

# **National Advocacy Programme for Older People in Residential Care**

## **Evaluation**

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## Executive summary

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### 1. Background to and origins of the Advocacy Programme

The Advocacy Programme for Older People in Residential Care was launched in 2007, in response to the recommendations made by the Forum on Services for Older People following the Inquiry into the revelations of abuse and poor quality of care in Leas Cross Nursing Home in North Dublin.

The Advocacy Programme was funded by the HSE and developed under the auspices of the National Advocacy Programme Alliance (NAPA), a multi-stakeholder group who came together to develop the Advocacy Programme. NAPA has effectively acted as an advisory group to the HSE, rather than a decision-making body.

The Advocacy Programme, which commenced in 2008, encompasses three main strands, for which Sub-Groups were formed by NAPA:

- Independent Volunteer Advocacy Programme;
- Training Programme;
- Information Programme

The Advocacy Programme is currently managed by a Programme Coordinator who is employed by the HSE's Advocacy Unit, based in the Quality and Clinical Care Directorate. Between 2008 and 2010 the Advocacy Programme was funded to a total of €385,000. This was insufficient to establish a robust and professional support structure for the programme in residential units/homes.

### 2. Evaluation

The evaluation was commissioned by the HSE in the autumn of 2010 to assess the outcomes, impact and learning from the pilot phase of the Advocacy programme, 2008-2010. The evaluation methods included:

- A questionnaire completed by Volunteer Advocates, Development Officers and participating residential units/homes;
- Case studies of eight residential units/homes;
- One-to-one interviews and focus groups with NAPA Group members, Volunteer Advocates, Directors of Nursing / Managers of residential units/homes, Resident's Committees, family members and older people in residential care.

Four Evaluation Bulletins were produced by the evaluator to provide information on the progress of the evaluation, initial findings and information about advocacy models. It was widely disseminated to all stakeholders.

The evaluation also examined different models of advocacy in Ireland and elsewhere, and in particular the Citizen's Information Board's Personal Advocacy

Service for People with Disabilities. These models did suggest that advocacy for older people should be located in an independent organisation that is independent from the service provider.

Eight detailed case studies were drawn up in the following residential units/homes, which provided an opportunity to highlight how the programme is being implemented at local levels:

- Ashford House, Dun Laoghaire, Co Dublin
- Dalkey Community Unit, Co Dublin
- Beneavin Lodge, Glasnevin, Dublin
- St Mary's Hospital, Phoenix Park, Dublin
- Cuil Didin, Tralee, Co Kerry
- St Joseph's Community Unit, Trim, Co Meath
- St Finbarr's Hospital, Cork City
- Middleton Community Unit, Co Cork

### **3. Outcomes and achievements of the Advocacy Programme**

Despite the low budget and a significant number of problems that are inherent in a programme that is heavily reliant on volunteers to provide support, the achievements and outcomes of the programme are significant:

- Sixty-seven residential units/homes are currently participating in the Advocacy Programme.
- 150 Volunteer Advocates have been trained in advocacy skills at FETAC Level 6.
- A further thirty-six Volunteer Advocates have undertaken a Continuing Professional Development course in Gerontology, and over 100 Volunteer Advocates attended a training day in 2010.
- 133 Volunteer Advocates are currently providing a volunteer advocacy service in one of the participating residential units/homes.
- Twelve volunteer Development Officers provide support to Volunteer Advocates;
- 118 staff in eight residential units/homes have been trained in 'Personal Excellence' values training on compassion and dignity in care;
- A web site [www.myhomefromhome.ie](http://www.myhomefromhome.ie) provides information on 295 residential units/homes.
- Policies and procedures for the Advocacy Programme have been put in place through a National Advocacy Programme Handbook and a Volunteer Advocate Policy.

The commitment, time and energy put into the development and implementation of the programme by NAPA and the Programme Coordinator has been exceptional, and there is a genuine commitment to establish a long-term sustainable structure for the programme in the future. There is an extraordinary commitment to the programme from Volunteer Advocates, many of whom have been providing a regular weekly advocacy service for over a year.

#### **4. Demographic ageing and the context of residential care**

Demographic ageing and an increasing demand for residential care, particularly for people experiencing dementia means that there is likely to be an increased demand for residential care in the future. Currently just under 5% of older people over the age of 65 years live in one of the 607 residential units/homes in Ireland (120 public and 487 private).

The Advocacy Programme is underpinned by the principles of dignity, person-centred care, empowerment and giving 'voice' to older people. Person centred care is embedded in the HIQA standards, and in HSE and DOHC policy, and is a key element of the HSE / DOHC *National Strategy for Service User Involvement in Irish Health Services 2008-2013*.

The HIQA *National Quality Standards for Residential Care Settings for Older People in Ireland* includes advocacy and information as national quality standards, although the current standards on advocacy and information do not have a regulatory base to them. Under the 2007 Health Act all 'designated centres', including residential care settings for older people must be inspected and registered, and the provision of independent advocacy has been included in the Inspection framework.

#### **5. The volunteer Advocacy Programme in residential units/homes**

The Advocacy Programme in residential units/homes has been rated 'excellent' or 'good' by the majority of residential units/homes. There is very positive feedback in most cases of the impact of the programme in contributing to the quality of care. Some residential units/homes would have benefitted from a greater involvement in the programme and in having a better level of communications and guidance in embedding the programme from the start.

Volunteer Advocates have identified the main elements of their advocacy roles to encompass:

- Empowering and enabling people to make choices and helping them to make decisions;
- Being able to speak up on behalf of an individual, which may be at odds with the institutional or care regime;
- Listening to people and taking them seriously, observing the dynamics of relationships.

Volunteer Advocates provide a weekly advocacy service for between two and four hours a week. In this early stage of the programme building relationships of trust with older people has been critical to the advocacy process. In practice, the majority of the concerns and issues are dealt with effectively by the designated Link Persons, while more serious issues are dealt with by the Development Officer assigned to support the Volunteer Advocates.

There have been some very effective systems put in place to provide communications and feedback with Directors of Nursing and Managers, and for supporting Volunteer Advocates through monthly meetings. However, in some cases, particularly in the early days of the programme, some Volunteer Advocates did not have a Development Officer to support them, which left them isolated and at risk of leaving the programme. Many of these gaps have now been resolved, but do point to the need for paid professional Development Officers to carry out this role.

The learning from the evaluation is that there are some key and critical success factors for the successful implementation of the programme, which have been implemented to varying degrees of success across the programme. These include having:

- Effective systems for the induction of Volunteer Advocates and introductions for residents, relatives and staff;
- Training and awareness of staff on the role and benefits of independent advocacy;
- Understanding the nature of advocacy in a residential setting and valuing the advocacy process of building relationships of trust to empowering older people;
- A close role and relationship with the Development Officer, including regular meetings with Directors of Nursing, Managers and Link Staff;
- Clarity of the roles of the Volunteer Advocates;
- Development of skills in advocacy for older people who are vulnerable or who have cognitive impairments; as well as skills in negotiation, mediation and listening;
- Systems for replacing Volunteer Advocates that leave;
- Systems for Volunteer Advocates to provide feedback and appropriate systems for responding to feedback given.

There is now a group of very experienced Volunteer Advocates, whose skills could now be used to provide mentoring for new volunteers as they come through the next training programme.

## **6. Volunteer Advocacy Training**

The provision of training for Volunteer Advocates has been a critical component of the Advocacy Programme, and deemed essential to provide Volunteer Advocates with the knowledge and skills of advocacy in a residential setting.

In 2009, the School of Community Studies, National College of Ireland (NCI), was contracted to provide eight Advocacy training courses in different locations across the country, and a 12-month programme of Continuing Professional Development (CPD) for Volunteer Advocates who had completed the initial training programme and who were actively carrying out a Volunteer Advocacy role in a residential home for older people.



As mentioned above total of 173 people were originally registered for the training and 150 Volunteer Advocates completed or were close to completing the training by the beginning of 2011. A further thirty Volunteer Advocates have participated in the CPD programme in Gerontology, which was put in place in response to an identified need to have more knowledge and skills in working with older people with cognitive impairments and dementia. Over 100 Volunteer Advocates attended a national training day in September 2010.

The main elements of the training are a taught course, orientation sessions to NAPA and to the clinical setting in residential units/homes and a work placement in a residential unit/home. During the work placements trainees were supported by a mentor, and Development Officers, where appointed provided support and links with the residential units/homes.

Feedback from the training has been largely positive, although some students did find the course to be very theoretical and 'top heavy' with assignments. Following a restructuring of the programme after the first cohort, the programme put a greater emphasis on building advocacy skills and communications.

The evaluation has made a number of suggestions about how the training programme could be further developed to meet the needs of Volunteer Advocates in a residential setting, and particularly to the specialist skills required in providing advocacy to people with dementia. There is also a need for regular ongoing training of existing advocates to keep them updated and motivated, and for a new cohort of advocates to be trained for the further roll-out of the programme.

## **7. Personal Excellence training for staff in participating residential units/homes**

One of the recommendations of the Forum on Services for Older People was the establishment of training for staff to enable them to put a value on compassion in the context of their care roles and in their personal lives. This was defined as 'Personal Excellence' and developed into a programme of training for 118 staff in seven residential units/homes across the country. The training has added a new dimension to the capacities of staff regarding compassion in care, and was positively received by staff.

Personal Excellence, as an approach to improving the quality of care relationships and compassion, is designed to improve self-awareness of the value of compassion and to empower staff to gain a sense of purpose of their care roles. The learning from the programme is that attitudinal change can lead to staff having a better understanding of their own personal values and attitudes to care and compassion, which can enable them to achieve personal excellence in the care relationships with the people in their care.

The evaluation of the training has been overwhelmingly positive, from the perspective of the participating residential units/homes and from the staff that participated in the training. The challenge is now to find a way to ensure that all staff

in participating residential units/home can benefit from the training, and for Personal Excellence Training to be integrated into the training and professional development of all health and social care staff working in a residential setting.

There are a number of suggestions in the evaluation of how the training could be cascaded through a 'train the trainer' approach, with networks of Personal Excellence Champions across all residential units/homes. The evaluation of the programme demonstrates the importance of the quality of the leadership in the individual nursing home to enable the learning to be embedded into work practices. As a result, the way that the programme is championed, supported and embedded into the culture of a residential home, is crucial for longer-term changes in the culture of residential care.

## **8. Information Programme**

Access to information has repeatedly been identified in consultations with older people as being essential to enabling older people to realise their rights and entitlements. Access to information about residential care, to enable people to make informed choices, was one of the three recommendations made by the Forum on Older People. This led the NAPA Information Sub-Group to establish a programme of information for older people, both inside and outside of residential care. Many stakeholders saw the value of having comprehensive and up to date information to enable choices to be made about residential care.

The establishment of HIQA standards on information has provided an incentive for residential homes to provide accurate information and a buy into the development of the web site that was created to provide accurate information about residential homes.

The web site went live in 2009, and although 295 unit/homes have posted information about their homes on the web site, there is still progress to be made before the objectives set out can be realised in practice. This includes ensuring that the HSE and Nursing Homes Ireland encourage and mandate all residential units/homes to participate. The verification of information posted is a critical issue and could be developed through a closer partnership with HIQA.

There is a need to devote more time and resources to promoting and publicising the web site, particularly amongst older people's organisations, if the information is to reach older people and their families.

There is also potential to extend the range and scope of information on the web site to include more detailed and accessible information about a wider range of rights and entitlements, including the provision of advocacy services.

## 9. The future development of the Advocacy Programme

A core recommendation from the evaluation is the need to develop an independent Advocacy Programme for Older People outside of the HSE. This would require the programme to develop a new strategic direction and leadership, and for the programme to be broadened out from residential care to hospital care and in the community, in all areas where care is delivered.

A new organisational, staffing and governance structure is recommended and scoped out in the evaluation. The governance of the organisation would be located in an independent National Advocacy Programme Board, with three Sub-Groups (on Advocacy, Information and Training), and a Regional Steering Group Structure to embed the programme at a regional level. A staffing structure to include a National Advocacy Programme Director / Coordinator, National Volunteer Coordinator and Four Regional Development Officers, would be located in the new organisation.

There are potentially three different organisational contexts for this:

- The Citizen's Information Board;
- An Independent Older Person's Organisation;
- The creation of a new Advocacy Organisation, through a partnership of existing older people's organisations across the country.

An outline budget has been drawn up that would be sufficient for the development of the new Advocacy Programme for Older People. These are outline costings that would need to be examined further by the NAPA group and the HSE.

**Over the three-year period a total budget of €1,505,000 would be required to implement the recommendations for the next stage of development for the programme.** This represents significant value for money for the development of a significantly expanded independent advocacy programme for older people.

## 10. Conclusions and key findings

- The Advocacy Programme has developed and grown significantly since it was first established in response to revelations that emerged from the Leas Cross Inquiry and the subsequent recommendations made by the Forum on Older People.
- The programme has demonstrated the significant and long-term contribution that independent Volunteer Advocacy can make to the quality of care in residential units/homes and to giving 'voice' to older people.
- Despite these some significant constraints and challenges the outcomes of the programme show innovation, significant achievements, with many positive outcomes, within the confines of a very modest budget and a short timeframe.

- Key issues of volunteer support, initial Volunteer Advocate training and ongoing training have been highlighted in the evaluation as issues that need to be addressed if the programme is to deliver a high quality, high value service to its users.
- The provision of training for Volunteer Advocates and Personal Excellence training for staff in residential units/home have been a very important contribution to ensuring professionalism and currency for the programme; competencies need to be developed in some key areas and reviewed for their impact on the delivery of the programme.
- The new Advocacy Programme for Older People should set as an early task a partnership with the Alzheimer's Society to develop a strategy for Dementia Advocacy and to develop a dedicated specialist Dementia Advocacy Programme in the future.
- The Information Programme is an important element of the programme's development and there is now scope for the further and more in-depth provision of independent information.
- There has been a significant amount of learning from the programme. Some key challenges and risks need to be addressed in order to overcome some of the organisational, structural, governance and funding constraints inherent in the current programme.
- The proposals for a new Advocacy Programme for Older People provides a framework and way forward, with costings, for an independent organisation to take on the role of delivering the three elements of the advocacy programme. The HSE will need to continue to play a key role both as a funder and as a partner, under the remit of the HSE Director of Advocacy (Quality and Clinical Care Directorate).
- If these issues and challenges can be realised in practice there is real scope for the establishment of a structure that is independent of the HSE, the further development and roll-out of the programme, and the application of the model to provide independent Volunteer Advocacy for older people in acute care and community settings.

## **11. Underpinning principles to inform the future development of the programme**

The next stage of development of the Advocacy Programme for Older People should be based on the following six principles:

- Older people are at the centre;
- Independence of the programme;
- Sufficient resources to ensure that professional volunteer support, accountability and supervision;

- Professionalism with the training and competence further developed for Volunteer Advocates and staff;
- Programme quality, with clear procedures, policies and quality criteria;
- Partnership with all key stakeholders, and particularly older person's organisations.

## **12. Critical success factors**

The evaluation highlights a number of critical success factors that are relevant for the future development of the programme. These can be summarised in relation to:

- Policy and procedures for independent advocacy, including indicators for assuring quality and assessing risks;
- Funding and governance for the new Advocacy Programme;
- Partnership and alliances between stakeholders;
- Standards for the three elements of the Advocacy Programme;
- Accreditation, training and retention of Volunteer Advocates.

## **13. Recommendations**

### ***a) Legal framework for advocacy and information***

- Independent advocacy and access to information for older people should be located in a robust legal framework.
- This should be examined with a view to implementing legislation on the rights of older people to independent advocacy and information requirements on public bodies, in line with the 2007 Disability Act.
- The HIQA Standards should embed clear and robust regulatory standards on independent advocacy and information, setting out what older people should expect and have a right to receive in a residential setting.

### ***b) A clear policy focus on advocacy in the DOHC and the HSE***

- As well as a legal framework, there is a need for a clear integrated policy focus to reflect the cross-cutting nature of the Advocacy Programme in relation the HSE, which is best placed to be provided from and coordinated by the Advocacy Unit (Quality and Clinical Care Directorate). This also needs to be embedded in DOHC policy and in the Positive Ageing Strategy.
- One way forward would be to reinstate the Older Person's Forum, to ensure that there is effective engagement with older people and the organisations that represent them.

### ***c) An independent and robust organisational and governance structure***

- The Advocacy Programme needs to be located in an organisation that is independent of the HSE, ideally in an independent Older Person's organisation.

As part of this is the need to ensure that a clear organisational and governance structure is in place.

- A structure for this organisation has been set out in this report, which requires funding for an independent structure and the appointment of two National Coordinators and four Regional Development officers.
- A new governance structure is also set out, on the basis that NAPA is formally disbanded and that a new multi-stakeholder Board and regional Steering Group structure be established for the new programme. It is essential that the HSE Director of Advocacy, Nursing Homes Ireland, the Citizen's Information Board, advocacy organisations and older people's organisations are brought into this governance structure.
- There is a key role to be played in utilising the learning and professional development expertise and resources in both the HSE and Nursing Homes Ireland.

***d) Volunteer Advocates and Development Officers: support, procedures and protocols***

- The recommendation for the appointment of four regional Development Officers will be critical to providing support and supervision to Volunteer Advocates across each the region, to liaise with residential homes and organise regular meetings with advocates.
- Clear protocols, policies, procedures and lines of reporting to be established so that Development Officers have clearly defined tasks and roles.
- A system for coordinating the roles of the Development Officers should be put in place, with regular meetings with the Programme Coordinator. This should also include opportunities for Development Officers to meet and discuss their work.
- Development Officers should receive specific training in advocacy models, facilitation and supervision skills, and in supporting, motivating and managing advocates.
- Existing Volunteer Advocates should be encouraged and supported to play a role as mentors to new trainees and also to provide an in-put into the training for new Volunteer Advocates.
- In the future it is suggested that Volunteer Coordinators / Mentors are selected within their groups to provide coordination at the level of the residential home or in a specific geographic locality. Local Volunteer Advocate support groups should also be established in all areas.

***e) Funding of the programme***

- A package of funding from the HSE, as a body responsible for public provision, and Nursing Homes Ireland, as the representative body for private nursing homes, needs to be put in place.
- The HSE had a key responsibility to fund the Advocacy Programme, and is now in a position to hand the programme over to an independent organisation to run the programme in the future. There needs to be a long-term funding

commitment from the HSE for this purpose so that the programme is sustainable.

- HSE funding should continue to be provided through the Advocacy Unit (Quality and Clinical Care Directorate), on the basis that this enables the funding to be strategically positioned within the HSE/DOHC Strategy for Service User Involvement.
- Further discussions should be held with the HSE and Nursing Homes Ireland with a view to providing funding Personal Excellence training in public and private nursing homes.

***f) Define more clearly the nature of advocacy for older people in a residential setting***

- There is evidence from the evaluation is that independent advocacy in a residential setting needs to be more clearly defined and articulated, particularly in providing advocacy to older people in vulnerable situations and older people with dementia. Many of the existing models of advocacy do not take into account cognitive impairment, and is a challenge that has been faced by Alzheimer's Society in relation to providing advocacy for people with dementia.
- It is recommended that a specialist Dementia Advocacy Programme be established as a specialist qualification for Volunteer Advocates, and developed in partnership with the Alzheimer's Society.

***g) Mitigate any risks in the programme***

- A number of risks have been identified for the Programme that will need to be mitigated in the next stage. The proposed management, governance and staffing structure for the new programme would be in a strong position to mitigate these risks, particularly in providing a robust system of support for Volunteer Advocates.

***h) Improve awareness and understanding of advocacy in a residential setting***

- One of the findings of the evaluation is that staff in participating residential homes can be resistant and suspicious of the role of the independent advocate. This is critical to embedding the programme into residential homes. For this reason it will be important to provide more information, awareness and feedback for participating residential homes, so that they appreciate and understand the role of independent advocacy as complementing person-centred care.
- This will be possible if improved systems for introducing and inducting Volunteer Advocates are put in place, and improved communications take place with residential units/homes.
- There is scope to extend and further develop the Personal Excellence training so that it includes an understanding of independent advocacy.

***i) Re-examine and further develop the training programme for volunteer advocates***

- Specific recommendations have been made for further skills development, in particular with regards to building communications skills (skills of communicating with and working with very vulnerable older people and in providing advocacy to people with dementia); in preparing Volunteer Advocates for volunteering in a residential setting; and in developing advocacy skills in relation to rights and entitlements. Another factor is the need to improve the understanding the role and boundaries of advocates in relation to their observations of the daily living situation of older people in institutional care.
- Consideration should be given to reviewing the current accreditation at FETAC level 6 and to examine the feasibility of providing more skills based training at FETAC level 5, with a progression route into level 6.
- Regular local / regional level training and ongoing continuous professional training and development should be provided for existing advocates.
- Consideration should also be given to delivery of the training through new technologies, distance learning and on-line learning.
- An Advocacy Programme web site, discussion forum and Facebook site, could assist in this process and in providing Volunteer Advocates with regular information and opportunities for learning. Regular Advocacy Programme Bulletins should also be disseminated on a monthly or bi-monthly basis.
- Examine the feasibility for developing continuous learning 'circles' or 'groups' for Volunteer Advocates at a local level, to enable Volunteer Advocates to reflect and discuss different advocacy situations and experiences, to invite external speakers, provide peer-support and learning and engage in ongoing learning.
- Consideration should also be given to monitoring how Volunteer Advocates can participate in training with staff in residential units/homes in core areas of training such as elder abuse, health and safety and other areas that may be relevant to Volunteer Advocates.

***j) Roll out the Personal Excellence training to all residential homes***

- A training manual should be developed, setting out the rationale for the programme, learning outcomes, modules and guidance for training, under the auspices of the Advocacy Programme. This training manual ideally should be funded by, disseminated from and embedded into HSE Learning and Development.
- A leaflet setting out the goals of Compassion and Personal Excellence should be drawn up and disseminated to all residential homes for older people in Ireland and through relevant bodies, such as the older people's organisations, Irish Society for Quality and Safety in Healthcare, Nursing Homes Ireland, the HSE, the Irish Nurses and Midwives Organisation, to name a few.
- A programme of 'train the trainer' workshops for learning and development staff in residential homes, HSE learning and development units, HSE leaders in older persons services across all HSE regions, and for learning and development practitioners in Nursing Homes Ireland. A dedicated 'train the trainer'



programme should be carried out for residential homes, whereby one representative / leadership champion of each residential home is nominated to attend the training, which s/he then disseminates and implements internally. This would be a more cost effective method than providing training in each residential home across the country and will have an important multiplier effect.

- Consideration should be given to developing a FETAC accredited module on Personal Excellence and Compassion for staff, and a similar programme for Volunteer Advocates.
- A plan should be put in place to ensure that every residential home in Ireland has a Personal Excellence Champion, who can then disseminate the learning on Compassion and Personal Excellence within their homes and units. There is also an opportunity for champions to network across the country.
- Funding would need to be sourced for these initiatives and development, which could result from a package of funding from the HSE and other external sources. Consideration should also be given to linking in with existing Skillnets Learning Networks developed within private health sector companies.
- An Annual Report setting out data, outcomes, evaluation of programmes implemented and planned developments should be submitted to the National Advocacy Programme Board at the end of each programme year.

***k) Put in place a strategy and funding to enhance and further develop the Information Programme***

- The information programme needs to be further developed and extended. There are key issues of verification and regular updating of information that need to be factored in and this will require cooperation with HIQA, Older Persons organisations, the HSE, Nursing Homes Ireland etc.
- The information programme should be widened out to include a wider range of information about rights and entitlements, information about the Fair Deal under the National Treatment Purchase Fund, and service entitlements from the HSE, particularly if a person take up a place in a private residential home.
- There is significant scope for including a wider range of information and greater detail about service entitlements, and it will also be important to examine how information can be accessed in other formats, given that older people themselves do not always have good access to the Internet.
- There is also further scope for the development of a joint approach between HIQA and the programme to spell out more concretely and in more detail specific information standards and indicators.
- The future location of the web site will be critical to its long term sustainability and development.
- A key consideration is how the web site is advertised, publicised and promoted so that it is widely known.

***l) Develop an Advocacy Programme web site and Facebook site***

- An Advocacy Programme web site and Facebook should be developed to enable Volunteer Advocates to receive regular information, have access to research and

developments in advocacy nationally and internationally, and provide a forum for networking and sharing of information and good practices. This should be independent of the Information Programme web site on residential units/homes and service entitlements.

***m) Develop a plan for new extending the Advocacy Programme to acute hospital and community settings***

- The Advocacy Programme has huge potential to be rolled out into acute hospital and community settings. Four new advocacy projects for older people should be developed, one in each of four regions proposed for the new Advocacy Programme. These should span advocacy in a hospital setting and in a community setting. These should be developed through an integrated programme and piloted through Primary Care. Consideration should be given to how advocacy could become a performance measurement in the provision of HSE Integrated and Primary Care.
- A Plan should be put in place for how these four projects could be roll-out and funded in the longer-term, with a view to developing a long-term flexible structure for advocacy in residential, acute and community settings.
- In this regard, it is proposed that closer links be made with local community organisations and networks of older people, local advocacy projects, such as the Cork Advocacy Service, and Local Development Companies, who are funded to implement the Local Community Development Programme.

***n) Enable the voice of older people***

- The new programme should have a priority to establish and develop appropriate methodologies for enabling the voice of older people. This should be developed in the light of the recommendation for the integrated provision of advocacy for older people in residential, acute and community settings.
- It is recommended that models of good practice in consulting with vulnerable older people, particularly people that experience communications difficulties, be examined and implemented. This will be important in ensuring that older people have a voice in the ongoing evaluation and development of the programme.

***o) Put in place a high level conference***

- The HSE and HIQA should jointly organise a high-profile national conference on advocacy for older people to showcase the project. This should be organised in consultation with older people's organisations and the members of the NAPA group. This would help to raise the profile of the Advocacy Programme nationally and to launch the roll-out of the programme, as well as launch the web site [www.myhomefromhome.ie](http://www.myhomefromhome.ie). In subsequent years there should be an annual conference / training day for Volunteer Advocates, with expenses and accommodation costs met within the programme.

## Section 1: Introduction

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### 1.1 Introduction and background to the Advocacy Programme

In 2006 the HSE established a Forum on Services for Older People as a direct outcome of the report of the Inquiry into abuse and poor quality of care in Leas Cross Nursing Home in North Dublin<sup>1</sup>.

The Forum was established following meetings between the HSE's Office of Advocacy Services and families of relatives and older people who had experienced problems in the quality of the care that they received while resident in the former Leas Cross Nursing Home. The Forum brought together advocacy groups for older people, family representatives, private nursing home providers and HSE officials, and was designed to listen to the views of these stakeholders.

The Forum made three core proposals for, a) information for older people and their families, b) an advocacy service for older people in residential care, and c) for the training of residential care staff. The Forum examined existing models of advocacy, and particularly the Citizen's Information Board's advocacy programme for people with disabilities, and the independent<sup>2</sup> advocacy programme for older people developed through the Massachusetts Long-Term Care Ombudsman programme<sup>3</sup>.

A proposal for the development and funding of a National Advocacy Programme for Older People in Residential Care was subsequently made by the then National Director for Consumer Affairs (now Advocacy Unit) in the HSE.

The resulting Advocacy Programme was funded by the HSE's Innovation Fund and the Health Services Partnership Forum and developed under the auspices of the National Advocacy Programme Alliance (NAPA), a multi-stakeholder group who came together to develop the Advocacy Programme. **The members of NAPA Implementation Group can be found in Appendix 1.**

The Advocacy Programme for Older People in Residential Care was launched in 2007 and the first training programme for Volunteer Advocates commenced in 2008. The three elements of the current advocacy programme are listed in Figure 1. They include the independent Volunteer Advocacy Programme in participating residential units/homes; the Training Programme, which encompasses training for Volunteer Advocates and Personal Excellence Training for staff in residential units/homes; and the Information Programme, which has been designed to provide access to information for older people and families about choices regarding residential care.

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<sup>1</sup> HSE (2006) *Leas Cross Review*, carried out by Professor Des O'Neill, Consultant Geriatrician, [http://www.hse.ie/eng/services/Publications/services/Older/Leas\\_Cross\\_Report\\_.pdf](http://www.hse.ie/eng/services/Publications/services/Older/Leas_Cross_Report_.pdf)

<sup>2</sup> Citizens Information Board (2007) *Advocacy Guidelines, Guiding Principles and Operating Procedures for the Delivery of Advocacy Services through Community and Voluntary Organisations*

<sup>3</sup> See Commonwealth of Massachusetts Executive Officer for Elder Affairs *A Bridge to Quality Care: Long Term Care Ombudsman Programme*.

