

## **Improving Home Care Services in Ireland: Have Your Say** *A Submission by the Citizens Information Board*

The Citizens Information Board (CIB) is a statutory body under the aegis of the Department of Employment Affairs and Social Protection with responsibility for the delivery of information, advice and advocacy services to the public and with a specific remit in respect of people with disabilities. The CIB funds and supports Citizens Information Services (CISs), the Citizens Information Phone Service (CIPS) and the National Advocacy Service for People with Disabilities (NAS). The Board also runs the Assist Ireland website and helpline which provides information on assistive technology (aids and appliances) for older people and people with disabilities.

This submission draws on feedback and case evidence from CISs, CIPS and NAS and details some of the challenges reported by people with disabilities and older people in getting the supports they need to live at home or to move into supported housing or a nursing home.

CISs dealt with over one million queries from citizens in 2016 and CIPS had 139,000 phone calls from the public. Some 8% of these queries referred to health service matters with a proportion relating to difficulties in accessing appropriate home care supports in a timely manner.

Some of the queries from the public refer to the struggles older people encounter when they are transitioning from hospital to home and highlight the fact that the absence of appropriate supports in the community sometimes result in people having to go to nursing homes or other residential care facilities.

### **General Questions**

#### **1. In your opinion, what are the good things about home care services in Ireland?**

There are many positive aspects of Home Care Packages (HCP):

- Enabling older people with care needs to remain living at home, where that is their preferred option
- Enabling families to continue caring for their relatives with a disability who have complex care and support needs
- Giving care recipients and their families a greater say regarding the source and types of care services used
- Providing a more cost effective response relative to the cost of nursing home or extended hospital care (except in the case of those with the highest levels of dependency requiring extensive nursing or medical care)
- Reducing the number of delayed hospital discharges
- Reducing pressure on existing, often over-stretched, HSE services, such as public health nursing and home help services
- Flexibility in the way services are provided
- Stimulating employment creation in the area of social care services

Those who succeed in getting a HCP are usually satisfied, even where the allocation of support hours falls short of what they feel they actually need.

In looking at the role of HCPs, it should be noted that in many instances the alternatives would be either increased pressure on carers and/or the person with care needs having to move into a long-term care residential setting which would often be much more expensive.

**2. Do you think that home care services work well alongside primary care and other community services to meet the needs of people who receive home care?**

Yes \_\_\_\_\_ **No\_✓** Don't know \_\_\_\_\_

The Home Care Package scheme, as it currently operates, is not established in law which means the individual has no automatic right to avail of services under the scheme. Each HSE Area has responsibility for the operation of the scheme within the resources allocated for it in that area. This means that the level of service or support a person receives may vary considerably in different parts of the country.

An important component in home care is the suitability or otherwise of a person's accommodation. In this regard, the Housing Adaptation Grant for People with a Disability and the Mobility Aids Grant Scheme provide funding through the local authorities for

adaptations to the person's home to make it accessible and safe for them. The grants are means-tested and funded from each local authority budget which means that funding can run out so a person may have to wait until the local authority's budget is allocated for the next year to access the grant. This also means that coverage differs from area to area, with some areas running out of funding earlier than others.

No work can begin on adapting the house until the application has been completed and approved as grants are not paid retrospectively. An Occupational Therapist's assessment is required to complete the application process. There are currently long waiting lists for occupational therapy services in Ireland which can lead to long delays in applications and getting the work done.

*"An elderly woman looking for a housing adaptation grant, Occupational therapist report required, HSE waiting list for OT assessment long, delaying application, impact on patient dignity"*

The Housing Adaptation Grant in its current incarnation is only really useful if the person has a slow onset of a difficulty and can wait for the funding for these grants to come through. Due to the slow administration of the grant and limited funding it is not really suitable when there is a sudden change in a person's mobility or ability that requires immediate changes to their home.

#### *Accessible Transport*

In order for a person with a disability to live comfortably at home, they need to have access to accessible public transport to attend hospital appointments, maintain social relationships and for general leisure needs. The CIB report *'Getting There – Transport and Access to Social Services'*<sup>1</sup> highlighted the fact that many people encounter difficulties in accessing social and health services because of the poor availability of public transport and the continuing inaccessibility of such transport. It also links these issues to their effects on social isolation of older people in rural areas. Currently many older people, especially those living in rural areas hold a free travel pass but do not have access to any suitable public transport in their area. Often the only alternative is a taxi service which can be expensive for someone living on the State pension. This lack of accessible and affordable transportation may lead to further social isolation, worsening health conditions if they cannot get to hospital appointments and in some cases result in people having to move into nursing home care.

