June 2005 |
| 32. | Care for Older People | Nov 2005 |
| 33. | Creating a More Inclusive Labour Market | Mar 2006 |
| 34. | Improving the Delivery of Quality Public Services | Feb 2007 |
| 35. | The Arts, Cultural Inclusion and Social Cohesion | Mar 2007 |
| 36. | Mental Health and Social Inclusion | Oct 2007 |
| 37. | Fifth Periodic Report on the Work of the NESF | June 2008 |

(ii) NESF Opinions

| 1. | Interim Report of the Task Force on Long-term Unemployment | Mar 1995 |
|----|--|----------|
| 2. | National Anti-Poverty Strategy | Jan 1996 |
| 3. | Long-term Unemployment Initiatives | Apr 1996 |
| 4. | Post PCW Negotiations – A New Deal? | Aug 1996 |
| 5. | Employment Equality Bill | Dec 1996 |
| 6. | Pensions Policy Issues | Oct 1997 |
| 7. | Local Development Issues | Oct 1999 |
| 8. | The National Anti-Poverty Strategy | Aug 2000 |

(iii) NESF Opinions under the Monitoring Procedures of Partnership 2000

| 1. | Development of the Equality Provisions | Nov 1997 |
|----|---|----------|
| 2. | Targeted Employment and Training Measures | Nov 1997 |

(iv) Social Inclusion Forum: Conference Reports

| 1. | Inaugural Meeting | Jan 2003 |
|----|-----------------------------|----------|
| 2. | Second Meeting of the Forum | Jan 2005 |
| 3. | Third Meeting of the Forum | Feb 2006 |
| 4. | Fourth Meeting of the Forum | Nov 2007 |
| 5. | Fifth Meeting of the Forum | Nov 2008 |
| | | |

(v) NESF Research Series

| 1. | A Study of Labour Market Vulnerability and Responses to it in Donegal/Sligo and North Dublin | Jun 2005 |
|----|---|-----------|
| 2. | The Economics of Early Childhood Care and Education | Sept 2005 |
| 3. | Delivery of Quality Public Services | Sept 2006 |
| 4. | Mental Health in the Workplace: Research Findings | Oct 2007 |
| 5. | In The Frame or Out of the Picture | Feb 2008 |

(vi) NESF Occasional Series

| 1. | Evidence-based Policy Making: Getting the Evidence, | |
|----|---|----------|
| | Using the Evidence and Evaluating the Outcomes | Jan 2007 |

(vii) NESF Seminar Series

| 1. | In The Frame or Out of the Picture | Feb 2008 |
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Annex X Structures and Working Arrangements of the NESF

Introduction

- 1. The following structures and working arrangements are designed to enable the NESF to work as efficiently and effectively as possible in the discharge of its mandate.
- 2. The NESF will work through:
 - Plenary Sessions;
 - A Management Committee;
 - Project Teams; and
 - Ad Hoc Working Groups.

Plenary Sessions

- 3. The functions of the Plenary Sessions will be to debate, inter alia,:
 - the NESF's draft Work Programme, on the basis of proposals submitted by the Management Committee; and
 - the Reports prepared by the NESF's Project-based Teams and Ad Hoc Working Groups.
- 4. Ministers may attend and participate at these Sessions at the invitation of the NESF or on their own initiative. Opposition Spokespersons may also be invited to attend and participate at these Sessions.
- 5. Plenary Sessions will be held between four and six times a year. The main venue for meetings will be Dublin Castle but one or two Sessions a year may be held in provincial locations.
- 6. Plenary Sessions will be held in public, except when dealing with issues relating to the internal management of the NESF. Invitations to concerned interests to put forward their views and attend such Sessions will normally be left to the discretion of the NESF's Chairperson. *"Public"* in this context will also be interpreted to mean that the media will be invited to attend.