**Figure 1: The three elements of the Advocacy Programme**

<b>Volunteer Advocacy Programme</b>	<ul style="list-style-type: none"> <li>• Volunteer Advocates</li> <li>• Development Officers</li> <li>• Participating Residential Homes</li> <li>• NCI FETAC Level 6 accredited training programme</li> <li>• Additional training programme (Gerontology)</li> </ul>
<b>Training Programme</b>	<ul style="list-style-type: none"> <li>• Personal Excellence Training programme for staff in participating residential homes</li> </ul>
<b>Information Programme</b>	<ul style="list-style-type: none"> <li>• Web site <a href="http://www.myhomefromhome.ie">www.myhomefromhome.ie</a></li> </ul>

## **1.2 Overview of the evaluation and methodological framework**

The evaluation of the Advocacy programme took place between September and December 2010. The evaluation marked the end of the pilot phase for the Advocacy Programme.

### **Evaluation objectives and methodology**

The objectives of the evaluation were to:

- Analyse and evaluate the degree to which the objectives of the existing Advocacy Programme have been met, the extent and efficiency of the services provided and whether the resources committed to their achievement are appropriate and realistic;
- Assess the current management, governance and support structures of the existing advocacy services;
- Provide an overview and description of each element of the programme and from this make recommendations on a model of service delivery that fosters a network of advocacy services;
- Identify gaps in service provision and make recommendations for immediate improvement in services;
- Make recommendations for the future role of the programme, including its funding, governance and lead organisation structure, and how the programme can be further developed to meet future demand.

## Analytical framework for the evaluation

The evaluation was informed by an analytical framework that provided for evaluation and assessment of outcomes, impact and learning by:

- Documenting the development of the Advocacy Programme from its inception;
- Drawing on national and international literature, and current policy;
- Engaging with national and local stakeholders involved in the National Advocacy Programme, including Volunteer Advocates, those who delivered the training to volunteers, older people in residential services, staff in residential services, the Health Services Executive and stakeholders in NAPA;
- Ongoing dissemination of learning from the evaluation to NAPA partners and through four Advocacy Programme Evaluation Bulletins.

## Methodology

The methodology for the evaluation encompassed:

- *Review of literature, policy and advocacy models:* carried out by desk research.
- *Interviews:* One-to-one semi-structured interviews (by telephone and face-to-face) with key stakeholders.
- *Questionnaire:* A semi-structured questionnaire was disseminated by post and email to Volunteer Advocates, Directors of Nursing/Managers in participating residential units/homes and Development Officers.
- *Focus groups with key stakeholders:* Focus groups were held with the key stakeholders, including Volunteer Advocates, Development Officers and representatives of the NAPA groups.
- *Case studies:* Case studies of the Advocacy Programme were drawn up in eight sites to provide more detailed picture of how the programme is working at the level of individual residential units/homes. These cases studies involved interviews with Directors of Nursing/Managers, Link Staff, Volunteer Advocates, Resident's Committees, family members and where appropriate residents receiving the advocacy service.

As part of the ongoing evaluation for the programme four Evaluation Bulletins were produced by the evaluator to provide information on the progress of the evaluation, initial findings and information about advocacy models. These were disseminated across the NAPA Groups, to Volunteer Advocates, to Development Officers, and to participating residential units/homes. Copies of the Bulletins can be found on [www.myhomefromhome.ie](http://www.myhomefromhome.ie).

**Appendix 2** provides a list of the people who were interviewed, the dates and locations of the focus groups, and the number of respondents who completed the questionnaires.

### **1.3 Demographic change in Ireland and the provision of residential care**

The Central Statistics Office projections are that the proportion of the population of over 65 years is to increase by 11.4% in 2011 and by 22.4% in 2041. The most notable increase will be among people over the age of 85 years, whose numbers will quadruple from 60,400 in 2011 to 255,100 in 2041. Currently 4.5 % of older people are in long term care. There are approximately 38,000 people with dementia in Ireland and a significant proportion of them will live in a care home for the last years of their life (Alzheimer's Society 2007).

There are 609 residential units in Ireland (120 public and 489 private/voluntary) According to the DOHC in 2008 there were 22,967 long stay beds (14,932 Private and 7,035 Public/Voluntary). Nursing Homes Ireland currently provides 65% of the country's long-term stay beds and has over 400 registered homes on their database. Given the increase in the older elderly population and the predicted increase in the numbers experiencing dementia in the future, residential care is likely to be necessary for an increasing number of older people in the future, unless there is a substantial increase in funding to support people in their own homes for as long as possible.

### **1.4 The 'voice' of older people as service users**

Advocacy plays a key role in bringing service users to the centre of service provision and in enabling service users to actively participate in decisions that affect the services and care they receive. One of the critical challenges for all service providers is how to genuinely bring older people to the centre of service provision. Person centred care is embedded in the HIQA standards, and in HSE and DOHC policy<sup>4</sup>. The 'voice' of clients/consumers is a central plank of the HSE/DOHC HSE's *National Strategy for Service User Involvement in Irish Health Services 2008-2013*.

Giving 'voice' to older people in a residential care settings has of enormous significance for the advocacy programme and to service developments in residential homes. This requires strategic leadership at the level of the residential home and needs to be embedded in staffing requirements and staff training. There are some excellent models of how the older person can be brought into the centre of care in Australia and New Zealand, and of participatory methodologies for effective engagement with older people. In Ireland there are positive developments, which in part result from requirements for the active involvement of older people in the HIQA standards, for example, through Resident's Committees.

The principles of independence, dignity and empowerment of older people and of inter-generational solidarity at a societal level have underpinned the development

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<sup>4</sup> National Health Strategy *Quality and Fairness – a Health System for You*, which identified the need for advocacy for people with mental health difficulties on the basis that "the strengthening of advocacy is a priority".

of the National Positive Ageing Strategy. The consultation document for the strategy sets out a vision “of a clear and inclusive framework within which all policies that have implications for older people can be developed and implemented”, across a continuum of care – self-care, home care, community care, acute care and residential care, while “residential care should enhance positive images of the self, rather than dismantle personal identity”<sup>5</sup>.

The *National Strategy for Service User Involvement in the Irish Health Service* (DoHC & HSE) is based on the principle that “the service user should be central to their own care and to the design and delivery of health and personal social services”. The objective is that this will result in the provision of more appropriate and higher quality services, and increased satisfaction and compliance with services. Service user involvement is defined as:

A process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing policies, in planning, developing and delivering services and in taking action to achieve change.<sup>6</sup>

The United Nation’s Principles for Older Persons (1991) have recommended that governments incorporate the principles of independence, participation, care, self-fulfilment and dignity of older persons into national programmes. These have subsequently been adopted by the Madrid International Plan of Action on Ageing in 2002. The ethics of care based on the principles of respect, equality, trust and dignity<sup>7</sup>, and underpinning principles have provided an important focus to the evaluation of the Advocacy Programme.

### **1.5 Advocacy standards in residential care**

The HIQA *National Quality Standards for Residential Care Settings for Older People in Ireland* include advocacy as a national quality standard. Under the criteria of ‘consent’ the standards state that: “The resident is facilitated to access an advocate/advocacy services when making decisions relating to consent to treatment or care, if necessary and in accordance with his/her wishes”. Under the criteria of ‘civil, political and religious rights’ the standards state that: “The resident has access to citizen’s information and advocacy services”. The Standards are designed to encourage continuous improvement. Although some of the Standards are regulatory, the current standards on advocacy and information do not have a regulatory base to them.

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<sup>5</sup> Department of Health and Children (2010) *In our own words: Report of the consultation process for the National Positive Ageing Strategy*, Office for Older People, Department of Health and Children: Dublin, page 15

<sup>6</sup> DoHC & HSE (2008) *National Strategy for Service User Involvement in the Irish Health Service*, page 7.

<sup>7</sup> Williams F (2004) *Rethinking Families, Rethinking Care*, CAVA Research Centre, University of Leeds / Calouste Gulbenkian Foundation: London

Under the 2007 Health Act all 'designated centres', including residential care settings for older people must be inspected and registered, regardless of whether they are run by the HSE, private providers or voluntary organisations. Since 2009 HIQA has been responsible for the inspection of residential homes for older people, under the Social Services Inspectorate, as established by the 2007 Health Act. Many of the inspections, that usually take place annually, are also asking residential homes if they have an advocacy service. Where they do not, the HIQA reports recommend that this be put in place. This has implications for the National Advocacy Programme and also does make the case for the programme to be extended to cover all residential homes for older people, public and private.

## **1.6 Models of advocacy**

As part of the evaluation a review of different approaches to and models of advocacy in Ireland across the world was carried out. The objective was to examine to organisational issues, approaches to volunteering versus paid advocacy, and how programmes are funded. The majority are independent of statutory or governmental bodies, and while they may be funded by the State they are delivered through independent NGOs / community and voluntary organisations.

Underpinning all advocacy programmes is that advocacy:

- Promotes independence and informed choices and decision-making;
- Gives people a voice;
- Empowers people to make decisions, and assert their views and needs;
- Independent representation of people who are unable to assert their needs themselves;
- Protects people's human rights.

Advocacy can be approached in a number of different ways, for example, through personal advocacy and casework. It can address specific issues, for example through complaints advocacy or hospital discharge. In some cases advocacy may provide a specialist service for a specific condition, for example, through dementia advocacy or mental health advocacy. Finally, advocacy can be provided regardless of capacity through methods of instructed and non-instructed advocacy. Advocacy roles can be instrumental and expressive. Instrumental advocacy entails 'doing' through practical support such as providing power of attorney or legal advocacy; and being a representative for the person, or expressive 'being' through emotional support where the advocate is a confidante witness, and enabler<sup>8</sup>.

There a wide range of different models of advocacy, ranging from self-advocacy, peer advocacy, family advocacy, group advocacy, citizen advocacy and professional advocacy<sup>9</sup>. There are well established models of advocacy for mental health service

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<sup>8</sup> Andrew Dunning (2005) *Information, advice and advocacy for older people: defining and developing services*, Joseph Rowntree Foundation: York

<sup>9</sup> Add references; xxxx; CIB *Jigasw of Advocacy*; and CIB *Advocacy Guidelines*

[http://www.citizensinformationboard.ie/publications/downloads/advocacy\\_guidelines\\_2007.doc](http://www.citizensinformationboard.ie/publications/downloads/advocacy_guidelines_2007.doc)



users and people with disabilities, while fewer exist for older people, particularly in a residential care setting. In Ireland there are a number of established national advocacy programmes. These include the Irish Advocacy Network is funded by the HSE to provide a peer-advocacy service to people with mental health difficulties and the Cork Advocacy Service has developed a programme for advocacy for older people living in their own homes in the community. The Citizen's Information Board Personal Advocacy Service for People with Disabilities was introduced under the Citizens Information Act (2007), and provides a statutory duty and remit for the Citizen's Information Board to deliver advocacy services for people with disabilities. According to the Citizen's Information Board:

Advocacy is a means of empowering people by supporting them to assert their views and claim their entitlements and where necessary representing and negotiating on their behalf. Advocacy can often be undertaken by people themselves, by their friends and relations, or by persons who have similar experiences. 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.

The Citizens Information Board's advocacy service commenced as a pilot Programme of independent Advocacy Services for people with disabilities in 2005. Following the evaluation of the pilot a new programme was introduced in 2010 with an annual budget of €3,200,000, encompassing a network of paid advocates across the country in five regions. The network of information providers, through the Citizens Information Service, will also be developed in some parts of the country to provide independent advocacy for people with disabilities.

Advocacy programmes for older people exist in many parts of the world. However, advocacy with older people remains a relatively under-researched area. According to research by Andrew Dunning:

Information, advice and advocacy are crucially important in promoting the independence, involvement and interests of older people. Information, advice and advocacy can help to support an older person in making choices, taking decisions, securing rights, acting in his or her own interests as well as contributing to the life of the community and being fully engaged in society<sup>10</sup>.

, There is a need for further work to be carried out in conceptualising and measuring the effectiveness of advocacy with older people. Dunning makes a distinction between a wide range of different advocacy approaches for older people, which encompass:

- Self-advocacy: 'speaking up for yourself' to represent your own needs, wishes and interests.

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<sup>10</sup> Andrew Dunning, op cit, page 1

- Collective advocacy, self-advocacy groups and organisations that provide mutual support, skill development and a common call for change.
- Peer advocacy: one person advocates for another who shares a common experience, difficulty or discrimination.
- Citizen advocacy: one-to-one, long-term partnership between an independent, unpaid 'ordinary person' and a disadvantaged 'partner'.
- Volunteer advocacy is independent and unpaid, but the advocate may work with a number of partners on a short term issue or casework basis.
- Paid advocacy: the role of advocacy workers who share the characteristics of volunteer advocates but are paid for the task.
- Professional advocacy: the partial advocacy role of staff in health, social care and other settings.
- Public advocacy: the activities of organisations that campaign on behalf of a particular group of people or collective issue.
- Legal advocacy: advocacy undertaken by trained lawyers.

#### **Examples of advocacy programmes for older people**

Three examples of advocacy programmes were examined for their relevance for older people. There is an emphasis in these programmes on developing good quality independent advocacy services, standards and quality frameworks. In addition, the approach taken has been to work with and fund older people's organisations to provide independent volunteer advocacy services. This does suggest that an independent advocacy service should, if possible, be located outside of the HSE. These programmes have been important in informing the development of the Advocacy Programme in Ireland.

- The **US Ombudsman Program** has been the inspiration behind the Advocacy Programme. It provides older people in long term care to a legal right to advocacy through government funding to provide volunteer advocacy programmes in all US States. A Long Term Care Ombudsman is an advocate for residents living in long term care facilities, whose role is designed to enable older people to have a voice and to ensure that their concerns are addressed so that they can live their lives with dignity and respect. The programme was first established on a pilot basis in 1972 and is now a national programme, organised and funded under the government's Administration on Ageing (Department of Health and Human Services). Since 1978 the Older Americans Act has required every US State to put in place an Ombudsman Programme. Paid 'ombudsmen development specialists' have been trained to coordinate, support and review the work of volunteers. Government funding has also led to the establishment of the National Association of State Units on Aging (NASUA), which has a Center for State Long-Term Care Ombudsman Resources, in conjunction with the National Citizens' Coalition for Nursing Home Reform. Currently there are 8,700 volunteers certified to handle complaints and more than 1,300 paid staff. In 2008 the Ombudsman Program investigated over 271,000 complaints made by 182,506 individuals and provided information on long-term care to another 327,000 people<sup>11</sup>.

<sup>11</sup> For further information about the Ombudsman Programme and NASUAD see <http://www.ltombudsman.org/about>; [http://www.nasuad.org/ombudsman/ltc\\_ombudsman\\_resource%20center.html](http://www.nasuad.org/ombudsman/ltc_ombudsman_resource%20center.html)

- In the UK the **Older People's Advocacy Alliance (OPAAL)** <sup>12</sup> is an alliance of 200 advocacy schemes and national and local organisations of older people and for older people. Their aims are to develop independent advocacy services with older people and to establish standards and quality frameworks for the delivery of advocacy, and through their on-line magazine and awareness raising activities to provide regular information about advocacy programmes for older people across the country. OPAAL provides a network for independent advocacy services for older people at the point of discharge from hospital, in the provision of care services in the community and in residential care. The definition given to advocacy is 'A one-to-one partnership between a trained, independent advocate and an older person who needs support in order to secure or exercise their rights, choices and interests.' OPAAL has received funding from the UK's Department of Health to carry out work in developing guidance and good practice, an evidence base for advocacy, standards and quality frameworks. Their objective is to establish a legal right to independent advocacy for older people. Across the UK there are many examples of Volunteer Advocacy Programmes for older people living in the community and residential care, including examples of specialist dementia advocates who have been trained with the skills to provide advocacy to people with dementia and to learn the skills, for example of, reminiscence and communications.
- In Australia, aged care advocacy agencies have been established in each State and Territory. They are funded by the **Residential Aged Care Advocacy Services Programme**, which is managed by the Commonwealth government to provide free and confidential advocacy services. The programme is delivered through community based organisations to provide advocacy to older people in residential care and who are receiving community care services. Advocates from the Residential Aged Care Advocacy Services Programme provide information about the rights of older people using older people's services, confidential and independent advice and advocacy to enable older people to make decisions and access the services that they need<sup>13</sup>.

<sup>12</sup> For further information about the Older People's Advocacy Alliance <http://www.opaal.org.uk/>

<sup>13</sup> For further information see on the Residential Aged Care Advocacy Services Programme [http://www.agedrights.asn.au/rights/whatis\\_formal.html](http://www.agedrights.asn.au/rights/whatis_formal.html)

## **Section 2: Overview of the current funding, management, organisational and staffing structure of the Advocacy Programme**

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### **NAPA Vision and Mission Statement**

The vision of NAPA is that older people in Ireland will have access to an accredited advocacy service which is appropriately resourced and sustainable for future years.

- Our mission is to promote and enhance advocacy services for older people in Ireland.
- We seek to enhance the health and social care of older people in care and community settings, thereby improving their quality of life.
- We will do this by strengthening their voice, or where needed, providing a voice.
- We aim to provide a client driven service in partnership with all other key service providers.

### **2.1 Funding of the Advocacy Programme**

Between 2008 and 2010 the Advocacy Programme was funded to a total of €385,000. In 2008 the programme received funding of €193,000 from two sources: €118,000 from the HSE Innovation fund and €75,000 from the National Health Services Partnership Forum. In 2009, the programme received funding of €142,000 from the HSE Innovation Fund, and a further allocation of €50,000 was received in 2010 from the National Health Services Partnership Forum. The majority of the funding was provided for the training of the volunteer advocates (€140,000 for the National College of Ireland) and for the Personal Excellence Training (€32,000). Other costs related to establishing and hosting of the web site, costs of seminars and events, and additional training costs.

This is a relatively modest budget given the extent of activity undertaken in the programme, which does not include the staffing costs of the Coordinator of the Advocacy Programme in the HSE. However, given the challenges inherent in the current programme and the objective to roll-out the programme to a larger number of residential units/homes and to acute and community settings, there is an urgent need to increase the budget to reflect these challenges and developments.

### **2.2 Management and governance structure**

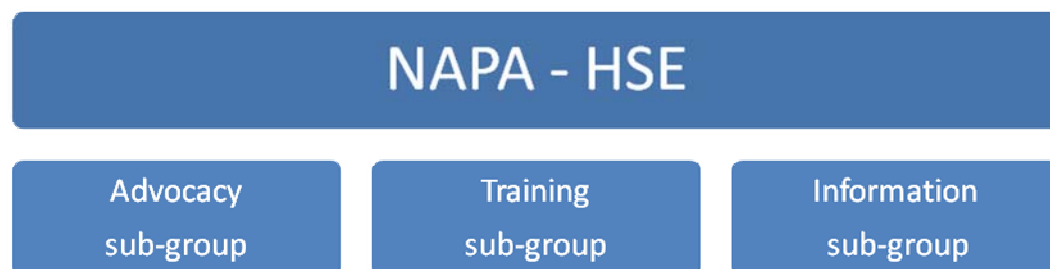
The overall management of the programme is located within the Advocacy Unit of the HSE's Quality and Clinical Care Directorate. The day-to-day management of the programme is carried out by a National Advocacy Programme Coordinator, based in the HSE's Advocacy Unit. She is responsible for managing and coordinating all elements of the programme, and was widely commended from NAPA members, Volunteer Advocates and Development Officers for her role implementing and coordinating the programme within such a short timeframe.

The overall governance of the programme takes place through the partnership formed through the National Advocacy Programme Alliance (NAPA), made up of representatives of the HSE, statutory and voluntary agencies and the Programme Coordinator, including Nursing Homes Ireland, Citizens Information Board, Care Local, Alzheimer Society, National College of Ireland, Volunteer Centres Ireland and Age Action. The NAPA group also includes representation of a family member of a resident who died in Leas Cross, who has been extremely active in establishing the programme and in progressing significant elements of the programme. She has devoted an exceptional amount of her own time and commitment in a voluntary capacity to NAPA.

Three sub-groups have been established under NAPA: Information Sub-Group, Advocacy Sub-Group and Training Sub-Group, to develop and progress these respective elements of the NAPA programme. The current governance structure can be found in Figure 2.

The NAPA Group and Sub-Groups have been extremely active in the development and implementation of the programme. A significant degree of time was given up by NAPA members in the early days of the development of the programme, much of which was provided through good-will and commitment to establish a viable structure from the start.

**Figure 2: Current governance structure**



Some NAPA members commented on the significant time that was spent in developing the proposal and framework for the three elements of the programme. In one case a former NAPA member, who was at the time a CEO of an older person's organisation, was disappointed that the process in drawing up the Information Programme in the Information Sub-Group did not honour the original proposals, consultations and plan that was subsequently presented to the HSE.

Other NAPA members have found participation in the NAPA Group and Sub-Groups to be rewarding and a valuable forum for discussion and feedback. It was suggested by several NAPA members that the NAPA group should be chaired by an independent Chair, and be enabled to make decisions.

### **2.3 Advocacy programme policies and procedures**

The policies and procedures for the Advocacy Programme were finalised in 2010, and are set out in the National Advocacy Programme Handbook. This covers:

- Introduction to the service
- Code of Practice
- Complaints policy and procedure
- Referrals policy and procedure
- Closure policy and procedure
- Resident empowerment and consent policy
- Anti-discrimination policy
- Confidentiality and information policy
- Advocate independence policy and procedure
- Personal Safety Policy and Procedure
- Appendices (Referral Form, Priority Assessment Form, Advocacy Plan, Case Record Sheet, Client Questionnaire, Referrer Questionnaire)

A Volunteer Advocate Policy was also finalised in 2010. The Policy sets out the procedures for Volunteer Advocates and provides guidance on the Volunteer Advocate role. The Policy represents an agreement between NAPA and the Volunteer Advocates. It sets out the requirements for Volunteer Advocates to practice including applications, garda vetting, training, relationships with staff in participating units, volunteering conditions, time commitments, confidentiality, record keeping, supervision, support, grievances and dismissal.

The Advocacy Handbook and the Volunteer Policy are clear and detailed, and address all elements of the advocacy relationship and role. Because they were drawn up during the pilot phase it is premature to evaluate how they have been implemented and integrated into the programme. As these policies and procedures were developed in a draft form when Volunteer Advocates commenced their advocacy roles, there is now scope for formalising them with Volunteer Advocates. It is evident from the evaluation that there is an inconsistent and low level of awareness of policies and procedures. There is an opportunity now to embed the policies and procedures into the practices of Volunteer Advocates. This could be carried out through local workshops and information sessions.

Similarly, there is a lack of knowledge of these policies and procedures in the participating residential units/homes. This suggests that there needs to be some awareness raising of the policies and procedures for Directors of Nursing, Managers and Link Persons.

During the evaluation, Volunteer Advocates welcomed the development of the National Advocacy Handbook. One Volunteer Advocate was disappointed that there was no consultation with Volunteer Advocates in the development of the handbook and reiterated the importance of consulting with advocates before finalising the document.

In the light some of the issues raised in the evaluation it would be expedient to review the Handbook and the Policy in relation to the new organisational and governance structure that has been recommended in the evaluation. This should be carried out in consultation with all stakeholders, including Volunteer Advocates and Development Officers.

## **2.4 Feedback from NAPA on the quality and quality and effectiveness of the Advocacy Programme**

There is a high level and commitment and support from NAPA group members for the Advocacy Programme, and for establishing a long-term sustainable structure for the future. Comments from NAPA members, the first from a representative of an older person's organisation, the second two from an HSE representative include:

The Advocacy Programme is a critical component to enabling the voice of older people to be represented, and it is critical to have a network of advocates to speak on their behalf.

The HSE has a low base regarding advocacy as a right and there is a low expectation of care in our units. Introducing the concept of advocacy to staff has been difficult; many staff believe that they are advocates but actually they are not, they are part of an organisation and a budgetary process.

Advocacy is badly needed, it has proceeded well with limited funding and has had to be flexible. It has real potential to grow.

There is a shared view from the stakeholders who were consulted as part of the evaluation that there have been significant improvements in the quality of care for older people in residential care. Higher expectations of quality of care from relatives and family members, greater visibility given to poor quality residential care, for example, in response to the Leas Cross Inquiry, and the introduction the HIQA standards for residential care for older people<sup>14</sup>, and regular HIQA Inspections of residential units/homes, have all had a positive impact.

However, we have such low expectations of what is possible in residential care, just because we are kind doesn't mean that they get good quality care. There are now more eyes in residential care.

As a result, the NAPA Group see that it is essential that Independent Advocacy became a regulatory requirement in the HIQA Residential Care Standards, since mandating an action will result in funding.

The struggle has been where should the programme sit. Ideally it should be outside of the HSE system. But in the early stages it was not possible for it to be located elsewhere. HIQA Standards in this area would be a significant boost to the programme.

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<sup>14</sup> HIQA (2007) *National Quality Standards for Residential Care Settings for Older People*

Overall there is a shared view that Independent Advocacy is a critical part of the quality of care agenda. However, it should not be seen as a 'soft service', but integral to the quality of care.

## **2.5 Support structure for Volunteer Advocates**

The establishment of the Advocacy Programme took place with very limited funding and the original plan submitted to the HSE for paid regional Development Officers was not funded. This was a considerable disappointment to the NAPA group. Best practice approaches and the experience of the CIB Advocacy Service did demonstrate the importance of professional support in mitigating the risks and challenges in providing a robust system of support and development for Volunteer Advocates. The absence of resources for Development Officer posts to provide a robust support structure led some organisations to pull back from their involvement in NAPA.

The absence of funding for a paid professional Development Officer structure led to an interim measure being put in place based on a volunteer network of Development Officers, linked to designated residential homes/units. Relying on this role in a voluntary capacity is a huge risk to the programme and is unsustainable in the long term. The role requires significant commitment, expertise and time. It largely works because of the commitment, experience and backgrounds of the Development Officers. The evaluation has found that the role, effectiveness and impact of the support structure provided to Volunteer Advocates by Development Officers, were as a result inconsistent and relied heavily on the exceptional commitment and time of the volunteer Development Officers. This finding does heighten the need for there to be paid Development Officers who can provide more consistent, sustainable and professional support to Volunteers.

## **2.6 The future direction for the Advocacy Programme**

NAPA members are aware of the need for the Advocacy Programme to be independent of the HSE and to be located in an independent organisation. Similarly, there is wide recognition that the learning from the programme and the future development of the programme requires a new strategic direction, with robust standards, protocols and procedures embedded in the new structure. This includes the need for quality indicators and reporting requirements to be put in place. These issues are discussed in greater length in Section 6 of the evaluation report, which makes proposals for a new organisational and governance structure for the Advocacy Programme.



## **Section 3: The Advocacy Programme in residential settings**

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### **3.1 Introduction**

This section provides an overview of the way in which the Advocacy Programme is currently being run in residential units/homes across the country. It provides feedback on consultations held with Volunteer Advocates, residential units/homes and Development Officers and highlights what is working. It highlights the critical success factors and challenges that can further enhance the further development and practical implementation of the programme.

**Critical success factors relating to the programme in residential units/homes can be summarised as follows:**

- Induction of Volunteer Advocates and introductions for residents, relatives and staff;
- Training and awareness of staff on the role and benefits of independent advocacy;
- Understanding the nature of advocacy in a residential setting and valuing the advocacy process of building relationships of trust in empowering older people;
- A close role and relationship with the Development Officer, including regular meetings with Directors of Nursing, Managers and Link Staff;
- Clarity of the roles of the Volunteer Advocates;
- Developing skills in advocacy for older people who are vulnerable or who have cognitive impairments; as well as skills in negotiation, mediation and listening;
- Systems for replacing Volunteer Advocates that leave;
- Systems for Volunteer Advocates to provide feedback and appropriate systems for responding to feedback given.

### **3.2 Participating residential units/homes and numbers of Volunteer Advocates**

The Advocacy Programme commenced in 2008, following its launch in 2007. The HSE wrote to all of the 607 nursing homes in Ireland to advise them of the programme and request their participation in the pilot of the programme. Ten residential homes responded positively to this call. During 2009 and 2010 the programme has expanded considerably to include a total of sixty-seven participating residential homes across sixteen counties in Ireland.

Currently there are a total of 133 Volunteer Advocates who are active in providing a regular advocacy service. The retention of such a high number of volunteers is a significant achievement of the programme. It is always anticipated that there will be reductions in volunteer participation over time, simply because volunteers have other demands on their time, family responsibilities or changes in their employment of living situations.