*"This client is living in a rural area. Since the rural transport scheme was cancelled she is finding it difficult to cover transport costs for her husband to his various appointments and to the Alzheimer Day Care centre. Client rang HSE and told funding for transport is only for those who are in wheelchairs. Client feels there is very little support and that she may have no alternative but to place her husband in a home."*

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<sup>1</sup> [http://www.citizensinformationboard.ie/downloads/social\\_policy/Getting\\_There\\_Report\\_2010.pdf](http://www.citizensinformationboard.ie/downloads/social_policy/Getting_There_Report_2010.pdf)

**3. Do you think that home care services work well alongside hospitals to meet the needs of people who receive home care?**

Yes \_\_\_\_\_ **No**✓\_\_\_ Don't know \_\_\_\_\_

The linkages between hospitals and community health services are underdeveloped. This results in people being discharged from hospital without adequate supports having been put in place for them in the community, which in turn can lead to readmission.

*“Elderly patient, suffered a stroke two weeks ago, is to be discharged from hospital and sent home without any provision for follow-up care.”*

Delays in getting adaptations and specialised equipment for people moving out of hospital mean that they may have to stay in hospital longer or move to a nursing home until their home has been adapted to suit their requirements.

**4. Do you think that home care services work well alongside informal carers to meet the needs of people who receive home care?**

Yes \_\_\_\_\_ **No**✓\_\_\_\_\_ Don't know \_\_\_\_\_

Many family carers report feeling inadequately supported by the State in respect of home support services and, as a result, overwhelmed by the caring role.

*“No HSE home help hours provided on weekend evenings even though the person has full care needs at all rising/bedtimes. Her husband who is her full-time carer has a heart condition and is the only other person in the house. The prospect of long-term care looms large and would not yet be necessary with the proper support”*

**If you have any comments in relation to how well home care services work with other providers of care, please include them below:**

Clearly home care supports such as home help, meals services and public health nurse services can enable many people with complex needs to live at home with family support. However, the absence of legislative entitlement and inadequate resources sometimes result in carers feeling overwhelmed by their caring role. The non-availability of or reduction in frontline services in certain cases mean that families can no longer cope and, as a result, the person requiring care may no longer be able to remain in their home.

**5. Do you think that people who receive home care should have more of a say in the range of services that are provided to them?**

Yes ✓\_\_\_\_\_ No\_\_\_\_\_ Don't know \_\_\_\_\_

Internationally, consultation is a core feature in regulated home care and is achieved through care recipients and other stakeholders having a voice in the way services are

delivered. Consumer Directed Care (CDC) is a model of service delivery designed to give more choice and flexibility to consumers. Consumer-directed services are aimed at empowering clients and family carers, giving them major control over the what, who and when of needed care.

Care recipient's own needs assessment and care planning are based on having a basket of services from which individuals can select services to meet their needs rather than a one size fits all approach. User choice as an ideal is implemented through choice of services, choice of funding approach (personal budget or service provision) and choice of provider. Choice of provider is facilitated through access to publicly available quality reports.

Typically, consumers are allowed and supported to hire, train, supervise and even fire the home care worker, and are given cash payments enabling them to purchase the services they want.

A HSE pilot initiative on consumer Directed Care set up in 2016 needs to be implemented more broadly taking on board the outcomes of the pilot.

**6. Do you think that people who receive home care should have a choice in who provides their care?**

Yes ✓  No  Don't know

**If you have any comments in relation to choice of home care services and providers, please include them below:**

Related to choice of home care services and providers and a consumer-directed approach is the concept of individualised funding and direct payments which is currently under consideration by Government. A personalised budget can be administered as a direct payment or through a broker and allow the individual to purchase the desired health and social care supports and services directly. Brokerage services allow the person to have choice and control over how the budget is spent while providing support to manage the budget and source supports and services.

The implementation of a personalised budgets approach would be important in the context of implementing a statutory home care scheme in that it would serve to promote personal responsibility, independence, capability and resilience through the delivery of cost effective and innovative services chosen by the service user. Personal budgets mean that "money follows the person's needs" and allows an individual to decide what services and supports they receive, and who provides those services and supports. In doing so, personalised budgets can empower people with disabilities and their families and give them greater flexibility, choice and control.

