

August 2004



# Submission

*to the*

**DEPARTMENT OF  
SOCIAL AND FAMILY AFFAIRS  
Consultation Document**

**ON THE**

**STUDY TO EXAMINE THE FUTURE  
FINANCING OF LONG-TERM CARE IN  
IRELAND**

## **Introduction**

Comhairle very much welcomes the Mercer Report and the related consultation process in respect of the issue of long-term care funding. The Consultation Document is a necessary and important step forward in progressing the issue. In particular, we welcome the move towards equality of funding and subvention for community care.

## **Consultation Document / Part A: General Comments**

In setting the context for considering the funding of long-term care, it is important that reference is made to the broader service delivery system and to its underlying principles. In particular, we feel that the following aspects of the system need further exploration than that given in the Consultation Document.

### ***Case Management and Packages of Care***

Care and case management is the process of service co-ordination and planning at management level and the delivery of individually tailored care plans, with a person-centred and multi-disciplinary focus, delivered through a Case Manager or team. In this regard we feel that, while the approach outlined in the Consultation Document is based on a needs assessment perspective, there is not enough emphasis on the concept of comprehensive packages of care and a case management approach linked to that assessment of need. It is reasonable to assume that the implementation of care and case management as a model of service delivery would be an integral part of a needs assessment approach to care and benefit.

### ***Needs Assessment***

We believe that needs assessment should start from the lived experience of people in need of care and not from how need is conceptualised in policy and practice. For example, the following questions need to be addressed:

- (i) How do we define quality of life for people in need of care?
- (ii) How can services operate to support and enhance this?
- (iii) How do we achieve dignity for those who are dependent in a context of promoting independence?
- (iv) What are the emotional impacts of dependency?
- (v) How can collective interdependence and intergenerational solidarity support and meet people's needs?
- (vi) What does it mean to be a recipient of care and how does this impinge on factors such as choice and autonomy?
- (vii) How can care be provided in ways that do not reinforce people's sense of being incompetent?
- (viii) What support services are required, e.g. advocacy, to ensure that people get services in accordance with the assessment of need?<sup>1</sup>

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<sup>1</sup> Goodbody Consultants (2004), *Developing an Advocacy Service for People with Disabilities*, Comhairle, Dublin.

These are questions that take us beyond a concern with meeting physical needs only towards addressing other equally important components of need, based on social participation and control over one's life. Essentially, they are questions about *how* need is defined and met and more work and research are required to address these.

The provisions of the forthcoming Disability Bill in relation to assessment of need and the provision of support services accordingly need to be taken into account in examining the issue of long-term care.

### ***Continuum of Provision***

Consistency and equity in services and supports require that there is a continuum of provision to meet the wide range of individual needs. There continues to be a mismatch between general welfare provision policy and the ability of individual citizens, particularly those on the margins, to access services appropriate to their needs.

While there has been much emphasis in recent years on the concept of inclusiveness, it is not clear that the position of people whose access to services has already been impaired by physical, psychological, educational, linguistic, socio-economic, cultural and technological factors has changed relative to the population as a whole. Three areas where the lack of adequate provision is evident are housing, respite care and affordable high quality residential care.

### ***Family Care***

In considering the future financing of long-term care in Ireland, it will be necessary to take full account of the role and contribution of family carers, both to the exchequer and to the broader society and to the implications of an evolving scenario where there will almost certainly be less family carers relative to need. Cognisance also needs to be taken of the long-term impact of caring on individuals and society in general in terms of people's health and well-being and, in some instances, career opportunities and income foregone. These issues are not given enough consideration in the Consultation Document. Also, many older people prefer to be independent of their families, and some family members may not be able to give adequate care to their elderly family member because of personal circumstances or limited resources

### ***Social Networks***

Close relationships and social networks are strongly related to the experience of well-being for both people in later life and people with disabilities. The notion of one-way help as between the carer and cared for person can produce a loss of social power as well as personal control on the part of the cared for individual. For older people, as is widely reported in research, maintaining continuity of place (in the sense of their own home and community) assumes considerable importance. Not only has it associations with family, friends and past memories, it offers a familiar environment within which to negotiate increasing disabilities.