Chart 1 shows the number participating residential units/homes in each of the sixteen counties where the Advocacy Programme is in operation. Of the sixty-seven participating residential homes, there is currently one participating residential unit/home in each of Laois, Tipperary and Sligo; two residential units/homes in each of Offaly, Meath, Longford, Westmeath, Galway and Leitrim; three residential units/homes in Louth; seven residential units/homes in each of Cork City/County and Roscommon; five residential units/homes in Wicklow; nine residential units/homes in Kerry; and ten residential units/homes in each of Dublin/Co Dublin and Mayo.

**Chart 1: Participating residential homes by County**

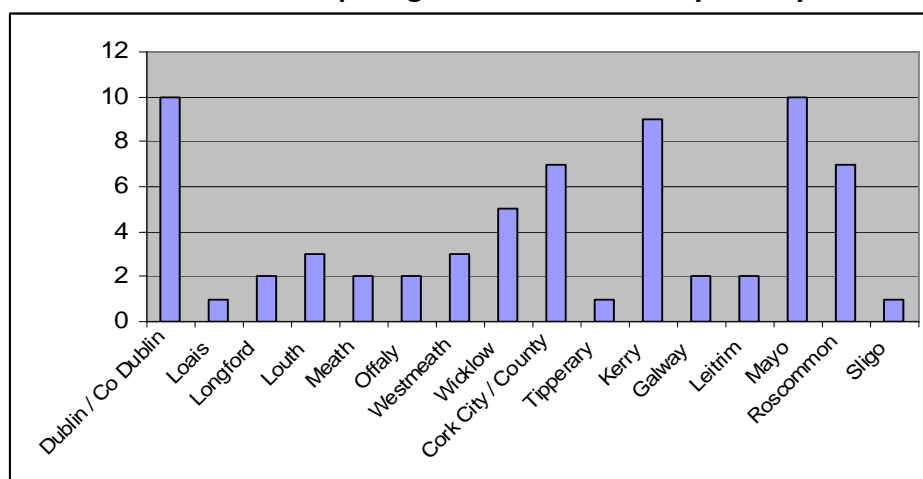


Table 1 shows the participating residential units/homes, the advocate placements following the completion of the advocacy training, and the numbers that are currently active as Volunteer Advocates.

Of the 150 Volunteer Advocates who completed the training and work-placements, 133 are currently active as Volunteer Advocates. Of these 127 Volunteer Advocates are in the units/homes that they were originally placed in, four moved to placements in other residential units/homes that were in closer proximity to where they live. Two Volunteer Advocates are currently working as independent Volunteer Advocates, providing a service to residential homes that have requested an advocate, but who are not participating in the programme at this stage. There are a considerable number of residential units/homes that are on the waiting list for the next stage of the programme.

**Table 1: Participating Residential Units and Volunteer Advocates in each Unit**

Residential Unit	No of advocates at start of programme	No of advocates (December 2010)	Place-ment in another unit*	Indepen- dent Advocate **
<b>Dublin / Co Dublin (10)</b>				
St Mary's Hospital, Dublin	10	2	2	1
Beneavin Lodge, Dublin	2	1		
Cuan Ros, Dublin	2	0		

Dalkey Community Unit, Co Dublin	4	3		1
Ashford House Nursing Home, Co Dublin	2	2		
Anam Cara, Glasnevin, Dublin	1	1		
Lusk Community Unit, Dublin	2	2		
St Clare's Home, Dublin	1	1		
Talbot Lodge Nursing Home, Malahide, Co Dublin	1	1		
Cuas Ros Community Unit, Dublin	2	0		
<b>Total</b>	<b>25</b>	<b>14</b>	<b>2</b>	<b>2</b>
<b>Co Louth (3)</b>				
St Joseph's Hospital, Ardee, Co Louth	1	1	1	
St Oliver's Home, Dundalk, Co Louth	2	2		
Beechtree Nursing Home, Co Dublin	1	1		
<b>Total</b>	<b>4</b>	<b>4</b>	<b>1</b>	
<b>Co Laois (1)</b>				
St Vincents Hospital, Mountmellick, Co Laois	1	1		
<b>Total</b>	<b>1</b>	<b>1</b>		
<b>Co Offaly (2)</b>				
Birr Community Unit, Birr, Co Offaly	1	1		
Riada House, Tullamore, Co Offaly	1	1		
<b>Total</b>	<b>2</b>	<b>2</b>		
<b>Co Meath (2)</b>				
Kilbrew Nursing Home, Ashbourne, Co Meath	1	1		
St. Joseph's, Trim, Co Meath	6	4		
<b>Total</b>	<b>7</b>	<b>5</b>		
<b>Co Longford (2)</b>				
St Joseph's, Longford, Co Longford	1	1		
Laurel Lodge, Longford, Co Longford	2	2		
<b>Total</b>	<b>3</b>	<b>3</b>		
<b>Co Westmeath (3)</b>				
Tearmann Bhríde Nursing Home, Athlone, Co Westmeath	2	2		
Mowlam Nursing Home, Moate, Co Westmeath	2	2		
St Vincent's, Athlone, Co Westmeath	5	5		
<b>Total</b>	<b>9</b>	<b>9</b>		
<b>Co Wicklow (5)</b>				
St John's Hospital, Enniscorthy, Co Wicklow	1	1		
Crookslin Hospital, Co Wicklow	3	3		
Earlsbrook Nursing Home, Co Wicklow	2	2		
Baltinglass Hospital, Co Wicklow	1	1		
St John's Hospital, Enniscorthy, Co Wicklow	1	1		
<b>Total</b>	<b>8</b>	<b>8</b>		
<b>Cork City / Co Cork (7)</b>				
St Finbarrs Hospital, Cork	13	12	1	
Middleton Community Unit, Co Cork	3	3		
Bandon Community Unit, Co Cork	3	3		
Bantry Community Hospital, Co Cork	1	1		
Sibereen District Hospital, Co Cork***	1	1		
Mallow Hospital, Co Cork		1		
Nazareth House Bantry, Co Cork	1	1		
<b>Total</b>	<b>22</b>	<b>22</b>	<b>1</b>	
<b>Co Tipperary (1)</b>				
Acorn Lodge, Cashel, Co Tipperary	1	1		
<b>Total</b>	<b>1</b>	<b>1</b>		

Co Kerry (9)				
Dingle Community Unit, Co Kerry	3	3		
Our Lady of Fatima Home, Co Kerry	4	4		
Cuil Didin Nursing Home, Co Kerry	4	3		
Kerry General Hospital, Loher & Dinish Wards, Co Kerry	4	4		
Ocean View Nursing Home, Tralee, Co Kerry	1	1		
St Columbanus, Kilarney, Co Kerry	8	5		
Aras Mhuire Greenville, Listowel, Co Kerry	2	2		
Caherciveen Community Hospital, Co Kerry	2	2		
Riverside Nursing Home, Co Kerry	1	1		
<b>Total</b>	<b>36</b>	<b>32</b>		
Co Mayo (10)				
Sacred Heart Home, Castlebar, Co Mayo	1	1		
Claremount Nursing Home, Co Mayo	3	3		
Brookvale Manor Nursing Home, Ballyhaunis, Co Mayo	4	4		
Mc Bride Community Nursing Unit, West port, Co Mayo	2	2		
Queen of Peace Nursing Home, Knock, Co Mayo	2	2		
Dalton Community Home, Claremorris, Co Mayo	2	2		
Blackrock Nursing Home, Foxford, Co Mayo	1	1		
St Attracta Nursing Home, Charlestown, Co Mayo	1	1		
St Fionnans Community Unit, Achill Island, Co Mayo	1	1		
Moy Ridge Nursing Home, Ballina, Co Mayo	1	1		
<b>Total</b>	<b>18</b>	<b>18</b>		
Co Galway (2)				
Aras Mhuire Community Unit, Tuam, Co Galway	1	1		
The Village Nursing Home Care, Oranmore, Co Galway	2	2		
<b>Total</b>	<b>3</b>	<b>3</b>		
Co Sligo (1)				
Baileys Nursing Home, Tubbercurry Co Sligo	1	1		
<b>Total</b>	<b>1</b>	<b>1</b>		
Co Leitrim (2)				
St Patricks Hospital, Carrick on Shannon, Co Leitrim	2	2		
Aras Carolan, Leitrim, Co Leitrim	1	1		
<b>Total</b>	<b>3</b>	<b>3</b>		
Co Roscommon (7)				
Fearna Nursing Home, Elphin, Co Roscommon	1	1		
Sonas Home, Roscommon, Co Roscommon	2	2		
Sacred Heart Home, Roscommon, Co Roscommon	6	6		
Oak Wood Nursing Home, Co Roscommon	1	1		
Aras Mhathair Phoil, Castlerea, Co Roscommon	1	1		
Plunkett Home, Boyle, Co Roscommon	1	1		
Fearna Nursing Home Castlerea, Co Roscommon	1	1		
<b>Total</b>	<b>13</b>	<b>13</b>		
<b>TOTAL NUMBER OF PARTICIPATING UNITS/HOMES = 67</b>	<b>150</b>	<b>127</b>	4	2

#### Notes

\*Volunteer Advocates moved to a another Unit usually because of proximity to where they lived

\*\* Two Volunteer Advocates provide an independent advocacy service based on requests made for advocacy from other residential home

\*\*one Volunteer Advocate provides a service in two Units (Bantry and Skibereen)

### 3.3 The benefits of the Advocacy Programme

The questionnaires disseminated to Volunteer Advocates, participating residential units/home and Development Officers asked for views on the main benefits of the Advocacy Programme in enhancing the quality of care for older people in residential care. The percentage distribution of the responses under each indicator can be found in Table 2. The indicators were established as part of the piloting process for the questionnaire.

**Table 2: The main benefits of the Advocacy Programme**

	<b>Residential homes</b>	<b>Volunteer Advocates</b>	<b>Development Officers</b>
Provides valuable and worthwhile volunteering opportunities for advocate	11%	9%	12%
A dedicated, confidential service is provided for older people who may not have access to information or help	13%	15%	12%
Enhances the rights of older people	15%	13%	12%
Provides advocacy for older people who may not be able to raise issues or concerns themselves	15%	13%	12%
Gives older people a chance to access new information and support	11%	13%	12%
Improves the quality of care in the residential home	12%	11%	14%
A safeguard against abuse or neglect taking place	12%	12%	12%
Other	11%	14%	14%
	100%	100%	100%

The benefits of the programme were further elaborated through the questionnaires, interviews and focus groups.

#### ***Benefits of the programme: residential homes/units***

Eleven of residential homes responding to the questionnaire stated that the Advocacy Programme had had a positive benefit for the care and support provided to older people. Four believed that it had some benefit, while none believed it had no benefit. The benefits were highlighted as contributing to person-centred care and in enabling residents to highlight concerns or issues in a confidential way. Responses from residential units/homes are that this “gives residents opportunities to explore any concern”; and helps support isolated residents “Excellent for residents who have no family/friends visiting, that advocate will visit and speak up on their behalf”.

The institutionalised setting of residential care impacts on both the residents and the staff, and for this reason the Advocacy Programme has been beneficial in raising awareness of how individual needs can be met in this setting:

Most care staff work to a strict ward routine. This often does not meet the individual requirements of the resident. Advocates raise awareness with staff that the individual needs of the resident have to be taken into account.

One residential unit/home stated that programme adds significant value to the care of residents and a possibility for residents to express their needs:

Though the Residents Forum and the independent advocates visiting the residents we have provided the residents in our care a protected environment to express their views/needs. It has also given them a voice in how they want to live their lives enabling them to be more involved in their care thus allowing us move to an environment that is empowering and person centre.

Another stated that the Advocacy Programme had helped to confirm that a good quality service was provided to residents, although offering an opportunity for residents to raise issues of concern:

A neutral voice on their behalf. It was good to hear from the advocates that our residents had told them that they were treated with dignity, respect at the home and all their needs were met. Some of the advocates felt that they were not adding value to the service apart from affirming to us that the overall care was of a high quality and residents knew what to do if they had a problem or concern.

In other cases the residential home/unit benefited from an outside perspective and an opportunity for feedback on the services provided:

Offers an alternative perception by the community on the services provided, as we invite in the public to act as advocates who potentially may be users of the service in the future and they can offer opinion on the service.

### ***Benefits of the programme: Volunteer Advocates***

Volunteer Advocates identified the main benefits of the Advocacy Programme to be the provision an independent role that empowers people to make decisions and choices. In particularly, the volunteer role was viewed as being critical to building trust and relationships with older people in residential care. As one Volunteer Advocate said:

People who are in paid positions to provide care are viewed as being part of the system and may not be trusted, many older people fear that if they complain they will be penalised for this.

Another stated that:

The situation older people are in makes them vulnerable; therefore, having an independent advocate who is not associated with the home can make a real difference.

Volunteer Advocates saw the main benefits of the programme to be building a relationship with a resident so that they feel that they have someone to speak up for themselves. As one Volunteer Advocate said: "Building this relationship leads into safeguarding their rights and against abuse, but as a start building that relationship is the most important I feel". Another said: "I feel it is a lifeline for residents who don't have any relatives". Another summed up the benefits of the programme as follows:

Although the Nursing Home I attend is excellent, I think the biggest asset of an Advocate is the fact that the staff know you are there and that you are there for the resident. I think the presence of an Advocate, particularly in a larger or a more institutional setting can have a major affect on staff thinking, particularly if the Advocate works on building up a good rapport with the staff. Handled properly a complaint need never be taken as criticism but rather as an appreciation of how 'busy' or 'under pressure' they are and letting them believe you are their 'third eye' as you all work for the benefit of the patient/resident. In most cases the quality of care takes up most of staff's time but the quality of life of the residents can be improved by the positive interaction between the advocate and the care staff/nursing staff.

### ***The benefits of the programme: Development Officers***

All but one of the Development Officers stated that they carried out their roles because they saw the benefit and value of the programme on the ground and had a huge commitment to making the programme work. Three Development Officers were of the view that the objectives of the Advocacy Programme had been achieved, while six stated that they had been somewhat achieved. One stated that the objectives had not been achieved. Five rated the Advocacy Programme to be excellent, four rated it as good, one as fair and one as poor. Overall the benefits were highlighted as being "The provision of an independent advocate who can help an older person have a 'voice' in their lives and in their care"; and "A real contribution to challenging and improving the residential care setting and improving the quality of care people receive".

### ***Benefits of the programme: older people***

Consultations carried out with older people who had had contact with Volunteer Advocates revealed that many were unaware of advocacy as a concept. This is a reflection of the sensitivity with which the advocacy programme has been implemented in practice by Volunteer Advocates. Those that were aware of the programme and who were able to provide feedback to the evaluator stated that the Advocacy Programme has been really important to their lives. As one person said "I know I have a regular visitor that I can confide in and it is really important to me". Several residents stated that they faced no problems or issues, while nonetheless

enjoying the company of the Volunteer Advocates. Many of the residents of residential units/homes that the evaluator met were really grateful for the visits, which helped to bring the outside world into the home.

Feedback was also given from several Resident's Committees and family members during the evaluation. For those that knew of the programme there was an overwhelming positive response to the programme and a real willingness to support the programme in the future.

### **3.4 The Advocacy Programme: feedback from residential units/homes**

Eight cases studies of residential units/homes were carried during the evaluation. In addition fifteen residential homes completed the questionnaire, eleven of which were in the public sector and four in the private sector. A number of issues and concerns were raised in relation to the training provided to Volunteer Advocates (these are detailed in Section 4: Advocacy Training Programme).

All residential homes rated the relationship with Volunteer Advocates to be excellent or good. In eight of the residential homes staff participated in Personal Excellence training. All of the responses were rated the quality of the programme as excellent or good. All were of the view that staff would benefit from further training in this area. (See Section 6 for the more detailed evaluation of the Personal Excellence training).

Overall, there was a positive welcoming of the Advocacy Programme: "Excellent service for our residents and needs to be expanded to all areas"; "I think that this has been an excellent initiative"; and "excellent service" were some of the responses from residential units/homes.

Several residential units/homes stated that they would benefit from a larger number of Volunteer Advocates, as there are insufficient advocates to meet the needs of all residents. This was particularly important with regards to replacing Volunteer Advocates that leave the programme. Some residential units/homes anticipated that as the service became better known and as relationships were built up over time with residents there would be a need for more Volunteer Advocates in the future:

As this service is very new there is still not enough awareness amongst residents or their families on how to use it. As they become more familiar with the service and make more demands on it we may need to increase the number of volunteers.

There is an overwhelming view that because of the nature of advocacy in a residential setting and the time that it takes to build relationships of trust with residents, that it is important for Volunteer Advocates to commit to a timeframe of two years:

Over time the advocates have developed good relationships with residents, their families and with the staff working on the wards. This relationship does take time



and it is very important that the advocates commit to the timeframe of 18 months minimum.

There are variations in the number of older people that are receiving an advocacy service. The most commonly reported number was of between 6 and 15 older persons per advocate. Retaining Volunteer Advocates has been very important to the credibility of the programme, in the case of one residential unit/home both of the Volunteer Advocates left the programme for personal reasons and were not replaced. In this case the Community Unit felt the service had the potential to grow and develop and that the Volunteer Advocate assigned to the Unit had developed a good relationship. However:

Both advocates assigned to Cuan Ros left for personal reasons. I felt the sudden departure without notice to the residents damaged the credibility of the advocacy programme for the residents and families.

In some cases residential units/homes are not aware of the presence of the Volunteer Advocates and stressed the importance of building relationships and contact with Link Persons. Some residential homes/units highlighted the strong links that have been established with relatives and family members who act as advocates for the residents:

Most of our residents have very attentive relatives and extended families that act as their advocates as required. Visiting is very open and there is a strong presence of the public in the home. We do not see the advocate as a safeguard as staff are very aware of elder abuse issues (as are the management) without the presence of an advocate.

### ***Embedding the Advocacy Programme into residential units/homes***

One of the biggest challenges is how the introduction to the Advocacy Programme is carried out. All residential homes/units highlighted the importance of the Development Officer in this regard, and to building concrete and clear methods for inducting Volunteer Advocates and introducing the programme to staff.

I believe initially that the introduction was rushed and there was a bedding in period when the advocate require support on the ground to function and appreciate their roles and boundaries of same. Since the appointment of the Advocacy Development Officer, this has assisted in supporting the advocates and the service immensely.

Some expressed dissatisfaction with the way in which the programme was introduced into residential homes, with one residential unit/home stating that there was a limited and sometimes confused role in introducing the programme to Link Persons and Director of Nursing, and insufficient information given to staff about the role and function of the programme.

A better overall induction to the programme would have minimised suspicion about the role and nature of the Advocacy Programme, which led some staff initially to

have fears that the programme represented “another HIQA inspection”, or “another complaints service” that conflicted with and potentially overrode the existing complaints systems developed in residential homes. A more comprehensive introduction to the programme, presented in more enabling ways, was regarded as being crucial to introducing and embedding the programme. However, once the programme was embedded in a residential unit/home, many staff quickly became aware of the benefits of the programme.

### ***Independence of the programme***

There was a general view that the Advocacy Programme should be independent of the HSE, this is particularly because the HSE no longer has a remit to inspect residential homes and because it is problematic for independent advocacy to be part of the HSE. One residential unit/home stated that:

I feel it is important that the advocates are independent to the organisation they are providing the service to and feel that by providing paid advocacy positions it will compromise who their loyalties lie with.

Another was of the view that:

I think it would be very useful if NGOs that represent older people become more involved with NAPA. While it is an excellent initiative on the part of the HSE, I do think that ultimately it needs to become an independent service.

### **Suggestions for the future of the programme: Residential Units/Homes**

- Improving and building relationships with staff, particularly in enabling staff to better understand the benefits and value of the Advocacy Programme;
- Training for Clinical Nurse Managers and staff on their role, and closer liaison with staff on the aims and objectives of the programme;
- The need for better training and awareness of Volunteer Advocates in providing advocacy for people with communication difficulties and dementia;
- Improved procedures for establishing the scope of practice, remit and roles;
- Ensure that a Development Officer is in place before the advocates begin their placement;
- Systems for providing regular feedback from Volunteer Advocates, in ensuring that there are regular meetings with Volunteer Advocates and a structured feedback/appraisal system for advocates;
- More initial, ongoing and regular information for staff in residential units/homes;
- Clarity in legal guidelines, procedures and training on how to gain consent from residents who have reduced capacity or cognitive impairment;
- Improved communications to ensure that if a Volunteer Advocate leaves the programme that the unit/home is informed of this, and a system for replacing Volunteer Advocates that leave;
- Training for Volunteer Advocates who may wish to facilitate a Resident’s Committee / Forum.

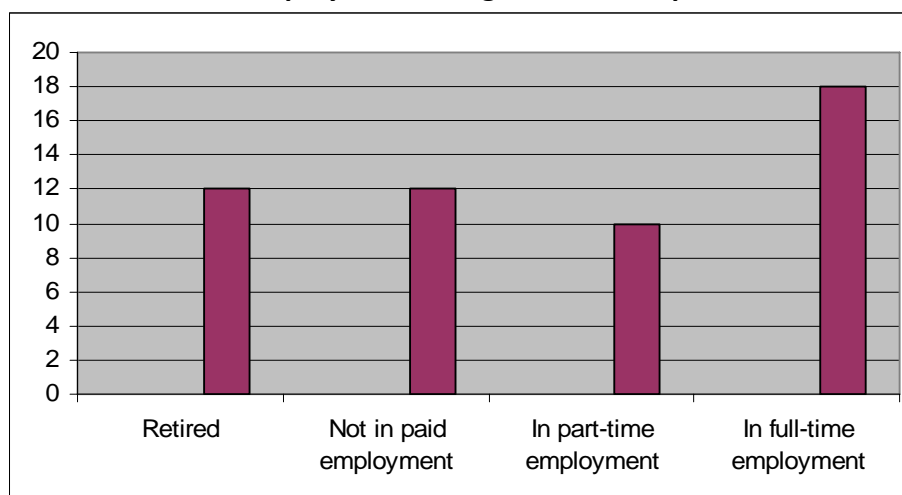
### 3.5 The role of Volunteer Advocates

#### ***Background of Volunteer Advocates***

The Volunteer Advocates come from all walks of life and bring a rich range of experience and skill to the Advocacy Programme. They include current and former carers of children and older people, people who work or had worked in health, social work, social care and community work; retired teachers, company directors and civil servants; and people who had engaged in advocacy work with NGOs. A significant number came to be volunteers because they had connections with residential care for older people, either as staff working in residential units/homes or as family members of residents in units/homes.

Of the total of fifty-two questionnaires completed by Volunteer Advocates, thirty-nine were women and thirteen were men. Chart 2 provides a breakdown of the backgrounds of participants, twelve of whom were retired, twelve were in paid employment, and twenty-eight were in employment (ten part-time, eighteen full-time).

**Chart 2: Employment backgrounds of respondents**



#### ***How advocacy is defined and practiced by Volunteer Advocates***

Through the consultations carried out in the evaluation Volunteer Advocates identified three main elements of the independent advocacy role that they provide:

- Empowering and enabling people to make choices and helping them to make decisions;
- Being able to speak up on behalf of an individual, which may be at odds with the institutional or care regime;
- Listening to people and taking them seriously, observing the dynamics of relationships.

In the early stages of their advocacy roles the Volunteer Advocates had some difficulties in relating their training to the practical situations that they encountered.

It is over time that these roles have evolved with confidence. Volunteer Advocates had to resist bringing their own perceptions and observations into their advocacy roles, and in many cases to learn the importance of standing back and building relationships of trust. As one Volunteer Advocate stated:

We don't see our role as trouble makers, we can see people's needs from a different perspective and sometimes someone's individual needs may be at odds with the collective. We are there to provide a perspective on an individual's needs rather than making assumptions. Sometimes this means that we have to approach the situation in a very slow and cautious way, and sometimes this means stepping back.

Advocates stated that it was crucial to have permission from the older people they were advocating before they raised issues or concerns with their Link Persons. In some cases advocates observed situations that they were concerned about, in which case the usual protocol was to approach the Development Officer, who then highlighted the issue in a meeting with the Director of Nursing. Advocates felt that they had to approach their advocacy roles with sensitivity, particularly in how they highlighted issues to Link Persons.

While some saw their roles as befriending, this was seen to be essential to building the relationships of trust. Many advocates do not encounter serious issues or concerns and many of the issues and concerns that arise in their advocacy roles are easily dealt with through the Link Person.

I have not encountered any issues or problems from any of the residents. I am really there as a befriender and still seem to be at the building a trust stage. Any issues that one or two of the people have mentioned, they have already solved them themselves. I am continually observing and observe things that don't necessarily need change now but as a future change could be dealt with i.e. residents in bed so early, lack of stimulation etc...

Many Volunteer Advocates saw their role as being present in the residential unit/home as a 'watchdog' and improving the quality of life for residents: "Just being present is an incentive to keep quality services going and an opportunity to view staff interaction with residents". There were other specific issues and concerns that Volunteer Advocates had addressed. Examples include:

- Providing support in accessing optical or hearing aids;
- Helping residents to find lost clothing from laundry;
- Advocating on behalf of the resident about meal times, having meals in their rooms and on dietary issues;
- Enabling a resident to have his own music, in this case the resident concerned was happy when he could have a portable CD player to listen to classical music;
- Assisting a resident to make a formal complaint about a member of care staff;
- Providing information about 'Fair Deal' and entitlements to services;
- Advocating for a resident with a family member, and in some cases mediating between the resident and the family member about financial issues.

Many advocates highlighted issues of loneliness and isolation of older people, and reflected on how important their visits were to them. One of the key issues that Volunteer Advocates have raised is that the staff in residential units/homes have very little time to spend with the residents.

While I find the physical care of the older person in very good, the psychological care leaves a lot to be desired. For example if I ask an older person if a member of staff has ever sat down and talked to them the answer is always no. It appears to me that the communication between the older person and members of staff is mainly superficial i.e. in passing rather than sitting down with the older person for 30 minutes every week and finding out how the older person is settling/progressing on the ward. I have discussed this issue with my Development Officer, Director of Nursing and the Clinical Nurse Manager on the ward.

### ***The role of Volunteer Advocates in the residential setting***

A number of procedures were put in place at the start of the programme, such as wearing of name badges and signing in during for each advocacy visit, which appear to have been observed by Volunteer Advocates. The majority of the Volunteer Advocates responding to the questionnaire provided an advocacy service for between 2 and 4 hours a week, reflected in Chart 3. This is in line with the guidance provided to Volunteer Advocates.

In the focus groups with Volunteer Advocates this was viewed the correct amount of time, both in terms of the time commitment that a Volunteer Advocate can give, but also in relation to the effort required. These times were deemed sufficient to meet the needs of older people for around half of the respondents, while for the other half there was not enough time. In these cases there was an insufficient number of Volunteer Advocates in some residential units/homes to meet to enable them to visit all residents who avail of the advocacy programme.

**Chart 3: Average weekly hours of Volunteer Advocates**

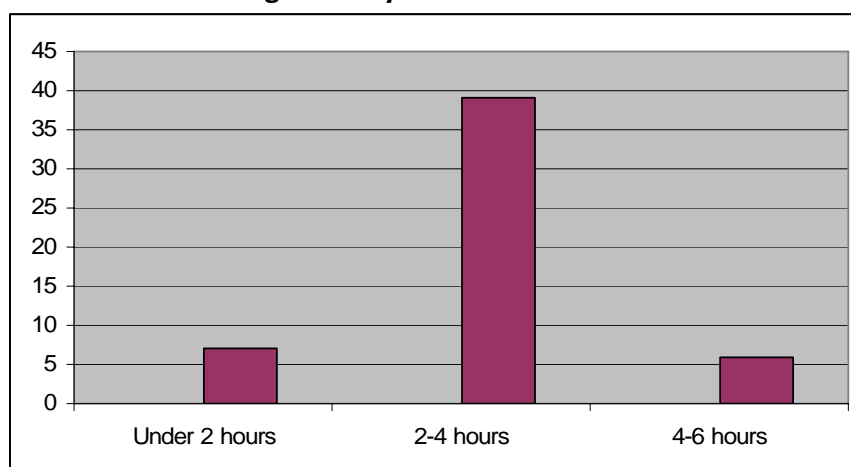
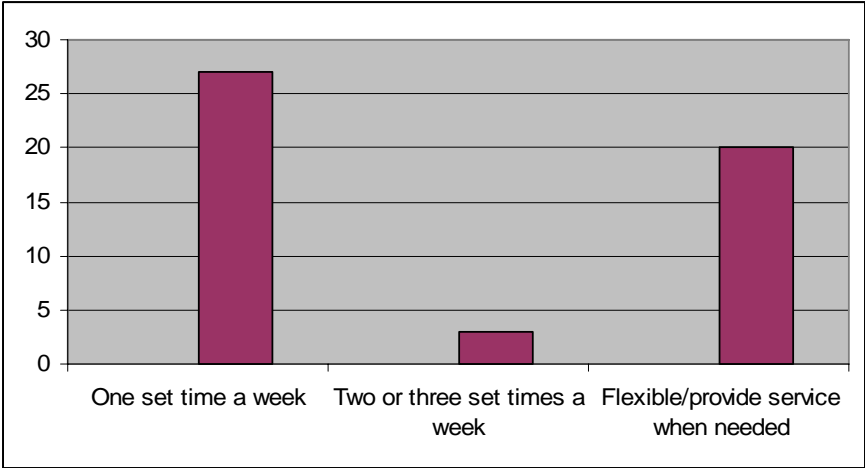


Chart 4 shows that just the majority (n=27) visited at a set time during the week, while under half provided a more flexible service at different times of the week (n=20), and a smaller number (n=3) had two or three set times a week. There were

mixed views about whether there should be a set time a week or whether this should be flexible.

