

A National Advocacy Service for Older People in Residential Care Facilities

A Proposal from the National Forum for Older People to the Health Services Executive (HSE)

December 2007

Introduction

The National Forum for Older People is a consultative body which was formed under the auspices of HSE's Office of Consumer Affairs in January 2007. It comprises over 30 statutory and voluntary bodies with a special interest and expertise in services for older people. Membership of the Forum is listed in Appendix One.

The Forum was set up in recognition of the fact that services for older people in Ireland across different settings – residential, hospital, hospice, and community - sometimes falls short of what is acceptable or desirable. These realities were dramatically illustrated and documented in the Leas Cross Review¹ and this provided the immediate stimulus for setting up the Forum.

The Forum has two objectives:

- To enable older people and their families to be active consumers of health services.
- To offer consumer-based advice and comment on older people's health services to bodies such as the HSE, HIQA, Department of Health & Children, etc.

In early 2007, the National Forum for Older People decided that a national advocacy service for older people in residential settings was a key requirement to enable older people and their families to become active consumers of health services. In light of this, a Working Group was appointed to draw up a framework for the development of a national advocacy service. Membership of the Working Group is listed in Appendix Two. This document is the outcome of the Working Group's deliberations throughout 2007. The document is evidence-based, and has drawn upon a review of different types of advocacy services² as well the invaluable experience and expertise of advocacy in the disability and mental health sectors in Ireland.

This document was fully endorsed by all members of the National Forum for Older People on 11 December 2007. The Forum is of the view that the time is now right to develop an advocacy service for older people in

¹ Available at <http://www.hse.ie/text/en/Publications/HSEPublications/LeasCrossReport/>

² A background paper was prepared for the Forum in January 2007 by Dr. Kieran McKeown entitled: 'Options for Developing an Independent Advocacy Service for Older People Living in Residential Care Facilities'.

residential settings because it is essential to the development of patient-centred care and is underpinned by the Draft Residential Care Standards. At the same time, the Forum also recognises that there is an additional need to develop advocacy services for older people at all levels of the health and social services system.

The National Forum on Older People endorses the view that the preferred model for a national advocacy service should comprise a National Advocacy Manager who reports to a National Steering Committee. In each of the four HSE areas, the national advocacy service will require a Development Officer and a Volunteer Coordinator supported by a team of volunteers who will be deployed in residential facilities for older people. The advocacy service in each of the Residential Care Facilities will be overseen by a Local Management Committee. The approximate start-up cost of the national advocacy service, as described in this document, is approximately €0.500m, based on current 2007 estimates.

Policy context

It is now recognised that older people who are in receipt of health and social care services in residential units are vulnerable, not only because of their needs, but also because the system of services in Ireland is not yet fully supported by an agreed and enforced set of standards. In addition, it is also recognised that caring for older people who are in receipt of services sometimes falls short of what is acceptable or desirable. Family members may also require support and advice from advocates in the context of care of their loved ones. These realities were dramatically illustrated and documented in the Leas Cross Review.

There now exists a consensus at all levels of the public service that the existing situation must change. In June 2006, the Social Partnership Agreement “Towards 2016” was published, stating that services for older people should be “joined-up, user-friendly, and customer-focused” while, for those who cannot live at home, “quality residential care should be available”. Consistent with the emphasis on quality, in December 2006 the Minister for Health & Children published the Health Bill 2006 which provides for the establishment of the Health Information and Quality Authority (HIQA) and the Office of the Chief Inspector of Social Services. These bodies will set and enforce ‘standards on safety and quality’ in centres providing residential services, including nursing homes. Currently a draft set of standards has been produced and has now gone for consultation before it will be accepted and become operational. It is hoped that this process will be concluded by the end of 2007.

Defining advocacy

It is now accepted that advocacy has an important role to play in supporting services to meet the needs of individual clients, particularly clients who are vulnerable. In recent years, there has been a growth in advocacy services, and some of these have been placed on a statutory footing. The Comhairle Act, 2000

authorised Comhairle to provide information, advice and advocacy to the public on social services and defined advocacy as representing the interests of a person seeking a social service and assisting in securing their entitlements, but not involving legal representation.

The Disability Act, 2005 provides an entitlement to advocacy for persons with a disability while the Citizens Information Act 2007 authorises Comhairle - now renamed the Citizens Information Board (CIB) - to provide this service through its Personal Advocacy Service.