## **Consultation Document / Part A: Specific Comments**

### ***(i) Dimensions of Long-term Care***

The Consultation Document states that long-term care **may** include:

1. *practical help with cooking, cleaning or shopping*
2. *personal care e.g. with dressing, bathing or eating*

3. *paramedical services such as chiropody, physiotherapy or occupational therapy*
4. *medical care including nursing and rehabilitation*

A comprehensive package of care and support should include all the above dimensions. In addition there is an essential housing component as well as the broader concerns of accessibility, transport and social networks and supports, which have a significant bearing on long-term care.

*(ii) Distinguishing between the needs of older people and those of younger people with disabilities*

While recognising that there are different issues to be addressed for older and younger people, as stated in the Consultation Document. We suggest that the primary emphasis should be on the provision of a universally available comprehensive care package based on the assessed needs of individuals requiring care and support irrespective of age. As already stated, the provisions of the forthcoming disability legislation need to be considered in the long-term care funding debate.

*(iii) Availability of 'Informal' Care*

We would suggest that the current availability of informal care by families is affected significantly by limited state supports and services as well as by demographic factors such as falling birth rates and greater participation by women in the labour force.

*(iv) Defining 'Community Care'*

The Consultation Document refers to community care services as including community nursing, home helps, respite services, day care centres and meals services together with paramedical services such as physiotherapy and occupational therapy. We feel that any consideration of 'community care' should include family carers who continue to be the key component in care in the community and, as such, make an essential contribution to the exchequer and to society in general.

## **Consultation Document / Part B: Needs Assessment**

### **B1 –B4**

In general we support the concept of *a formal needs assessment based on objective and transparent criteria set at national level*. We recognise the need for uniformity of approach, which would prevent inconsistencies in the system.

We support the concept of a National Expert Committee for this purpose but feel that family carers need to be represented in their own right and their expertise fully recognised. The voice of care recipients must also be included in the needs assessment process.

It is also essential that the work of such a committee is integrated with any needs assessment structures that emerge from the implementation of the forthcoming Disability Bill.

### **B5**

There should be a right to appeal a needs assessment and a transparent and easily accessible process for this purpose. The Appeals Body should be an independent group within the system who would work on a speedy response within a defined timescale. The Social Welfare Appeals Office may be an appropriate model for this purpose.

B6

The needs assessment should include social networks, housing and transport as well as other health and any other services/supports that may be required. It should also take into account services and supports provided by voluntary/community organisations.

B7

It is vital that carers' needs are taken into account and that adequate supports and services are put in place to allow the carer to continue to provide the level of care required. These support services should include respite, training, counselling, home respite service and other services as identified. The contribution of carers will vary from individual to individual depending on skills and personal support networks and this needs to be taken into account in the assessment of need.

B8

Any assessment tools or protocols used should ensure that there is provision for an ongoing review of needs as these will not remain static but will change over time. Engaging carers and care recipients in the assessment process will be very important.

B9

Assessment should be carried out by social and health experts in consultation with the carer and care recipient. Care is required to ensure that the social component of the needs assessment is weighted appropriately vis a vis the health/medical component.

B10

Participation in the workforce is a factor which should be taken fully into account in that it would have an important bearing on quality of life and would affect the level of care and support required.

B11-B14

We would favour a general approach to needs assessment, which ideally would be accompanied by individually-tailored care and support packages. The concept of a National Expert Committee to draw up criteria on long-term care needs assessment is one we would be in favour of in principle. Its role and functioning should be tied in with both the provisions in the forthcoming disability legislation and the proposed health delivery structures.

## **Consultation Document / Part C: Detailed Benefit Design**

C1

The rationale for the cash benefit alternative being set at 60% of cost of formal services requires further elaboration and clarification. While it is based on the principle of a partnership between the State and families, there is a danger that this fails to give due recognition to the contribution of family carers. A key issue for family carers is that frequently the formal services are simply not available when required and the "cost" has then to be borne by the family.