The benefit of a set time is that residents, who are used to routines, become familiar with and look forward to the Volunteer Advocates visiting them. However, as several Volunteer Advocates stated it is very useful to go in at different time, particularly as a regular time may mean that “the staff will be on their best behaviour or not do anything wrong when they know the advocate is there”. In practice, some Volunteer Advocates have more flexibility than others, and the times for visiting the residential units/homes are very much dependent on the regularity or irregularity of work, family and other commitments. For example, one volunteer advocate visited the residential home on her way home from work, while others realised that weekends were not such a good time to visit as this was the time when family members were more likely to visit.

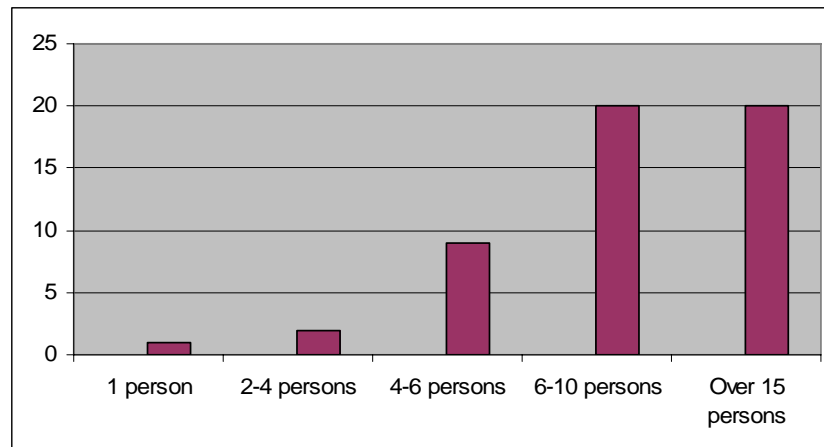
**Chart 4: Regular or flexible visiting times**



It appears from feedback from residential homes, Development Officers and the Volunteer Advocates that the optimum number of residents per Volunteer Advocate should not exceed ten per week. Chart 5 shows that twenty advocates regularly visited more than fifteen persons, a further twenty regularly visited 6-10 persons and a smaller number visited less than six persons.

Although the guidance given to Volunteer Advocates was that they would visit approximately ten residents a week, in some units/homes the Director of Nursing or Link Persons have been prescriptive in identifying a small number of residents. In one case, following discussion with the Development Officer and the Director of Nursing, it was agreed that the advocate would advocate for all resident in the unit.

**Chart 5: Number of people visited on a weekly basis by Volunteer Advocates**



Volunteer Advocates have worked out their own strategies for visiting the residents they provide an advocacy role for. Visits range from between five minutes to twenty minutes. As one Volunteer Advocate who provides a service to fifteen residents stated “Although I visit each resident every week I try to arrange my schedule so that I have a real good in depth chat at least every 3<sup>rd</sup> week with each of them”.

There are huge differences in providing advocacy for people who are mentally aware and those that experience cognitive impairments. The biggest challenges faced by Volunteer Advocates have been in providing advocacy for people with cognitive impairments and dementia. As one Volunteer Advocate stated:

I feel that going once a week can be difficult when you are dealing with people at various and changing stages of dementia. Some of the residents know who I am most of the time, not sure they would always remember that I am an Advocate – despite badge – but know I visit and I enquire as to their needs, talk about their families etc., others vary between knowing who I am and thinking that I am a resident.

Another was unsure about how to relate to older people with dementia and asked for guidance on non-instructed advocacy:

I have 15 residents in a ward of 39 that I visit. I visit with them all each week, except where one may be asleep at the time I am there. I was advised by the nursing staff that as the other residents are uncommunicative and in the advanced stages of dementia an advocate would not do them much good. So far, I have not really visited with them and thus feel guilty as non-instructed advocacy is important too. Guidance on this would have been appreciated in the training.

Prioritising who to visit when time is restricted for a volunteer is something that many Volunteer Advocates have to deal with. As one Volunteer Advocate stated:

It does vary who and how many residents I get a chance to speak to. Some of the residents know me well by this stage and like to call me over when they see me to have a chat. It is not possible to sit with that many of the residents on a given week

– this is due to the time frame of my visits. I try to give priority to those who call me over to speak to me and those who do not have any family who come to visit.

For others there are too few Volunteer Advocates to enable them to provide an adequate level of advocacy and to have time to build relationships with the residents they visit. As one Volunteer Advocate stated:

I don't feel I have enough time to see all of the patients. There are about 26 patients in the unit and there are two of us providing advocacy. We try to see as many people as possible but it isn't always possible.

### ***How advocacy issues are dealt with***

There are a wide range of approaches to dealing with issues raised in advocacy, ranging from no systems in place to well structured system for giving feedback. In most cases Volunteer Advocates referred issues or concerns to their Link Person, and these were usually dealt with swiftly. Some participating homes had developed a more structured approach to dealing with issues that are raised from their advocacy role. This includes monthly meetings organised by the Development Officers with the Director of Nursing / Manager to give feedback from Volunteer Advocates and to address any issues arising.

In St Finbarr's Hospital, for example, a log form has been drawn up. The actions are logged by the advocates and are then followed up and actioned by the Director of Nursing. This system has enabled the Development Officer to see how issues have been dealt with and to discuss outcomes. The advocates are then able to give feedback to the residents concerned about how the issue they raised was dealt with.

### ***Involvement in Residents Committees***

There is a general lack of clarity of Volunteer Advocacy roles in relation to Resident's Committees. Some advocates had built good relationships with the Residents Committees, either in relation to supporting advocates to participate in meetings or playing a more direct role in the meetings themselves. Several residential units/homes saw a potential for an advocate to chair the Resident's Committee. However, some advocates saw that participation in the meetings would shift their role away from their role in working with individuals through independent advocacy. As a result, there is a need to clarify the role of Volunteer Advocates in relation to their engagement with Resident's Committees.

One Volunteer Advocate had been instrumental in setting up a Resident's Committee in the hospital in which he volunteers as an advocate and saw this a very positive contribution:

I feel that I have made a difference in a very short period of time and for me this is very rewarding...The inception of the resident's committee will be a momentous episode in the history of the establishment. By working in unison with the staff, management committee the forum will strive to enable the individual resident to

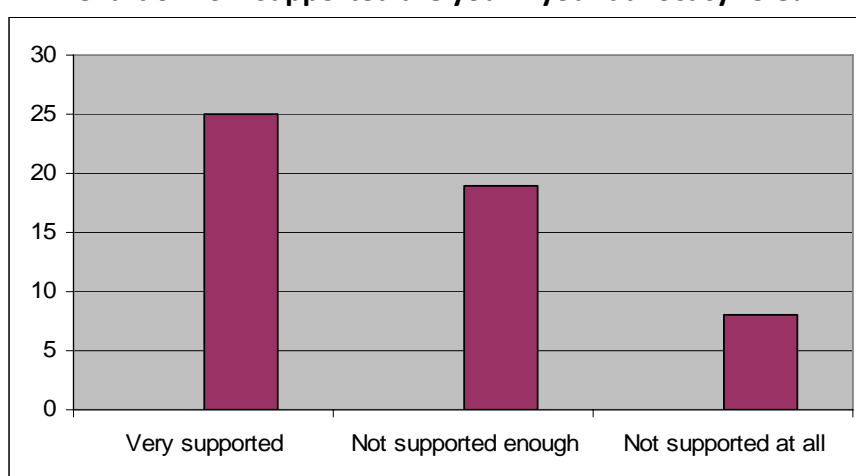


develop positive self esteem through empowerment in an attempt to build a happy living environment and personal fulfilment in life.

### ***Support for Volunteer Advocates***

Support for Volunteer Advocates has been raised consistently across all of the consultations held during the evaluation. Those that did not feel supported tended to be either working in an isolated capacity or with no Development Officer support. Chart 6 shows that of those responding to the questionnaire twenty-five felt very supported, while nineteen were not supported enough and eight were not supported at all. This is an extremely important issue that needs to be addressed in the next stage of the Advocacy Programme.

**Chart 6: How supported are you in your advocacy role?**



Those Volunteer Advocates who are the sole volunteer in a unit/home stated that there should be a minimum of two advocates per unit/home: “It is important that there are at least two volunteer advocates in each residential home to ensure support and assistance when dealing with daily issues”. For those Volunteer Advocates who were part of a team, team support and an opportunity to discuss the advocacy roles and issues arising was very important. As one Volunteer Advocate stated

I was extremely lucky to have had two other independent volunteer advocates in our residence and we worked as a team discussing various issues, giving one another support and learning from good practice. This teamwork has made our work very rewarding and enjoyable.

There were very mixed experiences of support from Development Officers, ranging from regular communications to irregular or limited communications. Volunteer Advocates at St Finbarr’s Hospital in Cork noted the professionalism with which their Development Officer supported them and the close liaison with Link Persons on the wards, and between the Development Officer, the Director of Nursing and the Clinical Nurse Manager responsible for the programme.

As one Volunteer Advocate stated it is “Reassuring to know that our development worker is only a phone call away” and knows she can contact him at any time.

I meet my Development Officer on a regular basis for lunch...He is most supportive and has helped me talk through any reservations or questions I might have had over time. I know he is only a phone call away should I have any major concerns. Two advocates attend at this nursing home and he meets us both individually and ever so often we meet as a group.

Some of those Volunteer Advocates who had limited or no contact with the Development Officer, had met regularly to provide peer-support.

Clarity about the role of the Development Officer and better systems of support are urgently needed if Volunteer Advocates are to be retained in the long-term. As one Volunteer Advocate stated:

I have never met my development officer or my Link Nurse since the initial meeting. My link nurse is always too busy and I don't like to bother her. I have not encountered any problems in my nursing home to need to meet with either the development officer or the link nurse, but it would be nice to actually meet the link nurse once every few months just to check in. Some of the nurses can be helpful. I also meet up with some of the other advocates at the same nursing home so we provide support and reassurance to each other. But it would be good I think to have another source of support to say whether we are doing right or wrong, or to provide advice.

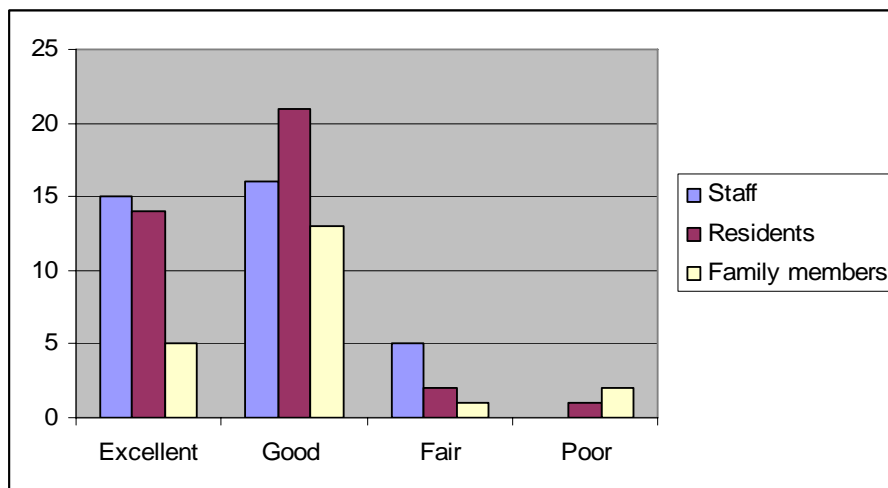
A large number of Volunteer Advocates welcomed the support and information from the Advocacy Programme Coordinator who is always available to talk to by phone. As one said she “keeps us up to date on what is happening in the area of elder care, conferences etc. She recently organised a dinner following a Conference in Dublin and it again was great to meet people on a less formal basis”.

### ***Relationships with staff, residents and family members***

Overall, respondents to the questionnaire had built either excellent or good relationships with staff, residents and family members. Chart 7 shows that relationships are generally excellent or good, with no respondents reporting poor relationships with staff, residents or family members.

Relationships with staff were excellent in fifteen cases, good in sixteen and fair in five cases. Relationships with residents were excellent in fourteen cases, good in a further twenty-one and fair in only two. Relationships with family members were excellent in five cases, good in thirteen and fair in only one.

**Chart 7: Relationships with staff, residents and family members**



Building relationships with residents was an important learning process for the Volunteer Advocates, many of whom stated that these relationships could take six months and sometimes up to a year to form before enough trust was established and residents felt confident in raising issues of concern. In some cases the creating and building of a relationship takes place each time they visit a resident. The following two Volunteer Advocates gave comments that are typical of much of the feedback given in the evaluation:

It is important to build a trusting relationship with the older person so that if they have any issues they can confide in me.

After only six months we are still on a learning curve and settling into our role as volunteer advocates. I feel up to now 99% of my time has been spent befriending and gradually building a relationship with the residents and helping them to feel less lonely and isolated. This building of trust is what advocacy is based on. The residents have only started speaking about their personal issues in the past few weeks.

Building relationships with staff was not always easy in the early days. However, a critical factor in the relationships with staff can be put down to the role played by the Director of Nursing or other responsible person for the programme and the Link Persons. Two critical success factors for good relationships include having a constructive induction into the residential unit/home, and ensuring that Link Persons and care staff were made aware of the role that the advocate plays in a residential setting. As one Volunteer Advocates stated:

The staff are always helpful in terms of providing me information and in relation to when I speak to them in terms of any issues, no matter what the issue is. Furthermore, they make me feel welcome and entitled to be there.

Many Volunteer Advocates felt that in the early stages staff were often suspicious of their roles: "We were in the early days seen like a HIQA inspector and this did not help us to settle in", while for another Volunteer Advocate "The members of staff seem reluctant to communicate as I think they do not fully understand the role of

the advocate". Some of the suspicion also resulted from the institutionalised setting and the embedded regime of care, while in others staff believed that they were the 'advocates' of the patients. Over time, however, the level of suspicion eased.

In some cases Volunteer Advocates have built very good relationships with family members, while in a few cases Volunteer Advocates provided mediation between family members and the resident. Overall, residential care staff and the Volunteer Advocates stated that the family members valued the role of the Volunteer Advocate and saw them as an important "watch dog who could ensure that they have the best quality of care".

### ***The role of Volunteer Advocates vis-à-vis HIQA***

Volunteer Advocates suggested that there was a need for better clarity regarding HIQA inspections. While many believed that advocacy should be a core standard and a requirement of inspections, there were mixed views about the role of the Volunteer Advocates in the inspection process. Some Volunteer Advocates had been interviewed by HIQA Inspectors because they happened to be in the residential unit/home at the time of the Inspection. One Volunteer Advocate was very 'put out' that she had to be interviewed, and was asked for records of how many advocacy sessions had been carried out and what issues had been raised. She saw this as been very inappropriate for a volunteer. Other Volunteer Advocates believed that the Volunteer Advocates should be involved in giving feedback to HIQA Inspectors, while also preserving the confidentiality of the issues and concerns raised.

### ***Further developing the Volunteer Advocates through mentoring and buddy roles***

There is now a group of very experienced Volunteer Advocates, whose skills could now be used to provide mentoring for new volunteers as they come through the next training programme. This could provide an important source of support that would help them deal with the challenges of first taking up a volunteer role. As one Volunteer Advocate said "In some cases this need for 'hand holding' for a period of time, particularly during the placements". The majority of Volunteer Advocates who participated in focus groups and interviews as part of this evaluation stated that they would like to provide this role in the future. However, several did say that they may need training on how to approach this role.

### ***Further development of the programme***

There is a key role to be played by the Volunteer Advocates in the providing advocacy to the significant numbers of older vulnerable people living in the community. It is possible to envisage a network of advocates who provide advocacy across in residential and community settings within a specific geographic location. This is particularly important as the development of HSE services under the Integrated Service Areas provides a framework for better integration between hospital and community care services. Discharge from hospital or respite care is a

key area identified for advocates to play a role in ensuring that there is access to benefits, services and information at this critical time.

Several advocates highlighted the important role that could be played by advocacy for people availing of respite care, not only in empowering people to identify their needs in residential care, but also when they return to the community.

#### **Suggestions for the future of the programme: Volunteer Advocates**

One Volunteer Advocate expressed the views of many advocates in that:

The programme must be available in all nursing homes in the country to ensure that all our senior citizens are well cared for, treated with respect and given the time and care they deserve.

Other suggestions included:

- Establish an Advocate Support Group at the local level and link this into a national Advocate Support Group;
- Provide more guidance on how to address serious complaints, how to link into existing complaints procedures and to avail of back up and held if needed.
- Provide opportunities for experienced Volunteer Advocates to provide inputs into the training of new advocates and in mentoring new advocates in their work-placement settings and when they commence their advocacy roles;
- Establish a web site for the Advocacy Programme, with opportunities for Volunteer Advocates to share information and support through a web based forum and through a Facebook for Volunteer Advocates. It was stressed that this should be anonymous;
- Additional advocates to share the workload in units/homes that have insufficient Volunteer Advocates;
- A group of floating advocates to visit residents in units/homes that do not currently have advocates;
- Clarity regarding insurance coverage if anything happened to a resident, for example, “if a resident fell while walking in our company”;
- Extend the programme to all residential units/homes across the country, so long as there are sufficient advocates in place to meet the demand;
- Continuous assessment and monitoring of the roles of Volunteer Advocates and in clarifying the roles of advocates;
- More information for relatives and families about the advocacy programme, and more visible publicity for the programme through newsletters and posters in residential units/homes;
- Improvements in the way that Volunteer Advocates are introduced to staff during placements as a basis for building good working relationships.

### **3.6 The role of Development Officers**

Some of the problems that are inherent in the Advocacy Programme relate to the lack of a professional structure of support. This led to some significant problems in some areas where either a Development Officer was no longer able to continue the role or where support provided was limited. Despite these problems, in at least four areas the Development Officers have given huge commitment and time to the programme, however, it is not possible for this to be sustained as a model in the future. In some cases the exceptional commitment, professionalism and skills of these Development Officers has resulted in very a very robust support structure.

Some Development Officers were surprised at the extent of the role that they were expected to play and that some were not prepared for this. This may explain why two Development Officers have dropped out of the programme.

The programme has benefited from two paid Development Officers who were recruited by Age Action to provide part-time Development Officer posts (at St Joseph's Hospital Trim and St Mary's Hospital, Dublin) as part of their HSE funding allocation. The Development Officer at St Mary's left the programme for personal reasons and there was a period of time when no Development Officer was in place. An interim arrangement was put in place through the appointment of a Development Officer employed by Age and Opportunity.

The position of a part-time Development Officer at St Joseph's Hospital Trim, does demonstrate the value that a paid position has to providing the ongoing support and development of the Volunteer Advocates, in liaising and meeting with Link Persons and the Director of Nursing and in enhancing the profile and impact of the programme in the hospital.

#### ***Backgrounds of Development Officers***

The backgrounds of Development Officers range from those that are retired to full-time workers who carry out the role in their free time. Of the ten Development Officers responding to the questionnaires, four were recently retired, while five were in employment (three full-time and two part-time). In the case of one Development Officer, who is employed as a social worker with the HSE, he had been able to incorporate the role into his existing job. This has enabled him to dedicate a significant amount of time to supporting the advocates, liaising with the participating residential homes and meeting regularly with the Directors of Nursing / Link Persons.

#### ***Role of Development Officers***

In an average week the volunteer Development Officers provide between three and four hours support to Volunteer Advocates. The Development Officer, who is employed part-time in the role, provided over ten hours a week. However, feedback from consultations with Development Officers is that there is a need for a greater

input of time in supporting Volunteer Advocates and in liaising with the residential units/homes, particularly when students are on work-placements.

Feedback from Development Officers is that they play different roles across the country. Roles are defined to include:

- Quarterly or monthly meetings with the residential unit/home liaison persons;
- Monthly or six weekly meetings with the Volunteer Advocate;
- Being available to volunteers when they need back-up;
- Regular email and telephone contact and support;
- Support and supervision of Volunteer Advocates.

One Development Officer defined the role as being:

To ensure the advocates are comfortable in their role, grow in confidence to question what they see. To assist them in valuing their independent role and to understand the myriad roles full-time staff in residential units perform...to assist the advocate to achieve their own goals as long as they match the aims and objectives of the NAPA committees.

Another stated that the role was in:

Facilitating support groups for advocates, liaison with staff in [the residential unit]...I have also facilitated a residents forum [in the hospital]. I am conscious of how little time I can make available to the role and have tried to focus on developing the group as a support structure.

Most Development Officers have set up regular meetings with the Director of Nursing/Manager of the residential unit/home to discuss how to work together as a team. Some Development Officers have participated in Resident's Committee meetings. In one case, in St Joseph's, Trim, a local Steering Group been established for the programme which has been put in place as structure to oversee, raise awareness of and develop the programme.

At the local level Development Officers have created structures and processes for volunteer support that in most cases have worked extremely well. One Development Officer had developed a booklet in her area 'Access to Independent Advocacy: A helping hand' to inform residents and families of her role and outlining the benefits of independent advocacy. Another Development Officer who supports Volunteer Advocates across Kerry produces a regular newsletter on the Advocacy Programme for advocates and residential homes in the County.

Those Development Officers that hold regular meetings with Volunteer Advocates, usually on a monthly basis, use the meetings as an opportunity to invite guest speakers and enable the group to participate in ongoing learning and development, peer-support and discussion. These meetings have been critically important in bringing together advocates from a wider network of residential units/homes, for example, in Kerry and Cork. In South Dublin it is planned to hold regular meetings

with all Volunteer Advocates in the area, in addition to the meetings currently held with Volunteer Advocates in each residential unit/home.

Support is provided through regular email and telephone contact with Volunteer Advocates. Regular supervision and group meetings provide feedback and opportunities to resolve any difficulties or challenges that the Volunteer Advocates face. Some Development Officers are available by mobile phone at evenings and weekends, and in the case of emergencies.

The Development Officer see their roles as being critical where issues and concerns are raised that cannot be dealt with directly through the liaison between the Link Persons and the Volunteer Advocates, and particularly where concerns are not dealt with or where, if arising in the future, there are serious cases of abuse or neglect.

It is crucial that Development Officers are supported in their roles and the formation of the national Development Officers Group has been important in this regard. The extent to which Development Officers feel that they are supported in their roles varies, with some stating that they have very good and regular communications with the Programme Coordinator. This support role is seen as crucial to particularly as one Development Officer stated that "I feel strongly that the role of development officers are crucial to retaining volunteers and assisting residents whom they met". The need for clear objectives and procedures, including information packs for Volunteer Advocates and Development Officers, was seen as crucial. As one Development Officer stated "Since I have not received any formal training, as Development Officer I need this support".

Overall the majority of Development Officers felt that they were supported in their role by the National Programme Coordinator, while three stated that they were not supported sufficiently. One stated that "I feel that the volunteer advocates should receive more support (both financial and professional)".

### ***Training of Development Officers***

Development Officers did not receive any training in preparing them for their role and as a result some were not fully equipped to carry out the role. As a result many learnt on their feet and grew into the role, developing their own procedures locally to support Volunteer Advocates. All Development Officers stated that they would benefit from initial and further training.

Some Development Officers already had some training in advocacy, and several had backgrounds in advocacy, Social Work and Community Work, which provided them with some relevant background and skills for the programme. Because of the absence of training for Development Officers several participated in the Volunteer Advocates training. As one Development Officers stated:

I elected to attend the Advocacy Training at NCI so that I could better know the volunteers and know in more detail the culture and guidance being taught. I would



strongly recommend that all Development Officers join the group they subsequently support.

Development Officers identified some specific training needs around the structure, process and protocols for supporting Volunteer Advocates and highlighted the need for “training on Dementia and how to facilitate the voice of people with dementia or indeed other frail people”, as well as elder abuse awareness in a residential setting, knowledge of formal complaints procedures, and regulatory and legislative matters. Other training needs were identified in areas such as supervision and team building, stress management and mediation skills. The need for improved procedures for the role of Volunteer Advocates was highlighted by one Development Officers:

Standardisation of role and its scope and the scope of volunteer advocate role [and a] structure of informing hospital staff about the role. A process of integration of volunteer advocate into the employing organisation’s communication systems.

### ***National Development Officers Group***

A national Development Officers Group has been established as a forum for discussion and support for Development Officers across the country. The Coordinator of the Group stated that this has become an important forum building “expertise in collating the shared experience of good practices and addressing shortcomings”.

Some of the Development Officers outside of Dublin have been unable to make the meetings. For those able to attend, the meetings have been a very valuable source of support for the sharing of information and exchanging different approaches, problems and issues. This has been a very important structure in clarifying and developing roles.

As one Development Officer stated “Where it is implemented I would say it is effective. Residents and family now have somebody to represent and negotiate on their behalf”. Some Development Officers are of the view that the programme’s objectives are not sufficiently clear or understood. As one Development Officer stated:

This is a valuable and worthwhile programme but there is a lot of confusion surrounding the roles of NAPA, Development Officers, advocates and service providers and this now needs to be urgently resolved in order that the benefits of the advocacy programme can be achieved.

### **Suggestions for the future of the programme: Development Officers**

- Retention of Volunteer Advocates in the long-term, and a process for replacing Volunteer Advocates who leave the programme;
- A new phase of training for Volunteer Advocates to extend to other residential units/homes, and to ensure that existing residential units/homes have a full complement of Volunteer Advocates;

- A structure of paid Development Officers who can devote time and expertise in providing professional support to Volunteer Advocates and in liaising with residential units/homes.
- The Advocacy Programme should be independent of the HSE, and also extends to those Development Officers who work for the HSE.
- Development Officers should receive expenses for travel or other incidental expenses arising from their role.
- Improved structures and processes for embedding the programme in residential units/homes, particularly during work-placements and in the ongoing awareness of staff, residents and family members of the programme;
- Clarity of roles and responsibilities to avoid misunderstandings of the role of the Development Officer;
- Utilising the skills and experiencing of existing Volunteer Advocates to enable them to provide a floating service to residents in other residential units/homes.

## **Section 4: Volunteer Advocacy Training and Support**

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### **4.1 Introduction**

The provision of training for Volunteer Advocates has been a critical component of the Advocacy Programme, and deemed essential to provide Volunteer Advocates with the knowledge and skills of advocacy in a residential setting. In 2009, the School of Community Studies, National College of Ireland (NCI), was contracted to provide ten Advocacy training courses in different locations across the country, and a 12-month programme of Continuing Professional Development (CPD) for Volunteer Advocates who had completed the initial training programme and who were actively carrying out a Volunteer Advocacy role in a residential home for older people.

A total 173 people were originally registered for the training and 150 Volunteer Advocates had completed or were close to completing the training by the beginning of 2011. This represents a relatively high retention rate of 87%. Reasons for non-completion of the training were related to primarily to personal circumstances, while one person left the course because of travel distance and another because of a conflict of interest. A final training course for up to thirty people is due to commence in 2011 in the border counties of the Republic and Northern Ireland. A further thirty Volunteer Advocates have participated in the CPD programme in Gerontology.

The course was accredited at FETAC Level 6<sup>15</sup> in Advocacy, which provided a NAPA 'licence to practice' as Volunteer Advocates. During the development of the programme careful thought was given to the level of accreditation in the Training Sub-Group and with the NCI. The rationale for accrediting the programme at Level 6 was considered to be crucial to giving professionalism to and currency for the Advocacy Programme.