Older people do not have a statutory entitlement to advocacy services although it is increasingly recognised that many vulnerable groups, including older people and their families need an advocacy service. The CIB has become a significant national resource in terms of resourcing advocacy services and, by the end of 2007, will be funding forty eight advocacy projects in the area of disability. It has published guidelines on setting up an advocacy service and also publishes a regular newsletter on projects and research relating to advocacy in Ireland and further afield. Its definition of a professional advocacy service offers a useful guide for setting up an independent advocacy service for older people in residential care facilities: “Delivering a professional advocacy service means providing a trained person who, on the basis of an understanding of a client’s needs and wishes, will advise and support that client to make a decision or claim an entitlement and who will, if appropriate, go on to negotiate or make a case for him / her”.

These developments illustrate why it is timely for service providers and organisations representing the interests of older people to consider how an independent advocacy service for older people in residential care facilities could play a role in improving the quality of these services. As the service develops and displays its value, it will be a matter for each HSE Local Health Office area supported by the Area Development Officer and Coordinator to develop an advocacy service for its catchment area, based on the national framework outlined in this document.

Current position in Ireland

The availability of an independent advocacy service to support individuals in a residential unit, who cannot advocate for themselves, is limited within current services and needs to be developed. There are a number of models for this type of advocacy, predominately in the mental health and disability sectors. However there are some examples in the older persons sector delivered in conjunction with organisations like the Alzheimer’s Society, Age Action Ireland, Cork Older Persons’ Advocacy Service (COPAS), The Carers Association and The Senior Helpline, amongst others.

The Government's health strategy, Quality and Fairness (*action 52*), outlines the need to include the voice of the consumer in the planning and delivery of services. A number of public and private nursing homes have established, or are in the process of establishing, patients' committees in residential facilities. Many of these have independent chairs and include family members to advocate on behalf of older people who cannot advocate for themselves.

Mechanisms whereby older people have an input into the ongoing monitoring of standards in residential care, by way of representation on inspection committees, are common practice in other countries. This concept should be developed in partnership with HIQA. It would be important that HIQA has a recognised advocate on all Inspection Committees.

Developing a national advocacy framework

It is envisaged that guidelines for the development of advocacy services specific to older people will be developed in partnership with the Citizens Information Board and other non-governmental agencies. These will include guiding principles and operating procedures/protocols for the delivery of advocacy services specific to older people. These guidelines/protocols will assist in the definition of the minimum quality of service by which projects will be measured.

Given the strength of the voluntary sector in older people's services, and the depth of life skills and experiences available, it is proposed that the development of a professional advocacy service, supported by a trained volunteer service, should be the primary model. It is essential that the wealth of experience and expertise currently available be utilised and further developed as part of this process. However other models to support specific needs can also be developed where appropriate.

The management of the advocacy service will rest within the HSE's Office of Consumer Affairs but the Development Officers and Volunteer Co-ordinators should come from voluntary / non-governmental sector in order to promote its independence.

A National Steering Committee will include representatives from the statutory sector who will assist in the promotion of the advocacy concept through the sector and also assist in resolving any difficulties that might arise. The Working Group will form the National Steering Committee. Local management committees will also be set up to support the local advocacy services and their composition is suggested later in this document. These committees may oversee the service in more than one residential facility within a city, town or county.

The recruitment, training and supervision issues arising as part of an advocacy service will be a matter for a committee in the individual home/area.

Funding for this project will be supported by a partnership arrangement with voluntary and statutory agencies. Once funding is made available, the next step will be to seek submissions from non-governmental agencies to provide advocacy services as outlined within the four HSE administrative areas. These organisations will have to demonstrate their previous experience in this area and their ability to deliver services. They will also need to demonstrate good governance arrangements within their organisation and have a proven track record in the field of services to the older person. The proposed structure is outlined below and further discussion will be required with the relevant bodies as to how this might be progressed. Arrangements for external evaluation will also need to be put in place once the service commences.

Proposed structure

Drawing on the experience of developing advocacy in the disability sector, it is proposed to put in place a clearly defined structure as opposed to the development of *ad hoc* 'pilot' projects developed in an opportunistic way. This structure would aim to provide an equitable rate of development across the country. Following the appointment of a National Advocacy Manager, each administrative area of the HSE will appoint a Development Officer and Volunteer Coordinator from outside the HSE. As a consequence of ongoing evaluation of this structure in the four administrative areas, and building on successful outcomes, it is hoped to develop this service even further.

National Steering Committee

The advocacy service should rest under the remit of HSE's Office of Consumer Affairs with close liaison with older person's services, elder abuse officers, and consumer affairs general managers. A National Steering Committee will be established for the service and chaired by the Head of the Office of Consumer Affairs. The National Steering Committee will comprise of representatives from HSE, relevant statutory agencies, and representatives from appropriate voluntary and non-governmental agencies and the National Advocacy Manager.