C2 –C7

We would favour a home subvention approach, (which would be in keeping with government policy to maintain people in their homes for as long as possible). However, we feel that it is very important to recognise a person's right to choice and also to take into account that the level of dependency will sometimes mean that

home care is not a realistic alternative. Where possible the funding of long-term care should favour home subvention care where adequate supports and services for carer and cared-for-person are put in place and where this option is acceptable to both carer and care recipient. The scale of home subvention should relate to the needs of both care recipient and carer.

#### C8-C10

Vouchers are good in principle in that they allow flexibility and choice around services. Ireland can benefit from the experience of other countries which use vouchers to purchase services and research should be carried out to examine the experience from other countries and relate this to the Irish situation. The provision of a list of care providers would be based on the assumption that there is potential for consumer choice. The reality, however, is that people frequently have to take whatever is available and have little choice in the matter.

In practice, voluntary organisations already provide many community-based services and it is reasonable to assume that such provision would continue and expand as greater resources become available. The contribution of private providers would depend very much on the attractiveness of the funding available and the purchasing power of consumers.

Both voluntary/statutory and public/private partnerships have potentially much to offer in the delivery of community-based services. This potential should be explored and developed and an appropriate infrastructure put in place, as there is no guarantee that it would happen without some form of incentive.

#### C11

The reality is that, in some instances, the 60% may be adequate and in others this will not be the case. Families caring for dependent relatives sometimes incur additional costs in relation to, for example, special dietary requirements, heating, special aids and adaptations and provision needs to be made accordingly.

#### C12

Confining contributions to direct payroll taxation does narrow the funding base and while we would support the proposal for all workers to pay more to fund a new care package it is also important that taxation is fairly levied. The levying of social insurance contributions on investment income (as is the practice in some countries), should also be considered.

#### C13

The care provider and the care recipient should be fully involved in decisions as to the level of need and the type of care package required. Where there is a main care provider, s/he should have a significant role in the assessment process.

#### C14

The benefit design should take full account of the fact that people with disabilities may wish to take up employment and should be designed with a level of flexibility to encourage and support this, e.g., provision for transport to and from workplace and work integration programmes.

#### C15-C19: *Carers Allowance and Related Payments*

We support the general principle of introducing a Long-term Care Benefit (cash payment for care at home), based on the degree of care required. However, we feel that the Long-term Care benefit must include a direct payment to carers for their caring work in the home.

The introduction of the Long-term Care Benefit should be based on an assessment of need as outlined and should be developed as a new support package for care in the home. The situation of people currently receiving payments, e.g., Carer's Allowance, and Domiciliary Care Allowance, should be looked at as a separate issue taking into account the need for carers to be allocated some part of the benefit payment.

It is crucial that carers, particularly those providing full-time care, receive an ongoing payment similar to the Carers Allowance or Benefit.

C20

On the question of to whom should the home care benefit be paid where there is a high level of dependency, we feel this should be worked out during the needs assessment process and in consultation with the carer and care recipient but that there should be provision for the carer to receive the benefit directly in some instances.

The question of what arrangements should be put in place to cater for people who are unable to look after their own affairs so as to ensure that their rights are fully protected needs to be considered fully.<sup>2</sup>

### **Consultation Document / Part D: Housing with on-site Care Facilities**

D1-D2

We agree with the principle that the full residential care subvention should be payable to people assessed as in need of care who are living in sheltered housing facilities which provide on-site care. However other aspects of community support would need to be taken into account, such as the availability of a high level of home-based care, support and surveillance, including nursing care. Local factors and availability must be taken into account in carrying out individual assessments in respect of sheltered housing facilities.

The rate of payment should be sufficient so that people are facilitated to live in the community for the maximum possible time.