### **4.2 Volunteer Advocacy training programme**

The first cohort of training course took place in Dublin (North) at St Mary's Hospital and in Trim at St Joseph's Hospital. The eleven week training programme for this first cohort comprised of:

- Taught course (6 half days and 2 full days)
- Work placement (over five days)
- Assessed course work

Following the completion of the first cohort of training, and in the light of feedback on the training, a revised programme was drawn up. In addition, a structure for supervision and support of learning in the classroom and during placements, and a clarification of academic roles and responsibilities, were put in place. The new

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<sup>15</sup> Further Education and Training Awards Council (FETAC)

programme, delivered in Cork, Dublin (South), Tralee, Sligo, Roscommon and in the Border Counties comprised:

- Focussed orientation sessions (2 half days)
- Taught course (6 half days and two full days)
- Work placement (over 5 days)
- Assessed course work

The main elements of the training are as follows:

- The taught course covered theoretical frameworks on advocacy and skills required by advocates' working with older people, interpersonal communications, advocacy skills, legal issues, rights of everyday living and self-advocacy strategies, and the role of supervision in an advocacy practice.
- The orientation sessions covered an introduction to NAPA, background to the programme, overview of the clinical setting in residential homes and introduction to the ailments affecting older people.
- The work placements involved five two-hour advocacy sessions in a residential care setting. Provision was made for access to an on-site Link Person whose role was to orientate the advocates to their work-placement settings, and an academic mentor who provided support, encouragement, advice and guidance on the application of the skills learned.

Table 3 sets out the locations and dates of the training courses, the numbers of students registered and information about the gender, age and numbers completing the training. A total of 173 students registered for the course and 150 had completed the course or were in the process of completing the course. There are still a number of students that are currently completing assignments and for whom final course completion has not yet been verified. The majority of those undertaking the training were women and in the 23 to 65 year old age group.

**Table 3: Training programme location, dates, numbers registered, gender, age range and numbers completing**

Training location	Date	Numbers registered	Gender	Age range	Numbers completed
Dublin (North) St Mary's Hospital	25.04.09 – 4.07.09	24	F =18 M=6	23-65 years	23
Trim St Joseph's Hospital	30.4.09 – 9.07.09	11	F =5 M=6	23-65 years	7
Cork St Finbarr's Hospital	10.08.09 – 7.11.09	28	F =26 M=2	23-65 years	23

Dublin (South)	19.1.10 – 24.4.10	25	F =19 M=6	23-65 years (21) 18-22 (1) Over 65 years (1)	23
Tralee	12.04.10 – 17.7.10	31	F =26 M=5	23-65 years	27
Mayo	22.09.10 – 11.12.10	24	F=21 M=3	23-65 years	19
Roscommon	19.10.10 – 05.02.11	30	F=27 M=3	23-65 years Over 65 years (3)	28*
Cross-Border	TBC	TBC	TBC	TBC	TBC
<b>Total</b>		<b>173</b>	<b>F=142 M=31</b>		<b>150</b>

\*Finishing 05.02.11

A partnership approach between NAPA and the NCI enabled there to be coordination between the recruitment of participants and to embedding the programme within the residential units, particularly during work-placements. This programme structure is reflected in Table 4, which sets out the roles and responsibilities of the different partners and the specific actions carried out by the Work Placement Mentor and the Development Officers in supporting the work-placement process.

**Table 4: Organisational structure, roles and activities**

<b>Role in the training programme</b>	<b>Activities carried out</b>
Advocacy Programme Coordinator (HSE)	<ul style="list-style-type: none"> <li>• Selection of participant</li> <li>• Liaison with residential homes in establishing work-placements</li> <li>• Induction of students and participating residential homes in the work placements</li> </ul>
Academic Programme Director (NCI)	<ul style="list-style-type: none"> <li>• Selection interviews to establish if participants met with the academic requirements of the programme</li> <li>• Supervision of the taught programme and work-placement mentoring processes</li> <li>• Management of internal and external validation processes</li> </ul>
Class Tutor (NCI)	<ul style="list-style-type: none"> <li>• Class tutor assigned to each training programme</li> <li>• Design, develop and lead the course</li> <li>• Set and mark course work; provide guidance and feedback to students on their course work and learning</li> <li>• Advice and guidance to the programme team regarding curriculum development and the programme overall</li> </ul>
Work Placement Mentor (NCI)	<ul style="list-style-type: none"> <li>• Assist in inducting students into their work-placements</li> <li>• Support and mentoring to students during work-</li> </ul>

	placements <ul style="list-style-type: none"> <li>• Monitoring attendance during work-placements</li> <li>• Support to students experiencing any issues or problems and advice on successful completion of work-placements</li> <li>• Liaison between the College, students and the Advocacy Programme Coordinator</li> </ul>
Development Officers (where appointed)	<ul style="list-style-type: none"> <li>• Support with the induction of students to work-placements</li> <li>• Involvement in the coordination and liaison with residential homes, and involvement in induction of residential homes</li> <li>• Support to residential homes in managing student learning and in acclimatisation of placements</li> <li>• Support in sustaining a learning culture in the work-placement setting</li> </ul>

Overall, there was an excellent partnership approach between the NAPA Advocacy Sub-Group and the NCI. The NCI was seen to be responsive to the issues and challenges raised during the first training cohort and were cooperative in refocusing the programme content. In particular, the programme became more focussed on 'hands on' practical skills and issues, which helped to balance the academic requirements of demonstrating learning through the assignments. In particular, the use of scenarios and case studies of practical situations that arise in residential settings were viewed by the Volunteer Advocates participating in the second cohort of training to be particularly valuable. The provision of support through the Programme's Mentor was also valued as a resource, and through telephone, email and face-to-face contact the Mentor was able to provide the support and guidance during placements when needed.

Some of these issues raised could not be resolved through a re-structured programme alone, since some of the problems encountered related to factors outside of the NCI's control. These related to the absence of Development Officers in some residential units, and problems encountered in the introduction to and induction of the work-placements in the residential units themselves. However, these issues have been addressed in a concrete way by the Programme Coordinator and particularly in ensuring that Development Officers were in place to ensure that the work-placement induction and support are in place.

Some Development Officers participated in the training alongside the trainee Volunteer Advocates. There were mixed reactions to this from Volunteer Advocates. Some were of the view that the participation of the Development Officer enabled the group to establish a close relationship and 'bond', while providing the Development Officers with an understanding the content and context of the training. This was particularly important in providing a link between the training and the work-placements. Several Volunteer Advocates commented that this was not an appropriate role for the Development Officer. In the absence of separate training for

the Development Officers during this phase of the Advocacy Programme, it was deemed important for Development Officers to gain this understanding and knowledge of advocacy.

### **4.3 Continuing Professional Development Programme**

One of the objectives of the Advocacy Programme has been to provide a programme of Continuing Professional Development (CPD) for Volunteer Advocates who completed the training programme and who are providing an advocacy service. The Continuing Professional Development Programme was developed by NCI as part of their contract to provide a 12-month CPD programme. Volunteer Advocates had identified the need for specific training on the development of skills and knowledge in working with older people in a residential setting, and particularly in relation to older people with cognitive impairments. This led to the development of a FETAC Level 6 accredited module in Gerontology.

In 2010 two CPD training courses were held in Cork and Dublin. Fourteen participants followed the training in Cork, which commenced in Cork in May 2010. Twenty-two participants followed the programme in Dublin (for Volunteer Advocates in South Dublin, North Dublin, Trim and Tralee), which commenced in September 2010. The programmes will be completed in 2011.

The programme, consisting of eight sessions of lectures/discussion and self-directed study, covered the following main themes:

- Physiological and psychological changes associated with old age
- Western society's response to old age
- Legislation and organisation in support of older people
- Self-directed protection of older people
- Residents' Committees
- Reminiscence Therapy/Life Stories
- Successful ageing
- Death and bereavement

A national training day for Volunteer Advocates from across the country was held in September 2010. Over 100 Volunteer Advocates attended the day, and costs of travel and accommodation were met by the programme. The programme for the day consisted of information about the Advocacy Programme, presentations from key people from the HSE, Volunteer Advocates and Development Officers, as well as from Dr David Sheard Director, from Dementia Care Matters (University of Surrey), and Marco Bertozzie on Reminiscence Theatre.

### **4.4 Evaluation of the initial and continuing training**

A core part of the evaluation was to seek feedback on the training from Volunteer Advocates, to assess whether it was providing them with sufficient skills and learning to enable them to provide a high quality advocacy service.

A questionnaire was disseminated to all Volunteer Advocates, and feedback was gained through focus group discussions and one-to-one interviews. Feedback was also provided from Directors of Nursing, Managers and Link Persons in the participating residential homes, and from Development Officers. NCI also carried out their own evaluation of learning.

### ***NCI learner feedback***

During the training programme learner feedback was collated by the NCI on an ongoing basis from tutors and the mentor, from mid-term learner evaluation forms and end of programme evaluation forms. This learner feedback enabled learners to comment on the strengths and weaknesses of the programme, improvements that could be made, the assessment process and the delivery of the programme.

The learner feedback from the training in Dublin (North), Trim, Cork, Dublin (South) and Tralee was collated by the NCI's Programme Overview Report (April 2009 – August 2010). The strengths of the programme were summarised by NCI as being well-organised, excellent lecturer and college backup, excellent course materials and 'energy and passion from the organisers to make it work'. Several participants commented that the programme offered a good theoretical framework for advocacy practice balanced by the practical experience gained in the placement. Comments included "the programme offered choice and freedom to speak openly regarding content of course" and "there was quite a lot of interaction and experiential learning through group discussion". It was clear that the training had been important in giving preparation and an understanding of the practice of advocacy.

The main weakness identified in the learner feedback were poor organisation and communication regarding work placements, a lack of awareness of the programme by staff in residential. The lack of a Development Officer, for example, in Trim impacted on the early stages of the programme, highlighted the need for a Development Officer to be in place for the work-placements to be successfully negotiated and supported, and for the long-term sustainability of the programme.

As a result of this feedback the programme was adapted and restructured for the Dublin South programme. The feedback received from NCI highlighted the strengths to be strong participation and interaction of the group, good quality guest lectures, having the Development Officer on the programme and good support from NCI. Recommendations for enhancing the programme included the need for more practical skills sessions, better understanding of the Link Person in the residential homes, more time on work placement, and clearer guidance on assessments. The suggestion for an input into the training of an existing Volunteer Advocate was subsequently included in the courses run in Tralee, Mayo and Roscommon.



### ***Consultations with Volunteer Advocates during the evaluation***

The evaluation was an opportunity to gain feedback on the training, since many of the Volunteer Advocates had been actively engaged in providing an advocacy service for between six months and a year. This enabled Volunteer Advocates to reflect back on the training and the extent to which the training provided adequate preparation for their advocacy roles.

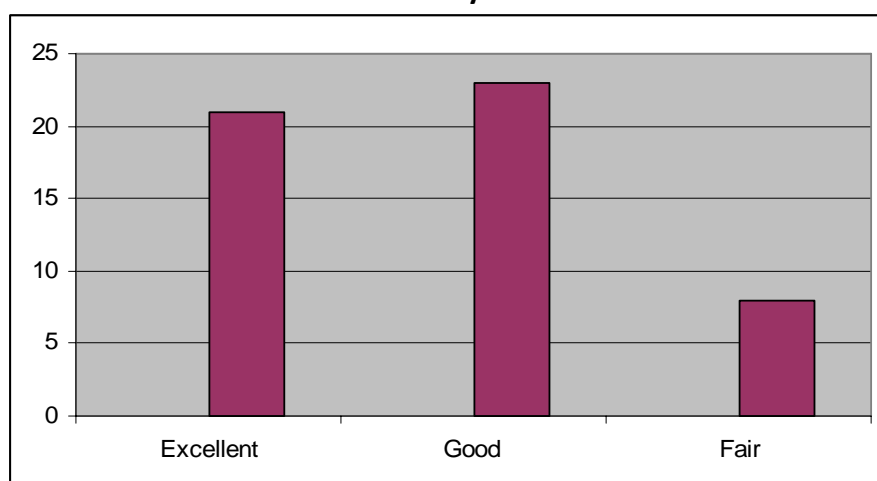
Overall Volunteer Advocates gave very positive feedback of the training, and particularly commented on the excellence and enthusiasm of the tutors. Tutors were described as being “well informed, excellent and enthusiastic”, “very motivating” and “inspirational”. For those following the training at the NCI in Dublin made were very positive comments about the learning environment and support provided by the NCI, particularly in having access to computers and library resources.

NCI gave us great support and this was really important, having access to the library and to tutors was really good. I have never been in a college that gives you so much support. We were given support in writing essays as well.

Those Volunteer Advocates who had time and educational experience stated that the training course had been extremely useful, and these advocates placed significant value on the theoretical perspectives provided and the setting of advocacy within overall human rights framework. Others, however, believed that the training had been too academic and ‘top heavy’, and that the assignments were a big burden and often not seen to be relevant to the practical skills required for advocacy. There was a general view that it is important to have knowledge of advocacy frameworks and human rights. A clear finding is that many did not feel adequately equipped to carry out an independent advocacy role in a residential setting.

Chart 8 gives the responses to the question: How would you rate the quality of the training that you received in preparing you for your role as volunteer advocate? Of the 52 responses, twenty-one stated that the training was excellent, twenty-three stated that it was good and eight stated that it was fair. No one rated it as poor.

**Chart 8: The quality of the training in preparing Volunteer advocates for the advocacy role**



Responses in the questionnaire and from the focus group discussions with Volunteer Advocates included the following positive responses:

I learnt so much myself, it changed how I viewed older people and how to recognise their individuality. I learnt a lot about myself.

FETAC level 6 gave people confidence and authority, but academically there were too many things that we had to do to tick the boxes.

The training was very good and prepared me adequately for the unexpected.

The training was well structured with clear aims and objectives that were met in full. This was achieved by an excellent standard of instruction from a trainer who used a variety of teaching methods to cater for the needs of the group and the individual.

As adults learn differently, by deploying a variety of teaching methods i.e. group work, round robins, question and answer sessions and didactic trainer input this ensured that learning outcomes were achieved.

I feel competent and adequately trained to perform my role efficiently and effectively. However, additional lectures might be of benefit in relation to dementia and Alzheimer's for example.

The benefits of group learning were highlighted by a number of Volunteer Advocates, who stated that this enabled them to bond as a group that led to a peer-support structure following the training:

The camaraderie of learning together and engaging in discussion was very important, it helped us to form as a group of advocates who worked together.

A number of Volunteer Advocates highlighted a number of specific challenges regarding the demands of the course and the course content:

There was an over emphasis on academic issues, e.g. 2 nights given over to how to write essays, and how to use the Harvard method of referencing. This discriminates against older people taking the course.

The training did not address fundamental issues such as ageism, social construction of ageing or challenge stereotypes e.g. people continually referred to older people as vulnerable, helpless, etc, no distinction was made to the fact that its people's situation that makes them vulnerable, helpless.

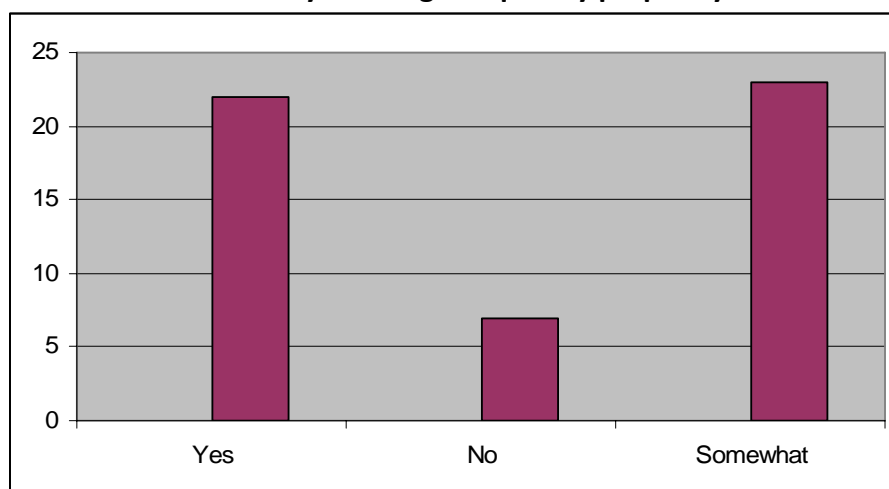
I feel the course did not necessarily prepare you well enough for the practicalities of working with people with dementia. Though there was a class on this subject, I felt that 1 was not enough. The nursing home where I am does not have a high number of residents with severe dementia or cognitive impairment, when I began I felt that if I had been assigned to a unit which did...I would have felt very out of my depth.

For those that missed some sessions or were unable to complete the course there was a suggestion for a policy to be introduced to enable students to join a later group in order to complete the course. As one Volunteer Advocate stated: "Could training run on some form of cycle so we might pick up on what was missed?".

#### *Preparation for advocacy roles*

Chart 9 gives the responses to the question "Did the Advocacy Training adequately prepare you for this role?". While twenty-two stated that the training did prepare them for their roles, twenty-three only stated that it somewhat prepared them, and a small number of seven stated that it did not prepare them.

**Chart 9: Did the Advocacy Training adequately prepare you for this role?**



The overwhelming majority (n=48) stated that they would benefit from further training, while only four stated that they did not feel that they would benefit from further training.

### *Structure and demands of the programme*

There was range of views of the structure of the training programme. A programme of fourteen weeks was seen to be too time consuming for some people, while for those that had time or were recently retired stated they would have benefited from a longer course. Some participants found the demands of course work, particularly at the end of the course, to be excessive. A large number of participants found that the training provided a useful theoretical framework, gave awareness of advocacy as an international movement and awareness of how advocacy fits into a human rights framework.

### *Utilising the skills and experiences of participants and staff in residential units/homes*

Suggestions were made to draw on the skills and experience of participants, many of whom had experience of working with older people in a residential setting and also from staff providing care in residential homes:

The course was very directive and there was a lot of experience amongst the participants who had experience of working with older people; it's a shame there was not more time for discussion and to draw on people's experience.

Rather, I would like to course to concentrate more on the various areas of mental health and physical health that Advocates are likely to meet in residential settings. Bringing in staff from residential settings would also be helpful as not only would they bring more reality and clarity to the Course but they would themselves become familiar with what the content of the Course. This would also I imagine make them more willing to have advocates present at their residential setting.

### ***Feedback on course content***

While many participants valued the breadth of the content of the course, there was an overwhelming view that the course needed to provide more understanding skills development in the following seven areas:

- Practical skills and scenarios of what to expect in a residential setting.
- Concrete guidelines on working in a residential setting, what is appropriate and what is not.
- Information and skills development on working with older people with cognitive impairments and dementia.
- Information on the conditions and impairments experienced by older people in residential care
- Information and guidance on how to deal with death and bereavement
- Information about rights and entitlements available to residents.
- Opportunities for ongoing learning and discussion

### *Practical skills and scenarios of what to expect in a residential setting*

Many Volunteer Advocates stated that they did not have sufficient practical skills of what to expect in a residential setting. This included understanding of how residential units/homes operate, their routines, models of care, and roles of staff.

Other issues were raised in relation to understanding “basics like approaching bedridden residents without intrusion”.

The NCI provided a very good theory course but on the ground it is very different from the classroom and more hands on information would be good. More case studies or work placement experience would have been of benefit. Courses should contain more hands on experience case study and item dealing with people who live in care homes.

*Concrete guidelines on working in a residential setting, what is appropriate and what is not*

Several Volunteer Advocates stated that would like more guidance on working in a residential setting, for example:

Guide lines of what is the minimum standard of caring for residents. Some information on caring for older people, guide lines of the carers function, what is acceptable in handling, feeding and moving people information given to the carers on their course.

*Information and skills development on working with older people with cognitive impairments and dementia*

A very large number of Volunteer Advocates stated that more training and skills development on working with older people with cognitive impairments and dementia was essential:

More input on dementia and how to communicate more effectively with residents who have this condition.

Some residents have no communication skills, are very frail and would spend most of the time I am there in bed (I go at 5 p.m. to 7 p.m.), when I can I go at weekends or if there is a special occasion I try to attend for that. Perhaps a nurse from a geriatric unit could advise on how to avoid these people feeling invisible as I find it difficult to spend a lot of time with someone who can't tell me to 'go away' if that is what they want. I feel very inadequate in this area. I realise that in my role as an advocate this may not be my brief but it would be helpful to hear from an 'expert' how I can make someone like this feel valued.

The facility I am working in has almost all residents with very severe dementia. Most of the residents cannot communicate at all. It is very difficult to interact with the residents. I was unprepared for this situation and have spent some time with the activity co-ordinator and following discussion with the previous Director of Nursing, arranged for training for some of the advocates to attend a short 2 hour input on dealing with dementia, a few months ago. I found this input very helpful but still feel that my role is really that of observation rather than discussion with residents. I am looking forward to the follow-up training, which I feel will be a real benefit to my work, which I really enjoy.

I think that we would benefit from further training on dementia, how to deal with residents who have very difficult circumstances and that we can empathise with

them without being condescending and helping them cope better and how to communicate more effectively with older people.

[A] course in gerontology is essential for all voluntary advocates, to understand the ageing process and to have an insight into dementia, Parkinson's. [I] found the course very informative on advocacy and human rights, but theory was not enough in understanding the day to day issues which arose in the residential centre. Therefore I think it is necessary for the Volunteer Advocates to get much more support and mentoring in the first few weeks in the residential homes.

### *Information and guidance on how to deal with death and bereavement*

A significant number of Volunteer Advocates stated that they needed more preparation, skills and guidance on how to deal with death and bereavement:

I had an experience where the first resident I started with died and found that it did affect me in ways that I was not prepared for. Bereavement needs to be dealt with in further training.

Since I started in my placement last April about five residents have died. Dealing with death in a residential nursing home setting is an inevitable part of the process of advocacy, both in visiting with other residents who can be affected by the deaths or indeed with the bereaved family members you have met over the course of time.

### *Information about rights and entitlements available to residents*

Having access to and information about rights and entitlements was highlighted as being very important to advocacy, and is an area that Volunteer Advocates would welcome more training. This includes having better knowledge of HIQA Standards and Inspection frameworks, and a better understanding of formal complaints mechanisms:

Principles of advocacy, legal capacity, provision for incapacity, nursing homes regulations, social services inspectorate, HIQA.

Training in entitlements and regulations regarding residents in Residential Care Units.

Legal issues related to advocacy work. Dealing with complaints against individual carers. How advocates can assist residents who want to change nursing homes.

Whilst enabling people to access information may be appropriate for people working as advocates in the wider community, it will not work for older people living in residential settings (very little access to outside world), so advocacy training for volunteers working with people in nursing homes should emphasis information provision and include module on sourcing information.

### *Opportunities for ongoing learning and discussion*

A large number of Volunteer Advocates, particularly those that did not meet regularly in a group stated that they would welcome the opportunity for more regular discussions with their peers and opportunities for ongoing learning and development. Several Volunteer Advocates stated that they would appreciate

training workshops every two or three months to keep them up to date and informed. This was seen to be particularly important to ensure that there is a consistent understanding of what advocacy is and for ensuring clarity about roles. In some cases staff in residential units/homes viewed the Volunteer Advocates as providing a befriending service, and for this reason having clarity of roles was seen as essential for the Volunteer Advocates.

### ***Feedback on Continuing Professional Training***

As part of the evaluation of the Advocacy Programme, the focus groups held with the Volunteer Advocates from Cork, Tralee, Trim and Dublin gave very positive feedback of the two courses. Overall the module has been very informative in providing a better understanding of the ageing process and in building the skills and awareness of Volunteer Advocates. A small number questioned the value of self-directed study. However, there was a shared view that the module should be integrated as a core component of the training for Volunteer Advocates, as this would have helped in providing a better understanding of how advocacy can be provided to older people in a residential setting, and particularly older people with cognitive impairments.

The Cork course was run as part of the monthly Volunteer Advocates meetings. However, access to the course in Dublin was limited to those who were able to travel to Dublin, which placed restrictions on some people. As one Volunteer Advocate stated:

More effort should be made to accommodate advocates who are working and cannot attend training in Dublin in the evenings or during working hours. Volunteer Advocates in other parts of the countries expressed a strong interest in having a course provided locally.

### ***Feedback from residential units/homes***

The extent to which the training programme prepared volunteer advocates for their advocacy roles elicited varying responses from Directors of Nursing /Managers and Link Persons. A significant number were of the view that the training did not equip Volunteer Advocates with the practical skills for communicating with vulnerable older people in a residential setting, and particularly with people with dementia. This issue was particularly evident in the first training courses held in Dublin and Cork, while some more practical examples and role plays were introduced in subsequent training courses. A key and unresolved issue is the need for guidance and protocols for advocacy that is provided to people with dementia who are unable to give their consent to advocacy. However, there was an overwhelming response from participating residential homes for the need to:

- Integrate into the training more 'hands on' practice based training in communicating with vulnerable older people and people with dementia.

- Consult with professionals/staff providing care in a residential setting, on the content and design of the training for volunteer advocates.
- Examine and implement clear procedures for the provision of advocacy for people with dementia, with regards to consent and risk assessment.
- Improved procedures for the 'work placement' element of the training, with back up and support for trainee Volunteer Advocates. In the next phase of training this could be supported through improved communications between the programme nationally and with link staff.
- Utilising the skills and experience of Volunteer Advocates in providing mentoring and a 'buddy' scheme for trainee Volunteer Advocates.

Throughout the cases studies the training of Volunteer Advocates was highlighted as being critically important to the programme. Eleven of the participating residential homes completing the questionnaires believed that the advocates had been sufficiently trained. Five believed that they had not received sufficient training to provide a high quality advocacy service. Interviews held with participating residential units/homes also revealed some concerns about the preparation and skills of Volunteer Advocates to work with very vulnerable and cognitively impaired residents. Nevertheless, there is a recognition that in some residential units/homes good liaison with Link Staff, activities coordinators, social workers and Directors of Nursing has helped to build these skills over time. The Continuing Professional Training provided for Volunteer Advocates in Gerontology was welcomed in this regard.

There were mixed views on the extent to which the training prepared the Volunteer Advocates. One stated that "We feel the advocate is well trained and well supported and provides a high quality service to our residents. Another said that:

I think the initial training did not prepare the Volunteer Advocates for communicating with residents who are unable to speak or who have dementia. I am also wondering if they had enough training on how to broach staff when there are issues they wish to discuss.

Another stated that:

The advocate is growing into the role but initially the needs of residents with cognitive impairment were not addressed sufficiently by the training.

The main concerns related to training in working with older people with communications difficulties and dementia. For example, one stated that "The support for the clients that are max dependency and dementia clients still provide a challenge to advocates". Another said that:

We in St Finbarr's Hospital are very fortunate to have a very proactive group of advocates. When the advocates initially came on site they felt that their initial



training had not adequately prepared them for the clientele they would be advocating for. Problems they encountered included communication difficulties with residents who have a cognitive impairment and dysphasia. With this in mind the advocates looked at additional training to be provided and are now undertaking a certificate in Gerontology.

Several Directors of Nursing and Assistant Directors of Nursing highlighted the importance of providing training to familiarise Volunteer Advocates of the policies and procedures in residential units/homes, and to have processes in place to provide feedback. One Acting Director of Nursing stated that:

Some internal training in relation to local policies and how to report issues etc would be useful. Some insight into the area they are working in. Feedback to Nursing Management – structure needs to be put in place.

Several Directors of Nursing / Managers believed that more consultations could have been held with them in the design of the programme, and several stated their willingness to provide guidance and inputs into the delivery of the programme. This was deemed particularly important in familiarising Volunteer Advocates with the policies, procedures and systems in place in the units/homes, and with regards to the formalised complaints procedures in place.

#### **4.5 Recommendations for the future development of the training programme**

- The training needs to give a greater emphasis on building communications skills, skills of working with very vulnerable older people, and in providing advocacy to people with dementia. Consideration should be given to establishing a specialist Dementia Advocacy training programme.
- Specific training to prepare Volunteer Advocates to the residential setting, including policies, procedures and complaints systems; more input on the issues faced by older people in residential care and of the conditions experienced by older people and medical related issues; and in dealing with death and bereavement.
- Specific training on rights and entitlements, the 'fair deal' and the role of HIQA Standards and Inspection.
- Regular local / regional level training and ongoing training, particularly for those advocates living outside of Dublin. Consideration should also be given to delivery of the training through new technologies, distance learning and on-line learning. The proposals made in the previous section for an Advocacy Programme web site, discussion forum and Facebook site, could assist in this process and in providing Volunteer Advocates with regular information and opportunities for learning.
- To examine the feasibility of putting in place continuous learning 'circles' or 'groups' for Volunteer Advocates at a local level, to enable them to reflect and

discuss advocacy situations, invite external speakers, provide peer-support and learning and engage in ongoing learning.

- Improve the understanding the role and boundaries of advocates in relation to their observations of the daily living situation of older people in institutional care, for example, difficulties observed for residents having choices about when they get up or have meals, noise levels, privacy issues or lack of activities. There is recognition that there are some issues that advocates are not able to resolve in the context of institutional care, but nonetheless need to understand the boundaries of their roles.