Management Committee

- 7. The Management Committee will be responsible for the management of the NESF and in ensuring its overall effectiveness and functioning. This role will include:
 - assisting the Chairperson of the NESF, in conjunction with the NESF Secretariat, in carrying out her Executive role;

- formally adopting the NESF's Work Programme in the light of the discussions at Plenary level; this should indicate a statement of the problem to be addressed under each main theme and serve also as the 'mission statement' for the subsequent work of the Project Teams;
- monitoring the Work Programme and the Structures and Working Arrangements on an on-going basis; agreeing amendments in both these areas which may be necessary in the light of experience;
- when work is initiated on a particular theme or sub-theme, the Committee may give broad guidelines to the Team concerned on the specific issues to be covered, give indicative timetables for completion of the project, make suggestions on sources of information, outside expertise, etc. but this should not be such as to unduly delimit or circumscribe the autonomy of the Teams;
- formally adopting the Reports prepared by the Project Teams and Ad Hoc Working Groups; these may be accompanied with a NESF commentary, as the Committee considers appropriate, based on the debate at Plenary level; in advance of the Management Committee meeting, the Project Team/ Working Group may meet to review and amend its Report, as it sees fit, taking into account the comments made at the Plenary Session;
- preparing the Periodic Reports on the work of the NESF and on the implementation of its recommendations; for this purpose, the Committee may prepare guidelines on the procedures to be followed in discussing follow-up action by Departments on recommendations contained in NESF Reports;
- in exceptional circumstances, and where action has to be taken at short notice such as a request from Government or an individual Minister, the preparation of Reports in this case may be undertaken either by the Committee itself or through its establishing an Ad Hoc Working Group for this purpose;
- the composition of such a Group, which will be drawn equally from all four Strands and decided on by the NESF's Chairperson, in consultation with the Management Committee, will have particular regard to involving Members with relevant expertise and experience in the area under examination; these Groups may also be assisted by outside experts; and
- in the above circumstances and because of the time constraints involved, these Reports will be adopted uniquely by the Management Committee (this will be referred to as the *"fast-track"* procedure).
- 8. The Management Committee will be chaired by the NESF's Chairperson. Each of the Strands will have three representatives on the Committee.
- 9. Finally, the quorum for meetings of the Committee will be a simple majority of Members. This will also apply in the case of meetings of the Project Teams and of Ad Hoc Working Groups.

Project Teams

- 10. Reflecting the NESF's new focus on policy implementation and evaluation, including the impact of policies in specific geographic areas, these Teams will be the main body involved in the preparation of Reports. The Teams whose membership should not exceed twelve at most will comprise balanced representation from the various organisations and interests involved, with particular account taken to ensure representation by the local and/or specialised elements of the national social partnership organisations.
- 11. To encourage as full participation as possible, and, the ownership of and input by the full NESF membership of the final results, Project Teams will:
 - at an early stage in their work make an interim presentation at Plenary Sessions on how their work is progressing; this will provide an opportunity for all NESF Members to make an input before reports are too far advanced and finalised by the Teams;
 - Plenary Sessions might break into smaller Working Groups for the above purpose;
 - for information purposes, periodic up-dates (1/2 pages), will be circulated by the Teams through fax/e-mail to all NESF Members on the progress made in their work; and
 - furnish attendance records to the Management Committee, with a view to addressing any problems that may arise in this area.
- 12. The work of the Teams will be specifically directed at:
 - evaluating the effectiveness of policies;
 - identifying corrective action and/or timely changes to ineffective policies; and
 - improving policy-making by better informing and influencing the reshaping of strategic policy analysis.
- 13. Save in exceptional circumstances when the NESF's Chairperson would need to be consulted, the appointment of Team Chairpersons, and/or Project Leaders if needs be, will be made by the Project Teams themselves.
- 14. The Teams will have particular regard to and take into account as fully as possible any guidelines prepared by the Management Committee to facilitate them in their work.
- 15. For this purpose, and to serve as a standard-type frame of reference, the Teams should take the necessary steps to ensure that:
 - within the framework of the NESF's agreed Work Programme and Management Committee's guidelines, specific and operational terms-of-reference are agreed to in the early stages of their work, in consultation with the Management Committee, together with an indication of the work-process, phasing and time-table involved and other related issues such as background documentation, speakers, research (if any) to be commissioned, etc.