**7. In your opinion, how could home care services in Ireland be improved?**

- 1) New legislation needs to be introduced to give people statutory entitlement to home care in accordance with assessed needs;
- 2) There should be a fully transparent national set of eligibility criteria for Home Care Packages;
- 3) In the short to medium term, additional resources for home care need to be increased significantly to cater for current demand.
- 4) In the longer-term, a funding system needs to be put in place which ring-fences the home care budget;
- 5) A regulatory framework should be put in place which includes appropriate standards in respect of home care provision provided by the public, private and NGO sectors;
- 6) Provisions for individual integrated needs assessment need to be standardised and based on key factors,
  - A case management approach
  - Consumer-directed care and support
  - A multi-disciplinary approach
  - Integrated with other supports, e.g., sheltered housing
  - Supporting family carers
- 7) Innovative models of delivery based on best practice internationally and the learning from Irish-based initiatives (e.g. Genio Dementia Projects<sup>2</sup> and the HSE Integrated Programme for Older Persons) need to be further developed and expanded;
- 8) The rollout of the Single Assessment Tool (SAT) must be made an organisational priority within the HSE;
- 9) There needs to be more planning in respect of home care provision for an ageing population, with particular reference to the projected increases in the number of

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<sup>2</sup> Evaluation of the Genio Dementia Programme

<https://www.genio.ie/multimedia/publications/evaluation-of-the-genio-dementia-programme-%E2%80%93-year-one>

<https://www.genio.ie/multimedia/publications/research-reports/genio-dementia-programme-evaluation-of-year-2>

people with dementia;

10) The discrepancy in the Irish health care system between the way care for people with acute illnesses and those with a slow debilitating illness (such as dementia) is funded needs to be addressed by Government and by society generally;

11) There is a need to proactively plan for the financing of long-term care of an older population who are living longer and to make decisions about how this is to be funded.

## **Questions on Information in relation to Home Care Services**

**8. If you, a relative or friend needed home care services, who would you ask for information first?**

**If you have any comments on this issue, please include them below:**

While there may be reference in a general way by the HSE and in other information publications as to what home care services are available, individuals may not be able to get the service they require in a timely or appropriate manner due to under-availability at a given point in time. Citizens Information Services and the Citizens Information Phone Service provide face-to-face and telephone information to members of the public and provide advice/assistance and advocacy support as required to people who require help in accessing a home care service or a Housing Adaptation Grant. However, gaps in availability sometimes mean the information and help provided by a CIS is not of any use to an individual. It is also the case that not all people may be aware of the availability of these services or be able to access them because of geographical factors or mobility or cognitive impairment.

The CIB also manages the [www.citizensinformation.ie](http://www.citizensinformation.ie) website which provides comprehensive information on health and social care matters including home care services. Again, however, there are people who may not be able to avail of web-based information because of cognitive impairment, lack of computer literacy or access to the Internet.

**9. Are you aware that tax relief is available to people that pay for home care services?**

Yes ✓  No

**If you have any comments on this issue, please include them below:**

While this information would be typically provided to clients by CISs and CIPS, the reality is that many people requiring care and support do not have an income tax liability and, therefore, this provision is of no benefit to them.

## Question on Standardisation

**10. Do you think that the same approaches should apply across the country in relation to the following?**

- How you apply for services **Yes**✓ \_\_\_ No \_\_\_ Don't know \_\_\_
- How your need for services is assessed **Yes** ✓ \_\_\_ No \_\_\_ Don't know \_\_\_
- Who can access services **Yes**✓ \_\_\_ No \_\_\_ Don't know \_\_\_
- What home care services are provided **Yes**✓ \_\_\_ No \_\_\_ Don't know \_\_\_
- How home care services are provided **Yes** ✓ \_\_\_ No \_\_\_ Don't know \_\_\_
- How home care services are monitored **Yes**✓ \_\_\_ No \_\_\_ Don't know \_\_\_
- How you can appeal a decision about your home care **Yes** ✓ \_\_\_ No \_\_\_ Don't know \_\_\_

**If you have any comments on this issue, please include them below:**

An objective, independent, comprehensive, consistent, integrated and nationally standardised needs assessment process is required to determine the nature and scale of support and care required by each individual. Such a needs assessment is essential in order to help determine an individual's eligibility for or entitlement to benefits or services on the basis of agreed and transparent criteria. Such criteria should include the following essential components:

- Providing for choice of provider where the services required have to be purchased from private providers to enable people to choose those that best suit their preferences
- The level of dependency and/or needs of individuals in respect of health, housing, social care and transport needs
- Establishing the will and preferences of individuals as to how the care and support they require should be provided
- Using a multi-disciplinary approach to assess needs and design appropriate responses
- Identification of the role of different State agencies in meeting identified needs relating to accommodation, home care supports and nursing requirements
- Establishing in a realistic and transparent manner the respective potential contribution of family members, community/neighbourhood networks and



voluntary/community organisations

- A realistic assessment of the support needs of carers – physical, social and psychological

## Question on Quality Standards

**11. Do you think that the same national quality standards should apply to all (public, private and not-for-profit voluntary) providers of home care?**

Yes ✓ \_\_\_\_\_ No \_\_\_\_\_ Don't know \_\_\_\_\_

**If you have any comments on this issue, please include them below:**

The regulation of home care and the implementation of standards is an important area and one that has received some attention in Ireland in recent years.