## Section 5: ‘Compassion in Care’: Personal Excellence training for staff in participating residential units/homes

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### 5.1 Introduction

One of the recommendations of the Forum on Services for Older People was the establishment of training for staff to enable them to put a value on compassion in the context of their care roles and in their personal lives. This was defined as ‘Personal Excellence’ and developed into a programme of training for staff in seven residential units/homes across the country. The training has added a new dimension to the capacities of staff regarding compassion in care, and was positively received by staff.

### 5.2 Participating residential units/homes and numbers trained

Seven residential units/homes participated in the pilot across the country, with a total of 118 staff participating in the training. Between seven and twenty-three staff participated in the training in each residential unit/home. They included a wide range of staff from nursing staff (Directors of Nursing, Clinical Nurse Managers and Staff Nurses), to care assistants, housekeeping, cleaning, administrative, kitchen staff, maintenance staff and grounds staff. Table 5 provides an overview of the units/homes where the training carried out and the number of participants in each.

**Table 5: Personal Excellence training (2008-2010)**

Name of participating residential home	Employment profile of participants	Number of staff participating
Ashford House Nursing Home Dun Laoghaire, Co Dublin	Director of Nursing, Nurses, Health Care Assistants, Activities Coordinator, Head Chef, Housekeeping staff	19
Beneavin Lodge Nursing Home Glasnevin, Dublin	Housekeeping and Cleaning Staff, Nurses, Care Assistants	24
Cuan Ross Community Unit Dublin	Health Care Assistants, Housekeeping and Catering Staff	7
Cuil Didin Nursing Home/ Kerry General Hospital Tralee, Co Kerry	Administrative, Housekeeping and Maintenance Staff, Health Care Assistants and Nurses	11
Middleton Community Hospital Cork	Health Care Assistants and Nurses	16
St Joseph’s Community Hospital Trim, Co Meath	Health Care Assistants, Catering, Housekeeping, Nurses	17
St Mary’s Hospital Phoenix Park, Dublin	Not available	24 (16 full, 8 part)
<b>Total Number of Staff</b>		<b>118</b>

An additional training programme was held in St Columbus Park House, Western Health and Social Care Trust, Northern Ireland (4-5 November 2010), which was carried out separately to the Advocacy Programme.

### **5.3 Content and format of the training**

Personal Excellence, as an approach to improving the quality of care relationships and compassion, is embedded in personal construct psychology, positive psychology and Neuro Linguistic Programming<sup>16</sup>. This approach is reflected in the training programme, which is designed to improve self-awareness of the value of compassion and to empower staff to enable them to gain a sense of purpose of their care roles, and through this to improve the well-being and safety of those in their care.

The core objective is to raise awareness of how a compassionate attitude can result in a values based change process of care for staff in residential homes to:

- Enable care staff to define themselves as human beings relating to other human beings and change attitudes towards the individuals they provide care for;
- Develop and put in practice a set of values that are at the centre of their care role and their lives;
- Generate commitment and compassion in their work;
- Articulate the value of Personal Excellence and Compassion and thereby enhance their commitment to person centred care based on dignity, respect, safety and excellence in care;
- Promote a work environment that fosters innovation and change and organisational values of Personal Excellence and Compassion;
- Bring out the best of themselves through Personal Development.

The learning from the programme is that attitudinal change can lead to staff having a better understanding of their own personal values and attitudes to care and compassion, which can enable them to achieve personal excellence in the care relationships with the people in their care. Core to the training was to develop an understanding of compassion:

A person displays Compassion when they carry out work, or engage in relationships which generate the following within an individual; a feeling of being validated as a person, a feeling that they matter, a feeling that their sense of themselves is reinforced and a feeling that their suffering is understood, with action to relieve it<sup>17</sup>.

The training addressed six levels of learning that focus on existence, identity, beliefs and values, capabilities and behaviours. In the evaluation of the training indicators of attitudinal change were measured.

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<sup>16</sup> This approach has been further documented in the Training Pack developed by Michael Brophy @Associates "Adopting a compassionate attitude to oneself and older people in care: An educational, values based, change process for care staff in residential homes (2010)

<sup>17</sup> Ibid p.3

The format of the training was four sessions of four hours. The four hours per session was deemed by some participants to be too long, particularly because the majority of participants attended the training in their own time. It was suggested by these participants that two hours a week over eight weeks would have been better.

According to Michael Brophy, who has designed and facilitated the programme: “The challenge for the HSE is to find a mechanism by which each member of staff can pursue such excellence and compassion in his or her own work and life”.

#### **5.4 Feedback on the Personal Excellence Training**

##### ***Feedback from participants***

The evaluation of the training has been overwhelmingly positive and this was verified through interviews carried out with staff in participating residential homes that were visited as part of the evaluation of the Advocacy Programme. Overall around 80% of participants stated that positive learning had taken place in relation to values, identity and existence.

An in-depth evaluation of the learning was carried out during and at the end of programme. At the end of each training programme participants were invited to write about the change that they have affected in their work practice and lives subsequent to the completion of the programme. The following are examples of some of the responses given:

- I know that I am a valuable part of the team in my Unit.
- I know that love is my gift and that caring is my Personal Excellence. I now have the confidence to carry this to the patients.
- There is nothing, if at all possible, that I would not do for the patients.
- I dealt well with a difficult patient. I listened to her and accepted her for what she was. I brought the following strengths to the situation; adaptable, balanced, caring disciplined, even-tempered, fair, honest, open-minded, persistent, trustworthy, warm-hearted.
- I have become more involved in person centred care.
- I have a greater ability to accept responsibility for the things that I do.
- I hope that I am more compassionate warm hearted and caring.
- I listen in an active manner.
- I am more open minded and generous.

##### ***Feedback from participating residential units/homes***

Directors of Nursing and Managers provided very positive feedback about the Personal Excellence training, and many stated that they would like more staff to attend the programme in the future. The training was seen to be very valuable in enabling people to develop their skills of empathy and listening and in responding more sensitively to the needs of residents. It was suggested that the Personal

Excellence training should be more closely linked to the work of the Volunteer, for example, one Director of Nursing stated that:

The training was very well received by the participants. The training came some time after the advocacy was introduced and from talking with the participants I do not consider they linked the training as preparation work for advocacy.

The training held in Tralee has led to the Manager of Cuil Dinín to involve the Volunteer Advocates, the Resident's Committee, the Relatives Committee and the Care Givers Forum in a proposal to develop a 'Compassion Forum' with other residential homes in the area. The Director of Nursing in St Patrick's Hospital in Cashel, although not participating in the Advocacy Programme, has equally been a champion in providing a focus to Personal Excellence. She organised a national conference in Cashel in 2010, and has developed a 'footprint' of compassion as part of the developmental work in this area. There is important learning from these initiatives that could be further developed for residential homes, and particularly how staff, Volunteer Advocates, Resident's Committees and Relatives Committees/Fora could be brought together to discuss methods for embedding Personal Excellence and compassion within their organisations, and in providing evaluation and analysis of outcomes. This could provide an excellent model for mainstreaming the training in to all nursing homes across the country.

## **5.6 Key findings from the evaluation of the Personal Excellence training**

There is significant scope for the training of all care staff to be reviewed in the light of providing high quality, person-centred care. There should be a systematic examination of how Personal Excellence Training could be integrated in the ongoing training and development of nursing and social care staff, and other staff working in a residential setting. It is relevant within the context of a framework for training under the DOHC's *Practice Development Strategy*. However, funding for training tends to be demarcated between nursing and non-nursing functions, rather than across the board training that is geared to reflective practice and changing the culture of care in nursing care.

While there has been very positive feedback about the programme the pilot reflects a 'drop in the ocean' regarding training for staff in residential homes. There is real scope now to develop the training further and offer it to a wider number of residential homes, and possibly to link the training to HIQA standards. In addition, the training offers a unique insight into care and compassion, learning from which should become part of the curriculum for the professional and ongoing training of all health care staff.

The key findings and conclusions from the evaluation of the Personal Excellence training are as follows:

- The evaluation of the programme demonstrates the importance of the quality of the leadership in the individual nursing home to enable the learning to be

embedded into work practices. It is evident that the programme has been most successful where the leadership of a residential home displays a commitment to lead a values driven organisation. As a result, the way that the programme is championed, supported and embedded into the culture of a residential home, is crucial for the learning from the training to be built into longer-term changes in the culture of residential care.

- The values that are addressed in the training have a focus on the individual's personal excellence in their care roles, behaviour and practices. There is valuable learning from this approach that needs to be underpinned by organisational values embedded in the quality of care in both national health policy and in the mission and remit of residential homes.
- There is significant scope for integrating this learning and approach into the training and development of all health care staff working in residential units/homes, and extended with a wider remit to health care staff working in hospital and community settings.
- For this reason it will be important that the training is further embedded into the HSE's Continuing Personal Development for the Health & Social Care Professionals and through Practice Development and training run by Nursing Homes Ireland.
- The Personal Excellence training could be further developed so that it links more concretely into the Advocacy Programme in participating residential homes. Few of the staff who participated in the training were aware of or understood advocacy and several suggested that it would be useful to link Personal Excellence to an awareness of independent advocacy.
- The Personal Excellence training would also be a valuable addition to the training of Volunteer Advocates, in helping to raise awareness of care values, compassion and self-awareness of volunteer advocates.

## **5.7 Recommendations from the evaluation**

Because the Personal Excellence training is relatively new as an approach, with a conceptual framework that differs from existing staff training and professional development, there is real scope for further developing the methodology and awareness of the methods used. As a result it is recommended that:

- A training manual should be developed, setting out the rationale for the programme, learning outcomes, modules and guidance for training, under the auspices of the Advocacy Programme. This training manual ideally should be funded by, disseminated from and embedded into HSE Learning and Development.

- A leaflet setting out the goals of Compassion and Personal Excellence should be drawn up and disseminated to all residential homes for older people in Ireland and through relevant bodies, such as the older people's organisations, Irish Society for Quality and Safety in Healthcare, Nursing Homes Ireland, the HSE, the Irish Nurses and Midwives Organisation, to name a few.
- A programme of 'train the trainer' workshops for networks of residential units/homes, including learning and development staff in residential homes, HSE learning and development units, HSE leaders in older persons services across all HSE regions, and for learning and development practitioners in Nursing Homes Ireland.
- A dedicated 'train the trainer' programme should be carried out for residential homes, whereby one representative / leadership champion of each residential home is nominated to attend the training, as 'Personal Excellence Champion'; the learning from which is then disseminated and implemented internally. This would be a more cost effective method than providing training in each residential home across the country and will have an important multiplier effect. An annual 'training the trainers' workshop should be held for 'Personal Excellence Champions'.
- A plan should be put in place to ensure that every residential home in Ireland has a 'Personal Excellence Champion', who can then disseminate the learning on compassion and Personal Excellence within their homes and units. There is also an opportunity for champions to network with units/homes locally, regionally and across the country.
- Consideration should be given to developing a FETAC accredited module on Personal Excellence and Compassion for staff, and a similar programme for Volunteer Advocates.
- A Personal Excellence web site and Facebook, linked to the Advocacy Service web site, should be updated regularly and provide access to a forum for discussion
- Funding would need to be sourced for these initiatives and development, which could result from a package of funding from the HSE and other external sources. Consideration should also be given to linking in with existing Skillnets Learning Networks developed within private health sector companies.
- An Annual Report setting out data, outcomes, evaluation of programmes implemented and planned developments should be submitted to the National Advocacy Programme Board at the end of each programme year.



## Section 6: Information Programme

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### 6.1 Introduction

Access to information has repeatedly been identified in consultations with older people as being essential to enabling older people to realise their rights and entitlements. For example, the consultations for the Positive Ageing Strategy have highlighted the persistent difficulties faced by older people in accessing information about availability, access and eligibility for services, “which results in confusion and ambiguity in respect of entitlements for older people”.<sup>18</sup>

Access to information about residential care, to enable people to make informed choices, was one of the three recommendations made by the Forum on Older People in 2006. As a result one of the core objectives of the NAPA group was to establish a programme of information for older people, both inside and outside of residential care.

An Information Sub-Group was established under NAPA and a process of consultation and programme development took place within the group, from which an information plan was scoped out and presented to NAPA. The plan included a risk statement that highlighted some key risks and risk mitigation measures that would need to be put in place to ensure that the Information Programme would be independent, impartial, comprehensive, accurate and reliable, up-to-date, complementary with other information provision, and supported by key agencies.

One member of the NAPA Information Sub-Group was disappointed that the final programme gave insufficient recognition to the process of developing the plan and to the commitment from a wide range of older person’s organisations to this process. The resulting information programme was seen, in this regard, to result in a less robust programme than had originally been scoped out.

The establishment of HIQA standards on information has provided an incentive for residential homes to provide accurate information and a buy into the development of the web site.

Agreement was made in the NAPA Group for the web site to be hosted by NAPA under the domain [www.myhomefromhome.ie](http://www.myhomefromhome.ie). During the developmental phase a representative from HSE Older Persons Services held focus groups and interviews with HSE staff, the HSE Residents Group, and with older people in St Josephs Hospital, Trim, and the Summerhill Centre for Active Ageing. The focus groups sought to find out if older people would access a web site, what information they

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<sup>18</sup> Department of Health and Children (2010 *In our own words: Report of the consultation process for the National Positive Ageing Strategy*, Office for Older People, Department of Health and Children: Dublin, page 15

wanted and how the information should be provided. Feedback was given on a draft set of information headings of the information that would be provided by residential homes. Older people also highlighted the need for information on alternatives to residential care and to enable older people to access services to remain in their own homes for as long as possible.

From the outset it was evident that the site should not be part of the HSE's own web site, which in any case older people themselves had pointed out was too complex to navigate. It was also seen to be critical to ensure that both the HSE and Nursing Homes Ireland would take a lead role in mandating the web site and ensuring that the residential units/homes for which they were responsible provided accurate information.

The web site went live in 2009. It provides clear descriptions of and locations of residential homes in Ireland, with a search engine to search a home by geographic location or name. Links to HIQA reports and to further information about the services provided and size of residential units/homes can also be found under each descriptor. Information about other services, rights and entitlements and links to the web sites of other information and service providers is provided. The web site is clear and easy site to navigate, and information can be sourced easily. However, there is significant scope for the further development of the web site, for example, to include the provision to search for information by specialist or specific services.

## 6.2 Residential units/homes listed on the web site

There are currently 295 residential units/homes listed on the web site; 65.4% of which (n=193) are private sector, 30.5% of which (n=90) are public sector and 4% of which (n=12) are voluntary. Currently there are 607 residential units in Ireland (120 public and 487 private/voluntary); of these 48.5% are listed on the web site.

**Table 6: Residential units/homes listed on the myhomefromhome.ie web site**

Homes listed on 'www.myhomefromhome.ie'	Private sector	Public Sector	Voluntary sector
295	193	90	12

One of the objectives of the Information Sub-Group was to achieve a critical mass of two-thirds of all residential units/homes listed on the web site. However, this has not been achieved and there is now an urgent need to ensure that the web site enhances the coverage of residential units/homes. This will be critical to its long term sustainability and credibility in the future.

There have to date been a total of 734,717 'hits' on the web site to date, although it is not possible to verify the extent to which and how the web site was used, and by whom. One way that this could be achieved would be to load a short on-line survey

for a period of, say three months, to gain feedback on how relevant and useful the web site is for users.

### **6.3 Awareness and visibility of the Information Programme**

The evaluation included questions to Volunteer Advocates and participating residential units/homes about their awareness of the web site and the benefits of the information resources provided. From this it was found that there is a low level of awareness of the resource, with relatively few of the staff in the participating residential units/homes and Volunteer Advocates knowing about the resource, or who had accessed the web site. Very few had actively used the information in the web site.

Feedback from residential units/homes, relatives and family members is that there is a lack of clarity regarding entitlements prior to someone being assessed under the Fair Deal. The evaluation also found that some older people and their families were unaware that they would lose key services, such as chiropody or physiotherapy, if they take up a place in a private residential home.

This lack of knowledge of the web site is not surprising given that the web site has not been launched nationally. It has not yet been linked into existing web based information provision from other agencies. For example:

- Nursing Homes Ireland's web site and search engine to find a Nursing Home in Ireland does not provide a link to '[www.myhomefromhome.ie](http://www.myhomefromhome.ie)'.
- There is no link to the web site on the CIB's information portal or information about how to find a residential unit/home in the section on health services for older people 'Moving from home to long-term care' on the citizen's information web site '[www.citizensinformation.ie](http://www.citizensinformation.ie)'. The citizen's information web site does provide a rich resource of information in areas of rights and entitlements to services, the 'fair deal', and HIQA regulations and inspection.
- The HSE's web site does not include a link to '[www.myhomefromhome.ie](http://www.myhomefromhome.ie)' under its section on Older People, which provides access to information and reports on HSE services for older people. The HSE's Guidance Document on 'Choosing a Nursing Home' contains no link to the web site. The HSE's Map on Nursing homes by each of the HSE LHO areas, while listing public residential units/homes, does not link to the web site. Information about the web site is listed under the Advocacy Unit, under the section 'What's new in Consumer Affairs?' and under information provided on the Advocacy Programme and NAPA. However, it is unlikely that a family member or older person seeking to find information about residential care would know to access information through this route.

## 6.4 Feedback from stakeholders

Many stakeholders saw the value of having comprehensive and up to date information to enable choices to be made about residential care. Feedback from members of the Information Sub-Group and other stakeholders are of the view that:

- The web site needed to be closely linked into both HSE and Nursing Home Ireland, particularly in encouraging and mandating residential units/homes to participate.
- The verification of information posted on the web site is very difficult to achieve and there is trust that the information provided is correct and up-to-date. HIQA needs to play a more direct role in linking their Inspection role to the publication and verification of information provided on the web site.
- More time and resources need to be put into the promotion and publicity of the web site and for all relevant agencies and stakeholder to provide information about and links to the web site through their own organisational structures and web sites.
- The information programme needs to be innovative and all information that is in the public domain should be provided in accessible ways in one location. If there was a one-stop-shop approach to information then this would mean that people would only need to navigate one web site.
- There is a need for more detailed information that can “pin point information about services to enable people to make informed choices and decisions”. In particular, being able to identify services such as physiotherapy, chiropody, GP, dental, specialist services for people with Alzheimer’s or dementia and other services, will be critical to developing the information programme further.
- There is a need for more current information about the costs of services in residential care, to inform choices.
- The web site has the potential to provide important information to enable people to remain within their own homes, and is particularly important for people living in the community and people who are being discharged from hospital.
- There is a need for a vision and plan for more interactive data and clear objectives about the direction that the Information Programme it is taking. This requires attention to governance issues.
- Providing examples of good practice and proactive work to enhance the voice of older people provides a potential area of development.

- There are key issues of verification and regular updating of information so that it is correct and valid at all times. This is a major task, but requires cooperation with HIQA Inspectorate and findings from HIQA reports.

## **6.5 Recommendations for the next steps for the Information Programme**

The NAPA Information Sub-Group is in the process of developing the next stage of development for the web site under the Information Programme. In this light it is recommended that:

- The location of the web site, how it will be managed, developed and kept up to date, and how it links with the web sites of the HSE, Nursing Homes Ireland and Citizen's Information Board, are urgent issues that need to be addressed.
- There is a strong case to be made the HSE and Nursing Homes Ireland take the lead responsibility for the web site in the future, in partnership with HIQA.
- New resources will be needed to further develop and maintain the web site so that it is up-to-date and relevant to information users. Ensuring that the web site provides for informed decision-making will be crucial to its longer term development.
- Publicity and promotion of the web site with older people's and community-based organisations needs to take place if there is to be real usage of the web site for older people and their family members.
- There is also potential to extend the range and scope of information on the web site to include more detailed and accessible information about rights and entitlements, information about the Fair Deal under the National Treatment Purchase Fund, and service entitlements from the HSE.
- There is significant scope for including a wider range of information and greater detail about service entitlements. This will become easier once these entitlements have been clarified under forthcoming legislation. It will also be important to examine how information can be accessed in other formats, given that older people themselves do not always have good access to the Internet.
- The future location of the web site will be critical to its long term sustainability and development. Some stakeholders believed that it would be appropriate for the web site and other information provision to be located in the CIB, since this is their expertise and mission, other stakeholders believed that it should be entirely independent.
- A key consideration is how the web site is advertised, publicised and promoted so that it is widely known. The overall feedback was that the web site needed to be promoted more actively. As one stakeholder said "It is important that it is in

the mind of the public and that people know how to access the information easily". This will require a significant effort and resource.

- During the evaluation participating residential homes, Residents Committees and Volunteer Advocates were asked about the value of the web site. There was a general view that it was easy to access and provided some useful baseline data, but could be further developed. Because residential homes are required under the HIQA standards to provide information about their services, the web site was welcomed as another location for this information to be provided.
- There is also further scope for the development of a joint approach between HIQA and NAPA to spell out more concretely and in more detail specific information standards and indicators.
- Links to the Advocacy Programme will also be important, since Volunteer Advocates may in some circumstances need to have access to information about rights and entitlements within an advocacy context, while older people and/or their families may wish to access information about advocacy services.
- The web site should also identify where independent Volunteer Advocates are providing a service, and where specialist services such as Dementia Advocacy will be provided in the future.

## Section 7: Case studies of the impact of the Advocacy Programme in eight residential units/homes

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During the evaluation visits were made to a sample of residential homes across the country in order to assess the impact of the Advocacy Programme at the level of the residential unit/home. Eight case studies were drawn up from these visits, during which time interviews were held with Directors of Nursing / Managers, Link Staff, Volunteer Advocates, representatives of Residents Committees and older people living in residential care.

The case studies are from the following residential units/homes:

- Ashford House, Dun Laoghaire, Co Dublin
- Dalkey Community Unit, Co Dublin
- Beneavin Lodge, Glasnevin, Dublin
- St Mary's Hospital, Phoenix Park, Dublin
- Cuil Didin, Tralee, Co Kerry
- St Joseph's Community Unit, Trim, Co Meath
- St Finbarr's Hospital, Cork City
- Middleton Community Unit, Co Cork

### 1. Ashford House, Dun Laoghaire, Co Dublin

#### *Background to the advocacy programme in Ashford House*

Ashford House is a small private nursing home for 28 older people. There are two Volunteer Advocates who have been trained to provide an advocacy service, and they visit the home once a week for two hours. The Volunteer Advocates are supported through regular meetings with their Development Officer. The programme works extremely well and there are good communications between staff and advocates. The programme is very visible in the home and there is excellent support and buy-in from staff, relatives and family members. Issues that are easy to resolve are reported to the Director of Nursing and the Development Officer has regular meetings with the Director of Nursing to discuss these.

#### *Feedback from volunteer advocates*

The advocates were very positive about their roles in providing an independent advocacy service. They are very well supported by their Development Officer and value the positive welcoming of their roles in the home. As one of the advocates stated "it has been great to have the support from the Development Officer, I know that I am supported if an issue arises, and it takes the pressure off me knowing that the Development Officer will follow up on any major problems". Having clear boundaries and support from the Development Officer has also helped advocates to know that they should not "act on impulse", but that they are there to empower older people to speak up for themselves. Ashford House has a Residents Committee, which has provided an opportunity to give feedback on the programme, and residents are very positive about the programme.

The advocacy training was found to be very enjoyable, although the advocates stated that they had to "learn on their feet" when they started. Having training on the terminology of medical conditions, more skills on working in a residential setting and communications skills

were identified as key areas for training. When the advocates started their programme, they were introduced to all of the staff and residents and their independent role was stressed as being very important. At the outset staff were very unclear about the roles of the volunteer advocates, but as the programme has been established staff have become very open and supportive of the programme.

The two Volunteer Advocates have identified some of the specific roles played in advocacy with vulnerable older people, which has been helpful in further defining the ongoing skills and training that are needed for Volunteer Advocates. They have built up substantial practical experience of advocacy, and have highlighted that it is fundamental to build trust and respectful relationships with older people before advocacy can be effective. If an older person asks the advocate to advocate on their behalf, the advocates always give the residents feedback and the outcome. One of the key advocacy roles is to provide advocacy to new residents, which has been very effective in ensuring that the needs of this group are met and in helping older people to adjust to residential care. As one of the advocates said "some of the little things can make a huge difference". The two Volunteer Advocates have identified some of the specific roles played in advocacy with vulnerable older people, which has been helpful in further defining the ongoing skills and training that are needed for Volunteer Advocates.

The advocates would like to meet with a larger group of advocates in the South Dublin area, to share experiences and support. They see the value of their experience being used in future training programmes and in supporting new advocates when they are placed in residential homes.

#### *Feedback from the Ashford House*

The Director of Nursing and the staff are very supportive of the programme and see it as being essential to bringing the 'external world' into the home and in providing residents with an opportunity to raise issues that are of importance to them, that would not necessarily be raised with staff. However, she did highlight the importance of advocates being fully prepared for their roles and building an understanding of the context that they are working in. She also believed that it was important for there to be more support and supervision for advocates during their placements.

#### *Personal Excellence Training*

Nineteen staff, including the Director of Nursing, Staff Nurses, Care Assistants, the Activities Coordinator, Chef and housekeeping staff, participated in the Personal Excellence Training. The feedback from staff during the evaluation was that the training has had a very positive impact on their awareness of their care roles, the quality of the personal care relationships that they have with residents, and also their understanding and awareness of the benefits of independent advocacy. A very positive evaluation was given to the trainer of the outcomes of the training.

The following are some of the comments made: "This workshop really contributed towards how to deal with our residents and colleagues"; "In our situation values should be considered also not only to the residents but also to the staff"; "The important things are respect appreciation and good listening"; "The course made me understand more about the value of work and in my personal life".



## **2. Dalkey Community Unit, Co Dublin**

### *Background to the advocacy programme in Dalkey Community Unit*

Dalkey Community Unit provides residential and respite care for fifty residents. It is a purpose build unit that opened in 2000. Three Volunteer Advocates have been placed in the Unit, providing a service of around two hours a week. There is good feedback from staff, the Director of Nursing, the Assistant Director of Nursing and from residents about the programme. Relatives and family members were informed of the advocacy programme when it commenced, and designated Link Persons on each ward link with the advocates if there are any specific issues arising on their ward. The Director of Nursing identified specific residents who had few friends or visitors who would benefit from advocacy. It was noted that the residents in the respite service were some of the most vulnerable clients. There is the potential for advocates to provide a service for this group of older people in the future, for example, in accessing benefits and services when they go back into the community. The Unit has an active Residents Committee and Relatives Committee, both of which have been important forums for improvement in the quality and provision of the services in the Unit. However, the advocates have not linked with the committee because they see their role as being dedicated to providing advocacy for individuals. The Unit also has a half-time social workers, who has is instrumental in advocating for the residents.

### *Feedback from Dalkey Community Unit*

The Director of Nursing describes the advocacy service as being very subtle, “the eyes and ears of the building”, but is not yet aware about the effectiveness of the service overall. However, she does believe that it is important to have a programme with autonomy and independence, and that there may be occasions when advocacy will make a real difference in enabling residents to speak up for themselves. Although the staff believe that they advocate on behalf of the residents in providing a quality service, there is recognition that the volunteer advocates provide an independent service and bring an outside role into the Unit. No significant issues have been raised to date, and those issues that have been relatively are small, but nonetheless important to the residents. Regular meetings and liaison takes place between the Development Officer and the Director of Nursing, which have been helpful in highlighting any issues regarding the organisation of the programme or arising from the advocacy provision itself. Advocates believe that they are very well supported by their Development Officer who is available to provide advice, guidance and address issues as they arise.

### *Feedback from Volunteer Advocates*

The Volunteer Advocates are very positive about their roles and are very appreciative of the support they receive from their Development Officer. Three advocates are deemed to be sufficient for the size of the Unit. The advocates stress the importance of being available for all residents and of having an independent and professional role. They have acquired skills as their roles have developed, some of which they would have benefitted from training on prior to starting their advocacy roles. Training needs identified included more practical skills in working with vulnerable older people. The advocates find the opportunity to discuss issues with the advocates group and with the Development Officer absolutely crucial for sustaining their motivation and interest. They have highlighted the importance of having clear procedures and protocols for supervision and support. Although these procedures have evolved, they are very much the result of the active role of the Development Officer locally and through discussion with the advocates. The advocates believe that there needs to be more clarity of their roles and more support and mentoring during the initial placement.

All three advocates are fully committed to providing the services in the longer term, and could see their role extending to other residential homes in the area and in supporting new advocates as they come on board. There is some interest in participating in a wider group of advocates in South Dublin and in engaging in further and ongoing training.