- on-going consultations and interaction are held with Departments/State Agencies so that up-to-date information is available on official thinking on policy issues and of whatever work may already be underway;
- the work process is geared to solving problems, addressing specific policy issues and bringing an *"added value"* dimension to bear on policy-making through identifying, where possible, new thinking and alternative options;
- recommendations are specific and actionable (both in their content and to whom they are addressed); they also need to be supported by underlying analysis, costed (where this is feasible) and prioritised;
- detailed drafting points are left to the Secretariat; and
- where possible, decisions on substantive issues are only taken when there is a representative and balanced attendance of Members present.
- 16. Project Teams may be assisted by outside experts. Decisions in this area will be taken by the NESF's Chairperson, on the basis of proposals from the Team in question. The task of these experts will be to facilitate the work of the Teams through the preparation of position papers, participation at meetings (but not voting) and, in some cases, the drafting of Reports or Sections of such Reports.
- 17. The tasks of Project Leaders will be to provide impetus and assistance in the overall management of the Project Teams.
- 18. The Teams will mostly meet in private but may, by agreement with the Chairperson of the NESF, hold public meetings or local hearings as appropriate. All such public meetings will be chaired by the NESF's Chairperson.
- 19. Finally, Ministers, Opposition Spokespersons, interest groups and public officials may be invited to attend meetings of the Teams. NESF Members not on a particular Team but who wish to contribute will be invited to make written submissions and follow this up with an oral presentation, subject to the agreement of the Team concerned.

Ad Hoc Working Groups

- 20. Working Groups may be established on the initiative of the full NESF meeting in Plenary Session, or of its Management Committee, to consider specific issues which form part of or are related to the NESF's Work Programme or to assist the Management Committee, for example, in the preparation of the Periodic Reports.
- 21. In contrast to the role of the Project Teams, which will be focussed on resolving problems on the implementation of specific policies and programmes, the above Working Groups may be used, in particular, to advance and accelerate the preparation of shorter Reports or Opinions which will be linked in with the Government's timetable and decision-making processes.

These Groups will function along the more standard lines of the NESF's former Standing Committees.

- 22. As a general principle, these Groups will consist of not more than twelve Members. The composition and chairing of such a Group will be decided by the NESF's Chairperson, following consultation with the Management Committee. Particular attention will be given in this regard to having Members nominated who have relevant expertise and experience in the area under examination. There will be balanced representation on these Groups.
- 23. Working Groups may also be assisted by outside experts, under the same arrangements as will apply in the case of the Project Teams.
- 24. Save in exceptional circumstances, Reports from Working Groups will be discussed and adopted in the normal manner through the Plenary Session/ Management Committee mechanism.

NESF's Chairperson

- 25. The Chairperson will seek to facilitate and encourage participation by all of the Members of the NESF so as to achieve consensus. She will have a key role in managing the operation and administration of the NESF. These tasks will include:
 - chairing Plenary Sessions, Management Committee meetings and hearings by the Project Teams which are held in public;
 - encouraging participation and consensus and facilitating groups not directly represented to put forward their views and make presentations to the NESF;
 - taking final decisions on membership of the Project Teams, as well as on related questions such as that of alternates, in consultation with the Management Committee;
 - liasing with the Project Teams and Ad Hoc Working Groups;
 - organising agendas and work programmes in consultation with the Secretariat and the Management Committee;
 - ensuring that the Work Programme is within the NESF's terms-ofreference and that its implementation has regard to agreed strucures, working arangements and timetables; and
 - dealing with publicity and media issues on behalf of the NESF.
- 26. In her absence, the above functions will be undertaken by the NESF's Deputy Chairperson.