There continues to be an absence of a regulatory structure for the delivery of professional care in the home – this issue was addressed comprehensively in a 2011 Law Reform Commission report.<sup>3</sup> The Commission noted that debate in this area has, in general, focused on whether the State is in a position from a financial perspective to extend the statutory regulatory role of HIQA under the 2007 Act and the extent to which the detailed standards and requirements of such a statutory regime could be met by all home care providers.

The LRC 2011 report called for action on a number of fronts to ensure that home care packages were delivered in a transparent manner and to the highest quality standards and set out a number of important recommendations in this regard.

The HIQA National Standards for Safer Better Healthcare provide a useful starting point for the development of home care standards as does the practice in other jurisdictions. For example, the Australian Government Department of Health has recently published a Draft Aged Care Quality Standards Consultation Paper<sup>4</sup> which is aimed at ensuring that Government funded aged care is safe and of a consistent quality.

## Question on Training for Care Workers

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<sup>3</sup> Law Reform Commission (2011), <http://www.lawreform.ie/fileupload/Reports/r105.htm>

<sup>4</sup> [https://consultations.health.gov.au/aged-care-access-and-quality-acag/single-quality-framework-draft-standards/supporting\\_documents/Single%20Aged%20Care%20Quality%20Framework%20%20Draft%20Quality%20Standards%20Consultation%20Paper.pdf](https://consultations.health.gov.au/aged-care-access-and-quality-acag/single-quality-framework-draft-standards/supporting_documents/Single%20Aged%20Care%20Quality%20Framework%20%20Draft%20Quality%20Standards%20Consultation%20Paper.pdf)

**12. Do you think that formal home care workers should have to complete a minimum level of training that would be set by the Government?**

Yes ✓ \_\_\_\_\_ No \_\_\_\_\_ Don't know \_\_\_\_\_

**If you have any comments on this issue, please include them below:**

Minimum training levels are absolutely essential in order to help ensure quality home care services. In this regard, existing accredited courses need to be proactively promoted as a necessary requirement for home care work. In the longer-term, all providers of home care should be required to demonstrate that their staff have the appropriate qualifications.

**Questions on Funding**

**13. Taking account of limited State resources, do you think that people who receive home care services should make a financial contribution to the cost, based on their ability to pay?**

Yes ✓ \_\_\_\_\_ No \_\_\_\_\_ Don't know \_\_\_\_\_

**If you have any comments on this issue, please include them below:**

- 1) There should be a shared funding approach between the individual and the State;
- 2) There should be equality of access to funding for home care and for nursing home care with some inbuilt bias towards the former;
- 3) State funding for long-term care should be on the same basis as State funding for acute hospital care – this is clearly not the case at present;
- 4) No individual or family should be forced to live at subsistence level – this is currently the case under the Nursing Home Support Scheme (NHSS) in relation to some people, for example, those whose only income is the Old Age Non-contributory Pension;
- 5) The funding model used for the NHSS where fees are negotiated between the National Treatment Purchase and service providers has fundamental shortcomings which renders it unsuitable for a statutory home care scheme;
- 6) Since in many instances people availing of the Home Care Scheme will continue to live in their own homes, any lien on the family home would almost certainly be inappropriate.

**14. If the State could only provide a certain amount of home care services based on health need, would you be prepared to purchase additional hours with your own money, if you needed them?**

**N/A**

### **Other issues**

**15. If there are any other comments that you would like to make, please include them below.**

There are a number of general factors relevant to home care which need to be considered fully in developing a statutory home care scheme:

- Integrated needs assessment
- Supporting family carers
- A Case Management approach
- Consumer Directed Care
- Provision for end-of-life care
- Integration with assisted living housing/housing with care

While virtually all health policy documents assert the desirability of promoting community care over residential care, in practice, this has not happened. Addressing this gap and the related budgetary implications is at the core of effective home care provision. It is generally acknowledged that there are gaps, mostly due to budget constraints and staff shortages, in the availability of many services, including public health nursing, occupational therapy, physiotherapy and chiropody, day care and specialist services (e.g., dementia services and night sitting services). Legislation for home care will only be effective to the extent that the provision of adequate funding for home care becomes a priority for society and for Government.