D3-D5

We would agree broadly with the idea of a minimum proportion of "assisted-living" housing being made a condition of planning permission in large residential developments because of the scarcity of such accommodation in Ireland. It would be necessary to ensure that the appropriate support infrastructure was in place at local level. For example, the fact that the provision for social housing (under Part V of the Planning and Development Act 2000) has proved difficult to implement in line with its original purpose would indicate a need for a fuller consideration of the question.

The State should subsidise the cost of on-site care services, which would then be available to individuals on the basis of assessed need.

### **Consultation Document / Part E: Role of the Family and the State**

E1-E3

Currently, the main responsibility for care often falls on the family, especially individual carers, without adequate supports from the State, e.g. respite care inside and outside the home, home help services and income support. There is a need for a more proactive policy and related National Carers Strategy to more fully integrate

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<sup>2</sup> See Law Reform Commission Paper on *Law and the Elderly*

the respective roles of the family and the State. Since the social and economic value that family carers bring to society cannot be easily substituted by the State, it is of crucial importance that economic and social policy supports the family. The availability of family carers in the future cannot be taken for granted but will largely depend on how we support our carers as a nation. The different needs of full-time and part-time carers and carers who work outside the home need to be identified and addressed.

The State should, as a first principle, support family carers and help to maintain people in their homes where this is the preferred choice. People who care in the home, whether on a full-time or part-time basis make a vital contribution economically and socially.

We believe that the cost of long-term care should be shared between the care recipient and the State and that full-time carers should not be expected to bear any of the cost. In some instances there will of course be a financial cost for carers in relation to income foregone through not participating in the labour force.

### **Consultation Document /Part F: Private Financing Options**

F1-F11

We believe that private financing options, while attractive to some categories of people, are not a realistic option for comprehensive provision of long-term care in the Irish context. We see only a marginal role for personal savings and private insurance policies. While more people will have private pensions and private insurance and while the State should continue to provide incentives in this regard, these are unlikely to be sufficient to cover the costs of ongoing long-term care.

Employers could be encouraged to make long-term care insurance available to their employees (similar to PRSAs) but to date this has not happened and we do not believe that it should be a mandatory provision.

We would encourage the concept of equity release in respect of the family home where people (including resident carers) see this as a reasonable option. Consideration should be given to providing State incentives to trigger equity release at an earlier age than that normally available from financial institutions at present. We feel that equity release schemes should be much more strictly regulated and monitored than is the case at present.

The possibility of clawback should be included in the means-test in respect of residential care. The state subsidy should not be subjected to such a clawback generally when the long-term care has been provided in the home and, particularly, where there is a full-time carer.

As already stated, we feel that contributions from family members are a matter of choice and that, specifically, full-time carers should not be expected to contribute.

We agree that options in these areas should be developed further but in the context of a universal system (paid for through a Social Insurance increase) with “front-end cover” for residential care.

F12

We believe that, since private insurance will have only a marginal impact in improving the way long-term care is funded in Ireland, the most favourable tax treatment possible should be afforded to funds ear-marked for long-term care.

## **Consultation Document Part G: Public Financing Options**

G1—G7

Our view is that state support for care needs should be universal and based on the premise of providing a care package to meet the needs of individuals.

We agree with the proposal that long-term care services should be funded by Social Insurance. We would, however, point out that general taxation must continue to play a significant role in health and service provision for people requiring long-term care and that the levying of social insurance contributions on investment income (as is the practice in some countries) should also be considered.

We do not have a definite view on what people would consider reasonable to pay per week.

The question of provision for people who do not qualify under the PRSI system requires careful consideration. We would make seven observations, which we feel to be central to the matter:

- (i) The Benefit scheme for people who would not qualify under the Social Insurance system must be established in such a manner as to ensure that people have an entitlement as of right and that there is not a two-tier system of access to benefit.
- (ii) There should be an exception made for low paid workers similar to the current PRSI exemption on low earnings.
- (iii) There should be an additional PRSI Tax Credit introduced.
- (iv) Consideration should be given to levying social insurance contributions on investment income (over a limit to be determined) as well as on earnings.
- (v) There should be a high degree of flexibility in the contributory conditions for entitlement to benefit to cater for people moving in and out of the labour force.
- (vi) Additional consideration needs to be given to the situation of homemakers.