### **3. Beneavin Lodge**

#### *Background to the advocacy programme in Beneavin Lodge*

Beneavin Lodge is private nursing home with 68 beds, based in Glasnevin, Dublin 11; over half of the residents experience some form of dementia. Two volunteer advocates were originally trained to provide an advocacy service in Beneavin Lodge. However, one volunteer advocate dropped out soon after the programme began. The remaining volunteer advocate has been very active, has developed excellent relationships with her link person and staff in the home. On the same campus is Beneavin House, which has 127 beds, and currently does not have an advocacy programme. This is something that the home would like to develop in the future.

#### *Feedback from volunteer advocates*

Feedback from the volunteer advocate is that she enjoys her role enormously and feels that she is “giving something back”. She visits the home one morning a week. It took nearly a year to build relationships and trust with the residents and they look forward to her visits each week. She says that “she absolutely loves being a volunteer and there are not many problems at all, and when there are problems they are dealt with very well” by her link person. However, she is isolated in her role and feels in “limbo” because she does not have someone to turn to if there is an emergency issue or if she needs advice. Although she had good and regular support from her DO in the first year, she has had very little contact with her new DO. During the first year she spoke to her DO once a week and there were regular meetings with herself, the link person and the Director of Nursing in the home. Currently she is providing a service to all residents at Beneavin Lodge. This has been very difficult and does indicate the need for a system for replacing advocates, so that there is not an undue burden on existing volunteers. She believes that the other Volunteer Advocate dropped out because she was not sufficiently prepared and trained for the practical aspects of the advocacy role, particularly in providing advocacy for people with dementia.

Overall, she believes that the training provided was too theoretical and difficult. She would have liked a more practical approach to the training and a better connection between the theory and the practice. Although she had experience of working in a residential home in the past she felt that “many people were thrown in at the deep end, it was a very daunting experience and very hard”. Having access to practical “hands on” training on dementia was identified as a key area. She would like to continue to provide the advocacy service in the future as she has built up very good relationships with the people she advocates for, but stresses the need for another advocate for the home and a better support structure.

#### *Feedback from the Home Manager and General Manager*

The Home Manager and the General Manager have been very pleased with the role and relationships developed with the volunteer advocate, and believe that her role has made a difference to residents. While the advocacy issues raised are relatively minor they are acted upon quickly and effectively. There are significant concerns about the way that the programme was developed and implemented, the lack of training in dementia and communicating with vulnerable older people, and the absence of a support structure since the first DO left. There is a serious practice gap that needs to be addressed regarding the

provision of advocacy services for people with dementia. This applies to the preparation and training for volunteer advocates and resolving the issue of how advocacy can be provided for people who are unable to give their consent to advocacy. The absence of practical training in this area was identified as a contributory factor to why one of the volunteer advocates left the programme at an early stage, which left her 'out of her depth and very scared'. In this light it would have been useful for the training providers to have consulted with professionals providing residential care services to people with dementia, in order to inform the content of the programme. The Home Manager and General Manager are also of the view that there is a need for a more active DO and a better implementation of the programme within the home.

#### *Personal Excellence Training*

Eighteen staff in the home participated in the Personal Excellence training that was rated as being very enjoyable and positive. This helped staff to see their role in providing care in the wider context of their own lives and experiences. It was suggested that the training could provide more insights and connection with the advocacy programme. One of the issues raised is that staff saw the advocacy programme as another 'HIQA inspection'. The General Manager was very aware from the start of the programme that an emphasis on 'complaints', during the information sessions held for managers of the Units where the programme was to be rolled out, was not helpful to embedding the programme in the home itself. This led to a suggestion that advocates could address 'concerns', within a framework of examining the positive elements of the care provided, which would in any case highlight any specific advocacy issues. The association of the programme with the HSE is not seen to be helpful for nursing homes in the private sector, and for this reason there is support for the programme to be located outside of the HSE.

#### **4. St Mary's Hospital, Phoenix Park, Dublin**

##### *Background to the advocacy programme in St Mary's*

St Mary's is the largest public sector residential hospital for older people in the country. There are 366 beds, 243 of which are residential, 117 of which are admission, assessment and respite beds. Currently there are 243 residents in long-term residential care. The advocacy programme has been welcomed in the hospital, particularly because many residents are medically unwell, frail, confined to their beds or chairs and are unable to attend the Residents Forum. The institutional setting impacts both staff and residents and having regular one-to-one communications with older people is regarded as being crucial to enable older people to divulge their fears and concerns.

There are currently three volunteer advocates providing an advocacy service to older people, which is insufficient for such a large residential setting. There were originally nine volunteer advocates allocated to St Mary's but over time they have dropped out. Lack of preparedness to carry out an advocacy role, a poor system of support and limited contact with the Development Officer, as well as personal factors, were reasons given for this. In the past the programme benefitted from a paid Advocacy Officer who was employed by Age Action, which has had a long standing relationship with the hospital. A Development Officer, is currently employed by Age and Opportunity, and provides support to the volunteer advocates. However, there was a period of time when there was no Development Officer, which left the Volunteer Advocates unsupported and isolated. There are no formal linkages with the Resident's Forum and advocacy is not an issue covered in residents surveys carried out every six-months. However, there is scope for the advocates to support participation of some of the more vulnerable older people in the Forum.

#### *Feedback from the Volunteer Advocates*

The Volunteer Advocates are very committed to their roles and provide a service on a weekly basis to older people. Building relationships and trust have been hugely important and the advocates have been able to assist the people that they advocate for in highlighting issues that they would not necessarily be prepared to raise with the care staff. The advocates highlighted the importance of improved communications between the care staff and link persons on the wards, and the need for more sustained and regular contact with the Development Officer, who they believe should be in a paid post. As one advocate “we need the Development Officer there for us, we need the support and chance to give feedback and also when there is a difficult situation someone to ring to talk to; the Development Officers should also have regular meetings with the Director of Nursing and the link persons”. The Development Officer role as seen as particularly important in “keeping us on track and giving us supported when needed, and making sure that the training is kept fresh in our minds”. One advocate also highlighted the importance of having someone who provides supervision for advocates and Development Officers nationally. One advocate has recently established a Facebook site for advocates and would like to see this developed as a support structure for advocates. The advocates saw an opportunity to roll out the programme into the community and saw an opportunity for themselves to work with vulnerable people in the community, and also to mentor and support new advocates as they are trained. There is a dedicated social work service at St Mary’s and one of the advocates spoke about the good links with the social workers on advocacy issues.

The Volunteer Advocates participated in the NCI’s first training course, which was found to be interesting, but in parts irrelevant to their roles as volunteer advocates. One of the advocates is now following the Gerontology training programme in Dublin and believes that many of the issues raised and skills developed in the course need to be part of the original training. Particularly valuable has been the training in communicating with people with dementia and understanding the specific illnesses and conditions of older people, have been particularly valuable. This practical emphasis on communications and preparing people for the vulnerabilities faced by older people was seen to be missing from the original training course. Other issues identified were the need for more training on bereavement and in advocating for people at end of life. The Acting Director of Nursing similarly shared these concerns that the training did not fully equip advocates to carry out practical advocacy roles with very vulnerable older people. She recommended the introduction of more practice based skills building, particularly as many advocates do not have experience of residential care settings.

#### *Feedback from the Acting Director of Nursing*

The Acting Director of Nursing stated that the advocates have been “very much left to their own devices”, and has recommended that a better system of communications and procedures be put in place to ensure that the benefits from the programme can be fully realised. She recently carried out an evaluation of the advocacy programme at St Mary’s with the Link Persons and CNMs, which highlighted the importance for two-way feedback between the staff and the advocacy programme, better communications between the Link Person at ward level and the advocates, an improved system for reporting issues that are raised, and procedures for addressing any risks that the advocates may face. There is also a need for advocates to have more information and awareness of the complaints system and clinical procedures, and training to be provided at inception on the policies and procedures in the hospital itself.

The Acting Director of Nursing would like to see the advocacy programme grow, with improved procedures and systems for communications. She recognises the huge potential that it has for St Mary's for empowering residents and improving their quality of life.

#### *Personal Excellence Training*

Thirty-two staff at St Mary's participated in the Personal Excellence Training. Eight staff participated in part of the programme and sixteen in the full programme. There was a very positive evaluation of the training from staff, who found the training course to be rewarding and valuable for them in their personal lives and in their work. Comments from participants included "Course gave a lot of insights about how to achieve personal excellence through work"; "It made me think about valuing myself more, to really feel good about myself, to give my best to the residents I work with"; "It made me feel special"; "I know now that I can give my best to the residents that I work with"; "This is the first time that I got an opportunity to attend such a class, to live as a human being, to understand myself and understand others"; "I do believe that I look at my job differently now"; "My communication with residents is now more effective"; "I realise I could make each resident I care for special".

The Acting Director of Nursing believes that the programme has huge value and potential and suggested that a 'train the trainer' approach be implemented so that each residential unit has a Personal Excellence expert. In St Mary's this could be progressed by the hospital's Practice Development Coordinator and Nurse Tutor. Training for staff in advocacy methods was also seen as a way in which embedded attitudes and resistance could be changed, and awareness raised. However, there are problems in releasing staff, particularly because there has been a significant depletion of staff at St Mary's since the moratorium on recruitment was introduced in the HSE.

### **5. Cuil Didin, Tralee, Co Kerry**

#### *Background to the advocacy programme in Cuil Didin*

Cuil Didin is a private residential home located on the outskirts of Tralee, Co Kerry. It was purpose built and opened seven years ago. Sixty older people live in Cuil Didin. Three Volunteer Advocates provide an advocacy service to the home, although currently only one of whom provides a regular service. Cuil Didin was the location for the training of 30 Volunteer Advocates in Kerry, and has become a location for meetings between Volunteer Advocates with the new Development Officer in Kerry. Two of the staff in Cuil Didin also participated in the training and they currently provide a volunteer advocacy service in other local residential homes.

#### *Feedback from the residential home*

The manager of the home believes passionately in the importance of advocacy and welcomed the introduction of the programme in her home. One of the challenges raised by the Manager has been retaining the interest of VA and ensuring that they provide a regular service. The new DO for Kerry is likely to have a positive impact in supporting the Volunteer Advocates, in the future, particularly because there has not been an active DO in the area for some time.

There is an active Residents Committee, Relatives Committee and Cuil Didin Caregivers Club, whose representatives stated that they appreciated the value of the advocacy programme to the quality of life for residents. Feedback from residents who benefited from the advocacy programme was equally positive. Bringing the 'outside into the home' has been

hugely important to residents, particularly those residents that are very vulnerable and isolated.

#### *Feedback from volunteer advocates*

While the Volunteer Advocates found the advocacy training to be very enjoyable and interesting, the training and support were not sufficient to fully prepare the advocates for their roles. As one VA said “the reality on the ground is very different, and there was no real orientation for the advocates when they started and many were left alone to fend for themselves”. There were some issues about the scheduling of work placements and support during placements, and the fact that the written information pack was presented at the end of the course, which would have been useful at an earlier stage. The Volunteer Advocates appreciated the practical scenarios and examples given in the course, but highlighted the need for specific practical skills in communicating with people with dementia.

There are mixed views from the Volunteer Advocates about the value of the programme. One VA stated that there were so few issues arising from her advocacy role that she is not sure what she is accomplishing; while the other two advocates stated that they felt their roles were hugely beneficial. Overall, the positive welcoming of the programme in the home has meant that issues that do arise are dealt with very well, and there are good relationships between the advocates, the link staff and the Manager. The advocates stated that they were able to spend time with residents that the staff do not have time for, while stressing the importance of building relationships with residents and empowering them to speak for themselves. As one advocate said: “It is very rewarding, it really is. The things that really matter can make a real difference. It means the world to me and to them”. Volunteer Advocates highlighted the need for more ongoing practical training, particularly in areas such as dementia and end of life. The advocates were not able to attend the Gerontology course held in Dublin in 2010 because of the time and costs involved in travel, and would appreciate that a similar course be run in Kerry. The Volunteer Advocates stated that they enjoyed receiving the evaluation Bulletins and recommended that they become a regular feature of the advocacy programme in the future. Having an active Development Officer was also highlighted as being very important.

#### *Personal Excellence Training*

Sixteen staff, including administration, maintenance, housekeeping, health care assistants and nursing staff, participated in the Personal Excellence training. In the evaluation carried out by the trainer at the end of the evaluation, the participants rated the training very highly. They spoke about the value it gave to their lives, that it made them reflect on their own care roles and compassion and gave them a social and life perspective. As one staff member said in the focus group held with staff as part of this evaluation “It made me reflect on how I provide care and it had a positive impact on me; I know not to dismiss residents and give them respect, even when I’m busy”. Another said: “It took me down to basics and made me think and reflect; I could see how compassion is important in an institution”. The course has led to a significant interest in developing a better understanding of compassion in an institutional setting, amongst the staff and the Manager of the home.

There are plans in place to take the issues raised forward in a concrete way through the creation of a Compassion Forum for residential homes in the area, discussion for which is planned to involve staff, Volunteer Advocates, representatives from the Residents Committee, the Relatives Committee and the Caregivers Club at Cuil Didin.

## **6. St Joseph's Community Unit, Trim, Co Meath**

### *Background to the advocacy programme in St Joseph's Community Hospital*

St Joseph's is a public sector Community Unit providing residential and respite care for older people. It has 110 beds and a dedicated Alzheimer's Unit. Six advocates were trained to provide a volunteer advocacy service at St Joseph's and four are currently fully committed to their roles, providing weekly visits to residents. Two advocates have been sick, one of whom is now in a position to return to his advocacy role. A Steering Group was established to oversee the Advocacy Project in St Joseph's and met monthly up to May 2010; there is now a commitment to reinstate the group as this has proved very useful in coordinating the various different elements of the project at St Joseph's.

### *Organisation of the advocacy programme: role of the development officer*

When the programme started there was no Development Officer in post, which created some significant problems in the embedding of the programme. The Volunteer Advocates felt largely unsupported during this time. However, a part-time Development Officer was appointed by Age Action in 2009 to coordinate the advocacy programme at St Joseph's. The post is funded by the HSE. The Development Officer reports to Age Action, but does have some contact with the programme through the national Development Officers Group that meets bi-monthly. Having a paid Development Office has added continuity and stability to the advocacy programme at St Joseph's, and this has helped to improve the interface with staff and the Resident's Committee, in providing regular support to the volunteers.

The Development Officer believes that there is now a very good relationship with the Clinical Nurse Manager, the Director of Nursing, the staff and residents and a positive acceptance of the programme. The monthly meetings held between the Development Officer, the Clinical Nurse Manager and the Director of Nursing have been very valuable for discussing issues flagged up by the advocates. Quarterly meetings are held with the Clinical Nurse Managers, who act as the Link Persons on for the advocates on each ward, and regular meetings take place with the Volunteer Advocates. There are plans to improve the linkages with the Residents Committee. The Development Officer has highlighted the need for a programme of training to replace existing advocates, who may not continue in the longer term as they have completed their 16 month commitment to the programme. In the early stages of the programme there was a lot of suspicion by staff, and advocates were seen as inspectors in another guise. As the service has developed and as relationships with staff have improved, there is now a greater buy-in from staff. The Advocacy Programme is now featured as a regular item in the quarterly newsletter and staff are now more aware of the benefits of advocacy.

### *Feedback from volunteer advocates*

The Volunteer Advocates are very positive about the volunteering experience and reap huge rewards from it. They work in teams of two, with each pair covering one ward, whose link person is the CNM on the ward. The training of the advocates took place in St Joseph's and was an enjoyable experience for the group. The need for more practical skills, skills in working with people with dementia, issues affecting older people at end of life, were some of the training issues highlighted as being particularly important for future training. Because there was no Development Officer in place when they completed their training, which meant that they were 'left to fend for ourselves'. One of the issues raised was that it is not always possible to provide advocacy in privacy, since the beds are very close to each other in the wards, which means that conversations are easily overheard. The lack of space also means that there is no room for a chair to sit beside the resident. The advocates do not

provide a service in the dedicated Alzheimer's Unit, because they have not received the relevant training to provide advocacy in this context. Most of the advocacy issues that are raised are dealt with very well by the link staff and to date there have been no major issues of concern arising.

#### *Personal Excellence training*

Seventeen participants, including health care assistants, catering and housekeeping staff and nursing staff participated in the Personal Excellence training held in St Joseph's in 2009. Participants evaluated the training to be overwhelmingly positive, and extremely useful and valuable at a personal and in relation to their care work. Comments included "It will give me a better outlook on life and my work"; "It gave me a greater understanding of how I approach my care of the elderly and the importance of taking an overall view at all times"; "It has improved my confidence in the delivery of care"; and "I would recommend the programme to everybody".

### **7. Middleton Community Unit, Co Cork**

#### *Background to the advocacy programme in Middleton Community Unit*

Middleton Community Unit is a public sector residential care home providing residential and respite services for 72 residents. Around one-quarter of the residents have difficulties in communications. Six advocates were originally trained to provide an advocacy service in the Unit, and currently there are three active advocates. Overall the issues raised have been relatively small but nonetheless significant for the residents. When the advocates were first placed in the Unit the Acting Assistant Director of Nursing and one CNM met with advocates to brief the advocates about the Unit and the residents. Briefings about the programme were also given to staff. The volunteer advocates have been allocated Link Persons on each ward in which they provide advocacy. Overall they provide a service to twenty residents each for between two and three hours a week. There are very good relationships between the Volunteer Advocates, the Acting Assistant Director of Nursing and the staff in the Unit. The hospital does not yet have a Resident's Committee but see this as a priority for the future. The problems faced with adequate staffing levels and administration has made it very difficult to organise a Resident's Committee.

#### *Feedback from Volunteer Advocates*

The Volunteer Advocates enjoy their roles enormously, although they initially had difficulties in settling into the home because they had no Development Officer to support them. While the training had been useful in giving the advocates confidence and competence, it was only when they started their placement that a lot of issues came to the fore. As one advocate said "It didn't prepare me fully, its kind of watchdog advocacy as many of the residents are not able to communicate what they want". This advocate is now really benefiting from the Gerontology training, which she believes needs to be incorporated into the training and more experiential training. The advocates have provided independent advocacy for people coming into the Unit for respite care, for example, on the Fair Deal, in contacting the Public Health Nurse and other services in the community.

However, they have built up good relationships with staff. The Volunteer Advocates are supported by their Development Officer and monthly meetings are held with volunteer advocates from all of the participating residential homes in County Cork. These monthly meetings are not only useful for advocates in sharing information with their fellow advocates, but the meetings have also been an opportunity to invite visiting speakers and provide additional training. The monthly meetings are very well attended and the volunteer



advocates value the role that they play. The Volunteer Advocates are currently following a course, with other Volunteer Advocates in Co Cork, based at St Finbarr's Hospital.

#### *Feedback from Middleton Community Unit*

The Acting Assistant Director of Nursing is very supportive of the Advocacy Programme and the benefits that it has in a residential setting. This has a particular role to play in helping to address the challenges of institutionalisation and structured care regimes on the residents. As a result the independent advocacy programme is seen to play a critical role in empowering people to be individuals and in speaking up for themselves. The institutional regime impacts on staff who may view the residents as dependent, which has the effect of limiting the voice and autonomy of older people in a residential setting. The Acting Assistant Director of Nursing has highlighted some key challenges for advocates in providing advocacy to residents with challenging behaviour, cognitive impairments and dementia. She is of the view that specialist training needs to be provided for advocates in these areas.

#### *Personal Excellence Training*

Eleven participants, including health care assistants and nursing staff, participated in the Person Excellence training held at Middleton Community Unit. Overall, the staff participating in the training gave a very positive evaluation of the training, which enabled them to reflect on their roles and their own personal values, to the benefit of the care they provide for older people. Participant's comments include "Very interesting and beneficial"; "Made me see how I can improve in a positive way"; "Help me to improve my interaction with the residents"; "Will help me to be more effective in my job"; "Will help me improve the care given to residents"; "Excellent programme to improve staff morale".

### **8. St Finbarr's Hospital, Cork**

#### *Background to the advocacy programme in St Finbarr's*

St Finbarr's is a 273 bed public hospital providing residential, rehabilitation, respite facilities, day hospital and continuing care for older people. There are currently 153 older people in long-term residential care. Twelve Volunteer Advocates have been trained to provide the advocacy service in St Finbarr's Hospital, and they work in pairs, covering a ward between each of them. The aim in the future is to have sufficient Volunteer Advocates to cover all wards in the hospital. The group is very proactive and there is a planned approach to the programme. The advocates are supported through monthly meetings and regular contact with their Development Officer. A process has been put in place for logging and addressing issues that are raised by the Volunteer Advocates and also for advocates to visit people outside of their normal visiting times. In addition, monthly meetings are held between the Development Officer, the Clinical Nurse Manager, who is responsible for the programme, and the Director of Nursing to discuss issues arising from the advocacy service. This example from Finbarr's does show that the Development Officer has played a key role in creating a support structure, a team approach and an effective independent process for addressing issues raised.

#### *Feedback from Volunteer Advocates*

The Volunteer Advocates are very positive about their roles in providing an advocacy service and of the support role played by the Development Officer. They raised some very important issues for the future role of the Advocacy Programme, which have been addressed in the evaluation. They are also clear about the need for advocacy to be part of more sustained policy developments that enhances the rights and quality of care for older people. This is

particularly because of the impact of institutionalisation on older people and the vulnerabilities of older people in residential care.

The Volunteer Advocates are a very active group and have huge commitment to the programme. The team approach has been very valuable and has helped to sustain the motivation and enthusiasm of the advocates. Much of this is put down to the “exceptional” role of the Development Officer. They have found that the programme has made a difference to residents and that the role has enabled them to grow themselves. As one volunteer advocate said “you know you are making a difference, it takes time to build trust and relationships”. Volunteer advocates are involved in observing situations around them, empower the older people they advocate for to speak up for themselves and in providing advocacy on behalf of residents to meet the needs that they have identified.

#### *Training and development of volunteer advocates*

The training for advocates in participating residential across the Cork County took place in St Finbarr’s. This included advocates from Middleton, Bantry, Skibereen, Mallow and Kinsale. Some of the advocates found the training to be very theoretical and that there was a heavy load of assignments, while there was an overwhelming view that the training was insufficient in providing the skills for working with older people with cognitive impairments. The group has stayed together since the completion of the training and meet on a monthly basis. The meetings are an opportunity to share information, to exchange and review journal articles, to give support and feedback to each other and to invite visiting speakers. They would like to see more training located locally, rather than in Dublin. The Volunteer Advocates also see the potential to provide a mentoring or buddy system for new advocates, and have recommended that a better system be put in place for introducing advocates on to the wards. The Volunteer Advocates are currently following a further training course on Gerontology, which they deemed to be an important to understanding advocacy within the context of geriatric care and in providing care for people with dementia.

#### *Feedback from the Development Officer*

The feedback from the Development Officer is that motivation of the advocates, particularly at the start when they started visiting and encountered residents with limited interaction, was difficult for them, but they supported and encouraged each other during this time. There is significant value in holding regular meetings as this helps the Volunteer Advocates to build up confidence, both in raising issues to the Link Nurse, and with encouragement from the Development Officer and their fellow advocates. This also provides them with a safe place to raise issues that they find difficult, for example, the death of residents or feeling of inadequacy in communicating with non-verbal residents. The Development Officer stated that “The advocates in St Finbarr’s are a special group of people who have great belief in the advocacy programme and a great commitment to the good of the residents. They all have different skills to bring to the programme and the meetings give us all a chance to gain from their skills and experiences. They are very supportive of each other”.

#### *Feedback from the hospital*

The hospital is very positive about and welcoming of the programme and are clear that there has been a real impact in ensuring that residents have a ‘voice’ and access to an independent advocacy service. The Clinical Nurse Manager who is responsible for the programme recognises the value of the programme in mediating the impact of institutionalisation on residents and to improving the quality of care provided. She stated that “Through the Resident’s Forum and the independent advocates visiting the residents

we have provided the residents in our care with a protected environment to express their needs/views...thus allowing us to move to an environment that is empowering and person centred". Initially there was some resistance from the nursing staff at St Finbarr's, and it took time for staff to become aware and comfortable with the advocates coming onto the wards. The hospital has a Residents Forum, currently chaired by the Clinical Nurse Manager, who is of the view that the committee could be chaired by an independent advocate in the future.

## Section 8: Funding, management and governance of the programme

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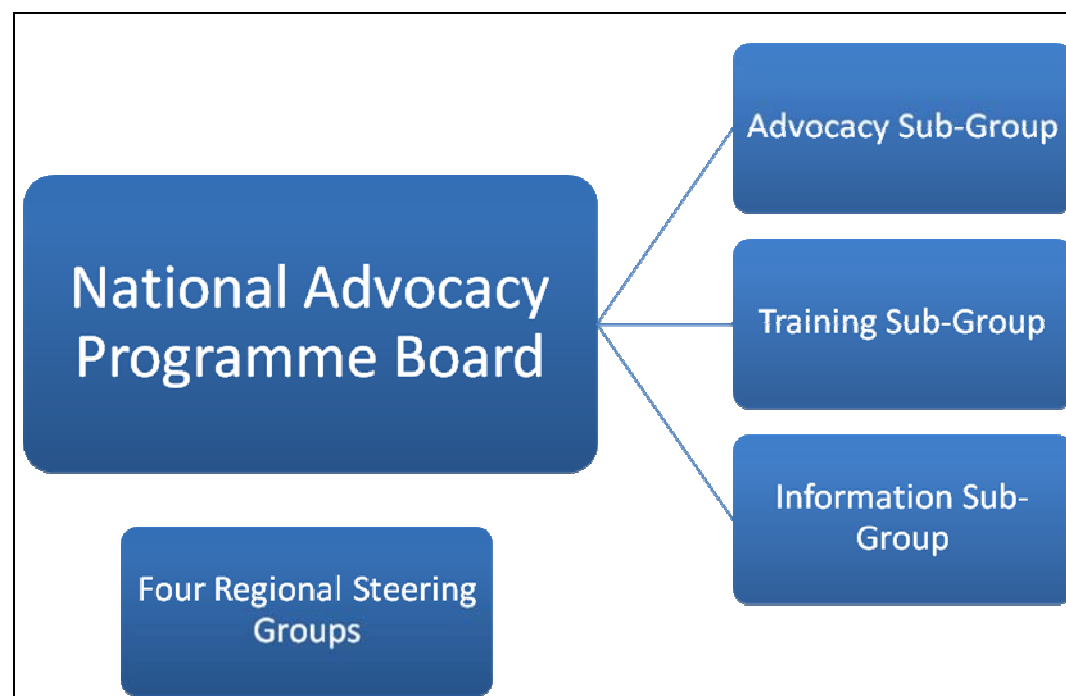
### 8.1 Proposal for a new National Advocacy Programme for Older People: structure, management and governance

There is now time for a new strategic direction and leadership to be given to the programme, and for the programme to be broadened out from residential care to hospital care and in the community, in all areas where care is delivered.

It is proposed that the programme be re-launched under the title of the **National Advocacy Programme for Older People**, on the basis that the programme may in the future be provided in a range of settings in addition to residential care, notably in acute hospital care and in the community.

It is suggested that NAPA be formally disbanded, since it was an interim group established to follow through the recommendations for the establishment of the advocacy, information and training programmes. However, the current NAPA sub-groups: Advocacy, Information and Training, should be retained as a structure under the new independent programme management structure that is recommended from the evaluation.

**Figure 3: Proposed new governance structure**



## **8.2 The role of the lead agency**

The evaluation has found wide support for an independent Advocacy Programme outside of the HSE. It is not appropriate or sustainable for the HSE to directly provide and manage the Advocacy Programme, as this has the potential to compromise their role and lead to conflicts of interest. The HSE share this perspective and recognise that its role should be as a funder and partner in the Advocacy Programme. As a partner it is possible for the programme to inform HSE service developments, for example, regarding the funding of residential care in the public sector and through the 'Fair Deal', the continuous professional development and training of health care staff, and to maintain close links into relevant services such as 'Your Service, Your Say' or elder abuse policies and prevention.

It is nonetheless important to stress that the HSE partner role should continue to be located under the remit of the Director of Advocacy (under the Quality and Clinical Care Directorate). This is important for two reasons. First, it positions the Advocacy Programme within the framework of the HSE/DOHC Strategy for Service User Involvement, of which advocacy is an embedded goal and principle. Second, it enables the HSE to continue a partner role that maintains a degree of independence from the direct provision of publicly funded services for older people.

For this reason the evaluation concludes that the Advocacy Programme would have more credibility and independence if it was located in an independent structure. There are potentially three different organisational contexts for this:

- The Citizen's Information Board;
- An Independent Older Person's Organisation;
- The creation of a new Advocacy Organisation, through a partnership of existing older people's organisations across the country.