Responsibilities of the National Steering Committee

1. Oversee the overall development and roll out of the service nationally.
2. Recruit the National Advocacy Manager.
3. Oversee recruitment of Development Officers and Coordinators.
4. Receive regular updates from the National Advocacy Manager

5. Oversee the allocation of funding to each local health office area following consideration of business cases submitted
6. Ensure that policies and procedures are developed in each local health office area including health and safety statement and confidentiality statement
7. Ensure that policies and procedures are consistent with national policies, procedures and standards

Key elements of the national advocacy service

In this section, we provide a more detailed description of the key elements required for developing an advocacy service including, principles, roles, responsibilities and governance arrangements. The purpose of the advocacy service is to empower older people and to protect their rights by supporting them to assert their views regarding health and social care needs and, where necessary, represent and negotiate on their behalf with service providers and any other relevant interests.

The service will be located in long-stay/continuing care residential facilities initially, with a view to developing a similar service for older people in acute hospitals in the future. The model of advocacy to be developed should include:

- The development of a professional advocacy service that comprises a person to head-up and manage the service and subsequently recruit Development Officers and Volunteer Coordinators.
- The development of a volunteer advocate programme, which will include older people advocating on behalf of other older people.
- The local volunteer advocate should on the basis of an understanding of a client's needs and wishes, support the client to make decisions, or negotiate or make a case for that person on any aspect of their health or social care. Where it is not possible for the advocate to establish the client's needs and wishes through communication with the client, the advocate may act on a non-instructed basis in accordance with service policy (i.e. asking questions as to how the client's rights and quality of life are affected by decisions taken about them).
- Developing Local Management Committees to oversee the roll-out of the advocacy service in each residential care facility.

Principles underpinning the national advocacy service

Advocacy, like any other service to those who are vulnerable, must be underpinned by strong values and principles, both among practitioners and within services and organisations that employ them. In view of the

highly sensitive nature of the issues involved with the target group, it is essential that the service is developed within a quality and governance framework³. It should be informed by the following key principles:

- Empowerment of the older person
- Respect for the person and his/her wishes and rights
- Protection of rights
- Acting in the person's best interests
- Acting independently
- Maintaining confidentiality
- Acting with diligence and competence

Plan for the development of a national advocacy service

A National Advocacy Manager, area Development Officers and Volunteer Coordinators will be appointed. A Local Management Committee will be established for each of the facility's involved with representation from a number of key stakeholders. A list of possible members for the Local Management Committee is outlined below but this will vary depending on the focus and local variations:

- HSE
- Citizen Information Centre
- Local financial institution
- Older people from the community
- Relative/s of a resident in long-stay care
- Resident/s of a long-stay care facility
- Person with legal background
- Representatives from local voluntary groups

It will be the role of the Development Officer to ensure that the Local Management Committee is established in line with the above principles. The Development Officers will work then closely with the Local Management Committee who will act according to guidelines and standards set down by the National Steering Committee. The purpose of the Local Management Committee is to oversee the day-to-day running of the advocacy service in the Residential Care facilities its area of responsibility and to seek monthly updates from the Development Officer and the Volunteer Co-ordinator. They also will agree a process for regular contact with the HSE in order to report on any issues arising.

³ See Comhairle Advocacy Guidelines 2005.

Scope and quality of service

Within the first three months of establishment, the national advocacy service will develop a Customer Service Action Plan. This will give a clear indication to clients and funders about the scope of the service and the standards required. The service will assist clients and their families to identify and understand their needs and options, so that advocacy services are tailored to the needs of the client. The primary focus of the advocacy service in each local area will be the provision of high quality case-based advocacy. Where appropriate, advocates will act on non-instructed basis to safeguard client's rights.

The local advocacy service will consult with clients and representative groups to ensure that their needs are met. The Local Management Committee will have representation from the residents of the long-stay care facilities in their area. The service must be welcoming and not unduly formal and should operate in a way that maximises the involvement of the client.

Prioritisation of cases

The advocacy service will be required to develop a policy on prioritisation of cases in line with National Guidelines and Procedures. This should include the following criteria:

- Urgency of the client's needs
- Likely benefits of having an advocate involved
- Risk of harm to the client if the advocate is not involved
- Likely effectiveness of the services

Eligibility of clients

All persons residing in a public or private long-stay / continuing care facility will be able to avail of the service. At a future date, this may extend to persons in an acute hospital. A non-instructed advocacy policy should be developed to respond to the needs of those with very minimal communication.