## **Consultation Document / Part H: The PRSI Option**

H1-H6

The PRSI option should operate on the basis of people contributing during their working lives, as with all PRSI contributions. However, further consideration needs to be given to the question of investment income.

The economic implications of an increase in PRSI is obviously an issue which would require thorough consideration and analysis by economic and financial investment experts.

We believe that increases in PRSI contributions should result in a direct benefit in respect of long-term care with appropriate and equitable provision being made for those who do not qualify under the PRSI system.

H7– H10

The benefit system should operate on the basis of universal access for all.

H11

We are of the view that the PRSI option should be developed further. We suggest that the following factors should inform the process:

- (i) a critical assessment of how access to Benefit can be guaranteed for those who are unable to meet the social insurance criteria, including, in particular, people with disabilities who cannot participate in the labour force;
- (ii) developing a continuum of service provision and supporting and building on the contribution of family carers;
- (iii) examining how full-time carers (some who may have no PRSI contributions) can be catered for under this model.

## **Consultation Document / Part I: Partnership Options**

*I1*

While we would recommend a strong bias towards care in the community, we would also point to the importance of choice for both carers and care recipients. In some instances, for a variety of reasons, people may need to move to residential care. We would also emphasise the need to take fully into account the wide range of environmental and social factors that impact on a person's independence and how these can be enhanced.

*I2- I7*

We support the view that home-based care should be universally and fully available according to assessed need and that residential care should be based on the proposed "front end" cover system, i.e. universal entitlement initially. The " front end" cover for residential care (first year covered and means-test applied subsequently) would give the family and the cared for person time to consider the situation and explore options. This system seeks to achieve a balance between statutory entitlement and personal responsibility which, while difficult to achieve, is presumably required in order to provide equity in the system.

*I8 - I9*

The PRSI funding option should be pursued further and a comprehensive actuarial assessment carried out.

*I10*

The provision of a universal system of long-term care to cater for all persons who need care, irrespective of age will require the active participation and endorsement of all the social partners.

## **Consultation Document Part J: Implementation Issues**

*J1 – J3*

The protocols and mechanisms for assessing need must be accompanied by a continuum of service provision in the community. The question of who will have

access to the new Benefit System must be answered with absolute clarity prior to its commencement as will the question of entitlement to Benefit for those who do not meet whatever PRSI criteria are put in place.

#### J4-J5

It is reasonable to assume that additional service provision by both the private and voluntary sectors will emerge as a result of the increased availability of funds. However, this cannot be taken for granted and will need to be monitored closely by the State so that there is not a mismatch between policy and the actual situation on the ground, e.g. the availability of community physiotherapists and occupational therapists.

#### J6

The question of increasing the supply of assisted-living facilities should be addressed in the context of overall housing policy and housing needs assessment.

#### J7

A national information campaign on long-term care would, we feel, be useful only if clear policies in relation to funding and provision have emerged.

#### J9 - J13

We consider that the concept of a Long-term Care Authority should be explored further. However, a number of key questions need to be addressed, e.g.,

- Who would the Authority report to?
- Who would be its members?
- How would it be constituted?
- How would such an Authority relate to the new Health Services delivery structures?
- What would be the relationship between the Authority and the proposed National Needs Assessment Expert Committee?
- How would the Authority relate to the structures that will emerge from the enactment of the proposed disability legislation?
- How can duplication of roles be avoided.

The role of housing policy in developing long-term care strategies would need to be acknowledged in the establishment and functions of such an Authority.

### **Consultation Document/Part K: Pre-Funding**

#### K1 – K4

The questions here are, we feel, essentially actuarial ones which require expert consideration and analysis. We would emphasise that any new system put in place must be robust in its costing and ring fenced and, in that sense, pre-funding would seem to be essential.