## **8.3 A National Advocacy Programme Board / Steering Group**

It is recommended that the governance of the programme will be established through a National Advocacy Programme Board / Steering Group. This should be a multi-stakeholder group reflecting the membership of the current NAPA group, and to include all older people's organisations (Age Action, Age & Opportunity, Care Local, Older & Bolder, Senior Citizen's Parliament, Third Age etc.), representatives from the Alzheimer Society, Nursing Homes Ireland, HSE Older Person's Care Group, the HSE Advocacy Service and Elder Abuse Officers, HIQA and the Citizen's Information Board. The Board / Steering Group will be responsible for all governance issues and for the overall management and strategic direction of the programme.

## **8.4 Strategic development of the service**

The strategic development for the National Advocacy Programme will need to have clear direction and purpose, with structures that define the relationships with

stakeholders, clarity of policies and procedures, and quality criteria. It needs to set out performance targets and indicators, management structures, support for Volunteer Advocates, and effective processes for the delivery of the programme. Underpinning the strategic development is the need for clear definitions and understandings of advocacy for older people in a residential setting and how the model of advocacy can be achieved in practice. It is recommended that the first task of the Independent organisation, that is recommended will manage and govern the programme in the future, will be to draw up a five-year Strategic Plan, linked to annual Work Plans.

### **8.5 Regional structure and Steering Groups**

It is recommended that a regional structure be put in place covering (Dublin Mid Leinster, Dublin North East, South and West). While it is recommended that the programme be managed, delivered and implemented through an independent organisation it would be expedient for the structure mirror the current HSE Integrated Service Programme. This provides a new framework for integrating services between hospital, residential and community-based care. A single national Integrated Services Directorate, delivered through four new regional structures (HSE Dublin Mid Leinster, HSE Dublin North East, HSE South and HSE West) has been created for this purpose. Regional Directors of Operations (RDOs) have the responsibility for delivering and managing services at a regional level, and a better integration across care groups, including Older Person's services.

It is recommended that a regional governance structure be put in place to include four regional Steering Groups to enable the programme to be embedded at a local and regional level and promote networks of support, learning and development in the programme. The Steering Groups will report to the National Advocacy Programme Board. The Steering Groups should be multi-stakeholder and include representatives from the HSE, Nursing Homes Ireland, representatives from participating residential units/homes, County Councils, CIB, older person's organisations, representatives of Resident's Committees in residential units/homes, nominated Volunteer Advocates and Development Officers.

### **8.6 Organisational, staffing and support structure**

#### *National Advocacy Programme Director / Coordinator*

It is recommended a National Programme Director / Coordinator will be appointed to oversee the management and delivery of the programme. It is suggested that the current Programme Coordinator be seconded into the new organisation that takes the lead role for the Advocacy Programme. This is important for two reasons. First, the funding for her position is guaranteed as an employee of the HSE Advocacy Unit (Quality and Clinical Care Directorate) through core HSE funding. Second, she holds the knowledge of the programme to date and has built good relationships with Volunteer Advocates, participating residential units/homes, policy makers and service providers.

Professional Development Officers would be appointed to manage the programme at a regional, provide support, learning and development for Volunteer Advocates, and meet with participating residential units/homes on a regular basis. Line management for the Regional Development Officers will be provided through the national Programme Director/Coordinator.

The National Advocacy Programme Director / Coordinator to be responsible for:

- Overall management and delivery of the programme;
- Developing, reviewing and implementing policies, procedures and protocols;
- Coordinating, managing and developing the training programme for initial and CPD training for Volunteer Advocates;
- The roll-out of Personal Excellence training for staff in residential units/homes;
- The coordination of residential units/homes participating in the programme;
- Liaising with fund holders and responsibility for the financial management of the programme;
- Line management of Regional Development Officers;
- Liaison with Regional Steering Groups and Development Officers;
- Overseeing, coordinating and further developing the Information Programme.

#### *National Advocacy Programme Volunteer Coordinator*

It is proposed that a new position be created to provide for the roll-out of the National Advocacy Programme to new residential units/homes, a new project in an acute setting and a new project in the community. This will require the training and support of new Volunteer Advocates and ensuring that the programme is embedded at the local level. The National Advocacy Programme Volunteer Coordinator will have the responsibility for:

- Overseeing the support and mentoring for trainee Volunteer Advocates and work-placements;
- Keeping up to date records Volunteer Advocate placements and relevant reporting requirements;
- Managing and overseeing Volunteer Advocates in residential units/homes, and ensuring there are clear lines of communications with units/homes to ensure that there are processes for volunteer replacement, where needed;
- Liaising with Development Officers in relation to volunteer support, learning and development;
- Establishing and maintaining Local and Regional Volunteer networks;
- Putting in place training and support for Volunteer Mentors from the existing cohort of Volunteer Advocates, to provide mentoring and support for new trainees and advocates.

#### *Regional Development Officers*

Four Regional Development Officers should be appointed to manage the programme at a regional level, provide support, learning and development for Volunteer Advocates, and meet with participating residential units/homes on a regular basis. Line management for the Regional Development Officers will be provided through

the national Programme Director/Coordinator. The Regional Development Officers will also provide the administrative and organisational support for the Regional Steering Committees.

#### *Local and regional Volunteer Advocate networks*

The findings from the evaluation suggest that the development of local and regional Volunteer Advocate networks will be crucial for Volunteer Advocates to share experiences, provide peer-support and learning, and engage in ongoing Continuing Professional Development (CPD). For example, ongoing and CPD training courses could be located at a regional level in some cases to enable there to be a critical mass of participants, while not removing the possibility for locally based courses to continue to be provided.

Local and regional networks can be further supported through regular Advocacy Programme Bulletins or Newsletters and links to an Advocacy Programme discussion forum and Facebook site for Volunteer Advocates.

It is recommended that a structure be put in place for Volunteer Advocates to be represented on Regional Steering Groups, and to be consulted and informed of programme developments via Volunteer Advocate representatives. For example, each local network of Volunteer Advocates, which may cover one or more residential units/homes would nominate a representative to attend the Steering Group meetings. The findings from the evaluation suggest that not only are current Volunteer Advocates very well informed about practice of the programme, many have reiterated the importance of consultation and engagement with them in the development of new policies, procedures or programme developments.

**Figure 4: Proposed Organisational, Staffing and Support Structure**





## 8.7 Funding 2011-2014

The following is an outline budget that would be sufficient for the development of the new Advocacy Programme for Older People. These are outline costings that would need to be examined further by the NAPA group and the HSE.

Table 7 shows the outline budget for 2011, which totals €515,000. There would be a slightly smaller budget for 2012 of €495,000 and 2013 of €495,000 (based on the one-off costs allocated in 2011 for the development of the Personal Excellence Manual). The rest of the costs are recurring costs, which also include an annual national conference to bring together all stakeholders and Volunteer Advocates.

**Over the three-year period a total budget of €1,505,000 would be required to implement the recommendations for the next stage of development for the programme.**

**Table 7: Proposed programme budget: 2011**

Funding element	Funding required
• National Coordinator, responsible for overall project management and governance, development of policies, protocols and collection of data, financial management	(funded post within the HSE)
• National volunteer coordinator, with remit for supporting and developing volunteer advocates and for managing the Development Officers (full-time post)	€60,000
• Four regional Development Officers (full-time posts)	€200,000
• Training costs (for new volunteer advocacy training programme)	€140,000
• Training costs for CPD / local and regional training of existing advocates	€20,000
• Personal Excellence Training ('train the trainer', seminar updates, and resource development (Personal Excellence Manual).	€35,000
• Information Programme, further development of web site and more detailed information	€5,000
• Programme materials and publicity, including Advocacy Programme web site and Facebook	€20,000
• Administration costs and discretionary travel expenses for Volunteer Advocates	€15,000
• High level conference to showcase the Advocacy Programme	€20,000
<b>TOTAL</b>	<b>€515,000</b>

It is recommended that the funding for the programme should come from a variety of sources. The HSE has a mandate and duty to fund the programme in the long term, and there is also scope to secure an annual contribution to these costs from Nursing Homes Ireland, whose members benefit from the Advocacy Programme. It may also be feasible to examine whether some or all of the costs for the Personal Excellence Training and resources could be met jointly by the HSE (Learning and Development and progressed under the DOHC Practice Development Strategy) and Nursing Homes Ireland. Consideration should also be given to funding from corporate and company sources in the remit of Corporate Social Responsibility.

## Section 9: Conclusions and recommendations

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### 9.1 Conclusions and summary of key findings

- The Advocacy Programme has developed and grown significantly since it was first established in response to revelations that emerged from the Leas Cross Inquiry and the subsequent recommendations made by the Forum on Older People.
- The programme has demonstrated the significant and long-term contribution that independent Volunteer Advocacy can make to the quality of care in residential units/homes and to giving 'voice' to older people.
- The original proposed programme structure did not materialise. This led to a revised structure being put in place for volunteer support, which compromised the overall effectiveness of the programme and some of the principles underpinning it;
- Despite these constraints the outcomes of the programme show innovation, significant achievements, with many positive outcomes, within the confines of a very modest budget and a short timeframe.
- There is now a significant geographic spread of provision across sixteen counties in Ireland; and there exists a network of very experienced and skilled Volunteer Advocates and Development Officers across the country, whose experience needs to be harnessed for the future roll-out of the programme.
- Key issues of volunteer support, initial Volunteer Advocate training and ongoing training have been highlighted in the evaluation as issues that need to be addressed if the programme is to deliver a high quality, high value service to its users.
- There has been significant commitment and dedication of time, expertise and contribution from NAPA members, Volunteer Advocates and Development Officers.
- There is a strong commitment to the future development of an independent programme from a wide range of stakeholders who formed the NAPA group, and from Volunteer Advocates, participating residential units/homes and Development Officers.
- The provision of training for Volunteer Advocates and Personal Excellence training for staff in residential units/home have been a very important contribution to ensuring professionalism and currency for the programme; competencies need to be developed in some key areas and reviewed for their impact on the delivery of the programme.

- The new Advocacy Programme for Older People should set an early task a partnership with the Alzheimer's Society to develop strategy for Dementia Advocacy. This could draw on some of the models developed through the Alzheimer's Society and models developed in other countries<sup>19</sup>. There is significant scope for developing a dedicated specialist Dementia Advocacy Programme in the future.
- The Information Programme is an important element of the programme's development and there is now scope for the further and more in-depth provision of independent information;
- The programme should be underpinned by regular evaluation and consultation with a view to determining outcomes based on the lived experiences of older people in residential care.
- There has been a significant amount of learning from the programme. Some key challenges and risks need to be addressed in order to overcome some of the organisational, structural, governance and funding constraints inherent in the current programme.
- It is essential that the Advocacy Programme be independent of the HSE and that there is a robust organisational structure that has clarity of roles. There are various reasons for this. The service cannot be independent if it is located and managed by the HSE, while the current low levels of trust of the HSE, undermines the credibility of the programme.
- The proposals for a new Advocacy Programme for Older People provides a framework and way forward, with costings, for an independent organisation to take on the role of delivering the three elements of the advocacy programme. The HSE will need to continue to play a key role both as a funder and as a partner, under the remit of the HSE Director of Advocacy.
- If these issues and challenges can be realised in practice there is real scope for the establishment of a structure that is independent of the HSE, the further development and roll-out of the programme, and the application of the model to provide independent Volunteer Advocacy for older people in acute care and community settings.

## **9.2 Underpinning principles and critical success factors to inform the future development of the programme**

The next stage of development of the Advocacy Programme for Older People should be based on the following six principles:

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<sup>19</sup> See for example, Sally Wells (2006) *Developments in Dementia Advocacy: Exploring the role of advocates in supporting people with dementia*. Westminster Advocacy Service for Senior Residents; Cantley C, Steven K and Smith M (2003) *'Here What I Say': Developing dementia advocacy services*, Dementia North, Northumbria University

- **Older people are at the centre:** It is essential that older people in residential care are empowered and facilitated to have a 'voice' and that they are at the centre of service provision.
- **Independence:** The programme achieves full independence, but continues to work in partnership with the HSE and other key stakeholders.
- **Resources:** Adequate resources need to be committed to the programme to ensure that systems for professional volunteer support, accountability and supervision are put in place.
- **Professionalism:** Ensure that there is a professional service and that volunteers have the required training and competencies to provide an independent advocacy service in a residential setting; that Personal Excellence training is rolled-out through a new method of delivery; and the Information Programme provides a wider range and scope of information;
- **Programme quality:** Establishment of clear procedures, policies and quality criteria for measuring the performance and outcomes the programme;
- **Partnership:** Continue to work in partnership and ensure that all key older person's organisations, statutory providers in health and social care, participate in the ongoing management and delivery of the all elements of the programme.

The evaluation has highlighted a number of **critical success factors** that are relevant for the future development of the programme. These can be summarised in relation to:

- Policy and procedures for independent advocacy, including indicators for assuring quality and assessing risks;
- Funding and governance for the new Advocacy Programme;
- Partnership and alliances between stakeholders;
- Standards for the three elements of the Advocacy Programme;
- Accreditation, training and retention of Volunteer Advocates.

The principles and critical success factors underpin the recommendations that are made below.

### **9.3 Recommendations**

#### ***a) Legal framework for advocacy and information***

- Independent advocacy and access to information for older people should be located in a robust legal framework.
- This should be examined with a view to implementing legislation on the rights of older people to independent advocacy and information requirements on public bodies, in line with the 2007 Disability Act.
- The HIQA Standards should embed clear and robust regulatory standards on independent advocacy and information, setting out what older people should expect and have a right to receive in a residential setting.

#### ***b) A clear policy focus on advocacy in the DOHC and the HSE***

- As well as a legal framework, there is a need for a clear integrated policy focus to reflect the cross-cutting nature of the Advocacy Programme in relation to the HSE, which is best placed to be provided from and coordinated by the Advocacy Unit (Quality and Clinical Care Directorate). This also needs to be embedded in DOHC policy and in the Positive Ageing Strategy.
- One way forward would be to reinstate the Older Person's Forum, to ensure that there is effective engagement with older people and the organisations that represent them.

#### ***c) An independent and robust organisational and governance structure***

- The Advocacy Programme needs to be located in an organisation that is independent of the HSE, ideally in an independent Older Person's organisation. As part of this is the need to ensure that a clear organisational and governance structure is in place.
- A structure for this organisation has been set out in this report, which requires funding for an independent structure and the appointment of two National Coordinators and four Regional Development officers.
- A new governance structure is also set out, on the basis that NAPA is formally disbanded and that a new multi-stakeholder Board and regional Steering Group structure be established for the new programme. It is essential that the HSE Director of Advocacy, Nursing Homes Ireland, the Citizen's Information Board, advocacy organisations and older people's organisations are brought into this governance structure.
- There is a key role to be played in utilising the learning and professional development expertise and resources in both the HSE and Nursing Homes Ireland.

***d) Volunteer Advocates and Development Officers: support, procedures and protocols***

- The recommendation for the appointment of four regional Development Officers will be critical to providing support and supervision to Volunteer Advocates across each the region, to liaise with residential homes and organise regular meetings with advocates.
- Clear protocols, policies, procedures and lines of reporting to be established so that Development Officers have clearly defined tasks and roles.
- A system for coordinating the roles of the Development Officers should be put in place, with regular meetings with the Programme Coordinator. This should also include opportunities for Development Officers to meet and discuss their work.
- Development Officers should receive specific training in advocacy models, facilitation and supervision skills, and in supporting, motivating and managing advocates.
- Existing Volunteer Advocates should be encouraged and supported to play a role as mentors to new trainees and also to provide an in-put into the training for new Volunteer Advocates.
- In the future it is suggested that Volunteer Coordinators / Mentors are selected within their groups to provide coordination at the level of the residential home or in a specific geographic locality. Local Volunteer Advocate support groups should also be established in all areas.

***e) Funding of the programme***

- A package of funding from the HSE, as a body responsible for public provision, and Nursing Homes Ireland, as the representative body for private nursing homes, needs to be put in place.
- The HSE had a key responsibility to fund the Advocacy Programme, and is now in a position to hand the programme over to an independent organisation to run the programme in the future. There needs to be a long-term funding commitment from the HSE for this purpose so that the programme is sustainable.
- HSE funding should continue to be provided through the Advocacy Unit (Quality and Clinical Care Directorate), on the basis that this enables the funding to be strategically positioned within the HSE/DOHC Strategy for Service User Involvement.
- Further discussions should be held with the HSE and Nursing Homes Ireland with a view to providing funding Personal Excellence training in public and private nursing homes.

***f) Define more clearly the nature of advocacy for older people in a residential setting***

- There is evidence from the evaluation is that independent advocacy in a residential setting needs to be more clearly defined and articulated, particularly in providing advocacy to older people in vulnerable situations and older people with dementia. Many of the existing models of advocacy do not take into account

cognitive impairment, and is a challenge that has been faced by Alzheimer's Society in relation to providing advocacy for people with dementia.

- It is recommended that a specialist Dementia Advocacy Programme be established as a specialist qualification for Volunteer Advocates, and developed in partnership with the Alzheimer's Society.

***g) Mitigate any risks in the programme***

- A number of risks have been identified for the Programme that will need to be mitigated in the next stage. The proposed management, governance and staffing structure for the new programme would be in a strong position to mitigate these risks, particularly in providing a robust system of support for Volunteer Advocates.

***h) Improve awareness and understanding of advocacy in a residential setting***

- One of the findings of the evaluation is that staff in participating residential homes can be resistant and suspicious of the role of the independent advocate. This is critical to embedding the programme into residential homes. For this reason it will be important to provide more information, awareness and feedback for participating residential homes, so that they appreciate and understand the role of independent advocacy as complementing person-centred care.
- This will be possible if improved systems for introducing and inducting Volunteer Advocates are put in place, and improved communications take place with residential units/homes.
- There is scope to extend and further develop the Personal Excellence training so that it includes an understanding of independent advocacy.

***ii) Re-examine and further develop the training programme for volunteer advocates***

- Specific recommendations have been made for further skills development, in particular with regards to building communications skills (skills of communicating with and working with very vulnerable older people and in providing advocacy to people with dementia); in preparing Volunteer Advocates for volunteering in a residential setting; and in developing advocacy skills in relation to rights and entitlements. Another factor is the need to improve the understanding the role and boundaries of advocates in relation to their observations of the daily living situation of older people in institutional care.
- Consideration should be given to reviewing the current accreditation at FETAC level 6 and to examine the feasibility of providing more skills based training at FETAC level 5, with a progression route into level 6.
- Regular local / regional level training and ongoing continuous professional training and development should be provided for existing advocates.
- Consideration should also be given to delivery of the training through new technologies, distance learning and on-line learning.



- An Advocacy Programme web site, discussion forum and Facebook site, could assist in this process and in providing Volunteer Advocates with regular information and opportunities for learning. Regular Advocacy Programme Bulletins should also be disseminated on a monthly or bi-monthly basis.
- Examine the feasibility for developing continuous learning ‘circles’ or ‘groups’ for Volunteer Advocates at a local level, to enable Volunteer Advocates to reflect and discuss different advocacy situations and experiences, to invite external speakers, provide peer-support and learning and engage in ongoing learning.
- Consideration should also be given to monitoring how Volunteer Advocates can participate in training with staff in residential units/homes in core areas of training such as elder abuse, health and safety and other areas that may be relevant to Volunteer Advocates.

***l) Roll out the Personal Excellence training to all residential homes***

- A training manual should be developed, setting out the rationale for the programme, learning outcomes, modules and guidance for training, under the auspices of the Advocacy Programme. This training manual ideally should be funded by, disseminated from and embedded into HSE Learning and Development.
- A leaflet setting out the goals of Compassion and Personal Excellence should be drawn up and disseminated to all residential homes for older people in Ireland and through relevant bodies, such as the older people’s organisations, Irish Society for Quality and Safety in Healthcare, Nursing Homes Ireland, the HSE, the Irish Nurses and Midwives Organisation, to name a few.
- A programme of ‘train the trainer’ workshops for learning and development staff in residential homes, HSE learning and development units, HSE leaders in older persons services across all HSE regions, and for learning and development practitioners in Nursing Homes Ireland. A dedicated ‘train the trainer’ programme should be carried out for residential homes, whereby one representative / leadership champion of each residential home is nominated to attend the training, which s/he then disseminates and implements internally. This would be a more cost effective method than providing training in each residential home across the country and will have an important multiplier effect.
- Consideration should be given to developing a FETAC accredited module on Personal Excellence and Compassion for staff, and a similar programme for Volunteer Advocates.
- A plan should be put in place to ensure that every residential home in Ireland has a Personal Excellence Champion, who can then disseminate the learning on Compassion and Personal Excellence within their homes and units. There is also an opportunity for champions to network across the country.
- Funding would need to be sourced for these initiatives and development, which could result from a package of funding from the HSE and other external sources. Consideration should also be given to linking in with existing Skillnets Learning Networks developed within private health sector companies.

- An Annual Report setting out data, outcomes, evaluation of programmes implemented and planned developments should be submitted to the National Advocacy Programme Board at the end of each programme year.

***m) Put in place a strategy and funding to enhance and further develop the Information Programme***

- The information programme needs to be further developed and extended. There are key issues of verification and regular updating of information that need to be factored in and this will require cooperation with HIQA, Older Persons organisations, the HSE, Nursing Homes Ireland etc.
- The information programme should be widened out to include a wider range of information about rights and entitlements, information about the Fair Deal under the National Treatment Purchase Fund, and service entitlements from the HSE, particularly if a person take up a place in a private residential home.
- There is significant scope for including a wider range of information and greater detail about service entitlements, and it will also be important to examine how information can be accessed in other formats, given that older people themselves do not always have good access to the Internet.
- There is also further scope for the development of a joint approach between HIQA and the programme to spell out more concretely and in more detail specific information standards and indicators.
- The future location of the web site will be critical to its long term sustainability and development.
- A key consideration is how the web site is advertised, publicised and promoted so that it is widely known.

***l) Develop an Advocacy Programme web site and Facebook site***

- An Advocacy Programme web site and Facebook should be developed to enable Volunteer Advocates to receive regular information, have access to research and developments in advocacy nationally and internationally, and provide a forum for networking and sharing of information and good practices. This should be independent of the Information Programme web site on residential units/homes and service entitlements.

***m) Develop a plan for new extending the Advocacy Programme to acute hospital and community settings***

- The Advocacy Programme has huge potential to be rolled out into acute hospital and community settings. Four new advocacy projects for older people should be developed, one in each of four regions proposed for the new Advocacy Programme. These should span advocacy in a hospital setting and in a community setting. These should be developed through an integrated programme and piloted through Primary Care. Consideration should be given to how advocacy could become a performance measurement in the provision of HSE Integrated and Primary Care.

- A Plan should be put in place for how these four projects could be roll-out and funded in the longer-term, with a view to developing a long-term flexible structure for advocacy in residential, acute and community settings.
- In this regard, it is proposed that closer links be made with local community organisations and networks of older people, local advocacy projects, such as the Cork Advocacy Service, and Local Development Companies, who are funded to implement the Local Community Development Programme.

***n) Enable the voice of older people***

- The new programme should have a priority to establish and develop appropriate methodologies for enabling the voice of older people. This should be developed in the light of the recommendation for the integrated provision of advocacy for older people in residential, acute and community settings.
- It is recommended that models of good practice in consulting with vulnerable older people, particularly people that experience communications difficulties, be examined and implemented. This will be important in ensuring that older people have a voice in the ongoing evaluation and development of the programme.

***o) Put in place a high level conference***

- The HSE and HIQA should jointly organise a high-profile national conference on advocacy for older people to showcase the project. This should be organised in consultation with older people's organisations and the members of the NAPA group. This would help to raise the profile of the Advocacy Programme nationally and to launch the roll-out of the programme, as well as launch the web site [www.myhomefromhome.ie](http://www.myhomefromhome.ie). In subsequent years there should be an annual conference / training day for Volunteer Advocates, with expenses and accommodation costs met within the programme.

## **Appendix 1: Members of NAPA Implementation Group**

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Ann Coyle, HSE  
Ann Judge, HSE  
Ann O'Riordan, Irish Health Promoting Hospitals  
Ciaran Mc Kinney, Age and Opportunity  
Declan Hynes, HSE  
Graham Long, Citizens Information Board  
Jackie Mc Cormack, HSE  
Linda Desmond, Care Local  
Margaret Feeney, HSE  
Mary Culliton, HSE  
Mary Fletcher Smith  
Michael Brophy  
Paddy Cunningham  
Robin Webster, Age Action  
Sinead Fitzpatrick, Nursing Homes Ireland  
Vena Doyle, Nursing Homes Ireland

## **Appendix 2: Interviews, focus groups and responses to questionnaires**

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### **Interviews were held with the following people:**

- Anne Harris, Advocacy Programme Coordinator, Advocacy Unit, HSE
- Mary Fletcher Smith, Academic Mentor, Training Programme and member of NAPA
- Mary Culliton, Advocacy Unit, HSE
- Ann O'Riordan, Director, Irish Health Promoting Hospitals
- Michelle Ryan and Martina Murray, National College of Ireland
- Marion Witton and Niall Byrne, Social Services Inspectorate, HIQA
- Graham Long, Citizens Information Board
- Helen Lahert, Citizens Information Board
- Máiríde Woods, Citizens Information Board
- Noel Mulvihill, Assistant National Director, HSE Older People
- Jackie Mc Cormack, HSE Older Persons Services
- Vena Doyle, Practice Development Co-ordinator, Nursing Homes Ireland
- Ann Coyle, HSE
- Declan Hynes, HSE Performance and Development
- Avril Dooley, Alzheimer Society of Ireland
- Ciarán McKinney, Director of Development, Age and Opportunity
- Robin Webster, CEO, Age and Opportunity
- Linda Desmond, Director, Care Local
- Maureen Caffrey, Area Co-ordinator of Services for Older People
- Michael Brophy, Personal Excellence trainer
- Bob Carroll, former CEO National Council on Ageing and Older People
- Mary Nally, Summerhill / Third Age Ireland
- Fiona Devlin, Cork Advocacy Service

In addition, interviews were held with:

- 15 Volunteer Advocates across the country
- 16 staff who had participated in Personal Excellence Training
- Directors of Nursing / Managers and Link Persons in eight residential units/homes

### **Focus Groups were held during October, November and December 2010 with:**

- Development Officers, Dublin (two focus groups)
- NAPA Group members, Dublin
- Staff who participated in Personal Excellence Training, Cuil Din, Tralee
- Volunteer Advocates from Cork City and County
- Volunteer Advocates from Kerry
- Volunteer Advocates from South Dublin
- Volunteer Advocates in Trim, Co Meath

## **Responses to the questionnaire**

**Fifteen residential units/homes responded to the questionnaire for participating residential units/homes from:**

- St. Finbarr's Hospital
- Dinish and Loher ward Kerry General Hospital
- Our Lady of Fatima Home
- St Marys Hospital, Phoenix park
- St Josephs Community Nursing Unit
- St Josephs hospital
- Cuil Didin
- St. Vincents Community Nursing Unit
- Cuan Ros Community Unit
- Middleton Community Hospital
- Caherciveen Community
- Beechtree nursing home
- Beneavin Lodge Nursing Home
- Ashford House, Co Dublin
- Dalkey Residential Unit

**59 Volunteer Advocates from 29 residential units/homes completed a questionnaire disseminated to all Volunteer Advocates, based in the following residential units/homes:**

- Acorn lodge, Ballykelly, Cashel, Co Tipperary
- Anam Chara Nursing Home, Glasnevin, Dublin.
- Anns Hospital, Caherciveen, Co Kerry
- Aras Mhuire Nursing Home, Listowel, Co Kerry
- Ashford House, Dun Laoghaire
- Beanvin Lodge, Dublin
- Cuil Didin, Tralee, Co Kerry
- Dalkey Community Unit
- Dingle Community Hospital
- Earlsbrook
- Fatima Home, Tralee
- Kerry General Hospital
- Killarney Community Hospital
- Lusk Community Unit
- Middleton Community Hospital
- Ocean View nursing home, Kerry
- Riada House, Tullamore, Co Offaly
- Seanchara Nursing home, Glasnevin
- St Annes Community Hospital, Cahirciveen, Co Kerry
- St Brigids Nursing Home, Crooksling
- St Columbanus Nursing Home, Killarney, Co Kerry

- St Elizabeth's hospital, Dingle
- St Finbarr's Hospital, Cork
- St Joseph's Hospital, Trim
- St Josephs Residential Unit, Ardee, Co Louth
- St Marys Hospital, Phoenix Park
- St Oliver Plunkett hospital, Dundalk
- St Teresa's Ward, St. Finbarrs Hospital & Kinsale Community Hospital
- St Vincent's Hospital, Mountmellick, Co Laois
- The Ashford Private Residential Nursing Home