Case management

The service in each care setting will develop a case management procedure which will cover the following:

- Initial interview and decision to proceed
- The development of advocacy plans
- Focus of the advocacy
- Case recording

- Outcome and exit referral procedures

Grievance and complaint procedures

A grievance and complaints procedure is an essential part of any advocacy service. The service will be required to develop robust procedures in line with best practice to deal with complaints about the advocacy service from clients, family or other professionals. Complaints will be dealt with under Part 9 of the Health Act which stipulates that the HSE must ensure a complaints policy and procedure.

Accountability

Office and accounting procedures will be developed in line with best practice to demonstrate good governance.

Monitoring and evaluation

In an area such as advocacy, monitoring and evaluation are critical to the success of the service and the evaluation should be conducted externally.

Principles of good practice advocacy for the national advocacy service

- Ensure that the service operates to nationally agreed standards.
- Members of the target group should have equal access to the service (in the initial stages there may be limited access as the numbers needing the service may exceed the capacity of the advocates).
- Advocates are trained, supported and supervised to the standards laid out in the service level agreement.
- Mediation rather than adversarial processes are used, wherever possible.
- The service follows best practices in terms of governance and financial transparency.

Roles and responsibilities of the National Advocacy Manager

1. Oversee the national development and roll-out of the service in line with policies, procedures and standards adopted by the National Steering Committee.
2. Oversee the allocation of funding to each area following consideration of business plans submitted.
3. Develop national guiding principles/protocols for the service in conjunction with the National Steering Committee.
4. Receive regular reports from the Development Officers and Volunteer Coordinators on the progress of the service.
5. Ensure that policies and procedures are developed in each area including health and safety statement and confidentiality statement.

6. Provide advice and guidance to Development Officers and Volunteer Coordinators as required.
7. Ensure that supervision and support is made available for the advocacy volunteers as appropriate.
8. To ensure that an evaluation of the service is carried out after a period of one year.
9. To attend meetings with staff of the Office of Consumer Affairs and be advised about complaints within the residential units.
10. To develop a service plan
11. To report to the Head of the Office of Consumer Affairs and to the National Steering Committee.

Roles and responsibilities of the Development Officers

1. Overall responsibility for the development of the advocacy services in the area.
2. In conjunction with the Local Management Committee, ensure that detailed policies and procedures are developed in line with the service specification and national guidelines.
3. Ensure that all activities of the services are in accordance with the national policies and procedures
4. Evaluate policies and procedures in light of experience
5. Ensure a process for regular contact with the HSE locally is established including a feedback process for any issues arising out of the advocacy activities.
6. In partnership with public and private residential facilities, support the development of new and ongoing resident committees and provide information on same as appropriate.

Roles and responsibilities of the Volunteer Coordinator

1. Develop advocacy services on behalf of residents
2. In conjunction with the Development Officers, establish regular contact with the service sites and agree referral and operational procedures.
3. Oversee the recruitment and training of volunteers
4. Allocate volunteers
5. Provide direct advocacy services where required.
6. Develop regular contact with care staff and managers of facilities to seek feedback on activities
7. To maintain records of all contact with clients, families and professional staff.

Summary

The development of a formal advocacy structure to support older people in residential care is a key to the development of patient-centred care and is underpinned in the Draft Residential Care Standards. The roles of the Citizens Information Board and the HSE will require further clarification and discussion with respect to,

for example, lead roles and funding. Equally the role of non-governmental agencies will have to be examined in respect of the need for partnership arrangements or alliances.

Drawing on the experience and expertise of the Working Group, it is clear that any comprehensive attempt to deliver advocacy to older people in residential care should involve three elements. Firstly, it requires extensive developmental work incorporating education, awareness and capacity building with the voluntary organisations. Secondly, high quality advocacy provision requires intensive support with complex issues and higher client needs. Finally, volunteer advocacy provision would also allow for longer-term lower level support.

The Working Group agreed that the preferred model would consist of a National Advocacy Manager with four area Development Officers and four area Volunteer Coordinators supported by a team of volunteers. The Working Group also felt that these three elements could not be effectively combined in one job description without severely compromising the quality of the service provided, particularly in the context of a large geographical area. Of great importance will be the need to link consistently with Elder Abuse Officers, Consumer Affairs Area Managers, and Directors of Nursing in residential units.

For cohesion and continuity, it is important that this document is brought to the attention of the Expert Advisory Group on Services for Older People. The Working Group request that the Expert Advisory Group endorse this document before it is forwarded for funding to the Strategic Planning Reform and Implementation Group.

Appendix One

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Appendix Two

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Marie Lynch	Irish Hospice Foundation
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