



**‘Let me speak, help me be heard’**

**Evaluation of Alzheimer Society’s Advocacy Programme**

**Praxis Care**

**&**

**Institute for Conflict Research**

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## 1. Terms of Reference

The Institute for Conflict Research (ICR) and Praxis Care were commissioned in February 2011 to conduct an evaluation of Alzheimer’s Society advocacy service for people with dementia. The following report is the product of this three month research and is divided into several chapters; an introduction outlining the background to the programme, the methodology, demographic information regarding referrals to the project, the experiences of those using the service, the organisation of the programme, conclusions and recommendations.

Alzheimer’s Society established Terms of Reference for the 3 month evaluation. These are listed in the table below together with a synopsis of the relevant key findings, which are detailed in the report.

Terms of Reference	Key Findings
To elicit the experiences of using advocacy services from the perspectives of people with dementia, their families and carers	A range of stakeholders, including clients, family members, statutory health professionals, advocates and other key individuals were invited to participate in the evaluation to provide their views on the advocacy service.
Identifying and evaluating changes that may have resulted from the involvement of advocacy services	Views from family members indicate that the advocates have had a positive impact on improving clients’ lives by helping them to make decisions about accommodation and by enabling them in other areas of their lives. Family members rated the advocacy service as ‘excellent’.
The views of people who made referrals to the advocacy service in respect of the referral experience, outcomes of advocacy involvement and whether their objectives in making the referral were met.	Health professional who had worked with, or referred clients to the service, stressed they had a positive experience of using the service and would be happy to use the service again or recommend it to other professionals.
The views of professionals working in the field of dementia on their experiences of working with the advocacy services	Health professionals noted the professional nature of the advocates, that they were well-presented and confidently able to assess clients, present information and explain situations to families.

<p>Identifying cost benefits of using advocacy services for people with dementia</p>	<p>It was recognized at the outset of the project that a 3 month timescale did not allow sufficient time for a full cost benefit analysis to be undertaken. However, overall findings from the evaluation suggest that the advocacy programme is clearly meeting its objectives and is an empowering and effective service.</p>
<p>Identifying areas for improvement in the delivery of advocacy services for people with dementia</p>	<p>Overall stakeholders were very positive about the advocacy programme. Where suggestions were made regarding areas for improvement, these are noted in the recommendations.</p>
<p>Exploring the efficacy of the means used to promote the advocacy services within the Alzheimer's Society and externally and recommending areas for improvement</p>	<p>The service has been promoted in several ways including talks, workshops, leaflets and some media exposure. A key recommendation is for staff to continue to target managers of services where uptake of the advocacy programme has been poor.</p>
<p>Identifying any advantages and/or disadvantages of dementia advocacy services being managed by a dementia specialist organisation</p>	<p>Alzheimer's Society is in a key position to offer this service, its presence in the sector, independent status, knowledge and contacts can promote and support the service whilst giving it credibility.</p>
<p>Identifying outputs from the advocacy service</p>	<p>Between June 2008 and April 2011, the advocacy project had 146 clients, of which 99 were 'closed cases' and 47 'active cases'. Referrals were made across the 4 Health and Social Care Trusts, with the majority coming from the Northern and Western areas.</p>
<p>Exploring the independence of the advocacy service</p>	<p>Stakeholders stated that a distinct feature of the programme is its independence from the statutory services or any external agency which may be involved with a person with dementia.</p>

## **Key Findings**

This section provides a summary of the key findings and recommendations from the evaluation.

- The ‘Let me Speak, Help me be Heard’ programme enables people with dementia to have access to an independent advocacy project with staff who are focused on delivering outcomes in accordance with their clients ‘wishes.
- All family members rated the service as ‘Excellent’ and would definitely recommend it.
- All health professionals noted the positive and professional service they had received from the advocates.
- A replicable model of dementia advocacy has been established and researchers noted the skilled interaction between advocates and clients.
- Family members noted the independence of the service with six of seven informants identifying the ‘independence’ of the service as its most noteworthy feature. The independence of the service was also highlighted by several health professionals.

## **Key Recommendations**

- Continue to target managers where uptake of the service has been poor in order to consider how one might foster relationships with workers in that area and maintain contact where existing relationships have been successful.
- Continuously review the marketing strategy which is being used at specific time points and adapt where necessary.
- Develop a quantitative measure of the work carried out by each advocate in order to show how intensively advocates work with individual clients. Such a measure could be “number of hours worked per week per client”.
- Further explore the potential for volunteer advocacy being involved in specific, time bound pieces of work e.g. assisting in the RQIA inspections.

## **1. Introduction**

The 'Let Me Speak, Help Me Be Heard' project is an independent advocacy service for people with dementia managed by Alzheimer's Society, Northern Ireland. It is based on the experience gained by a dementia advocacy pilot funded by The Atlantic Philanthropies and managed by Alzheimer's Society. The advocacy pilot was directed in accordance with their jointly agreed governance procedures and management systems. It was focused on testing and evaluating models of advocacy for people affected by dementia in different situations and environments. In operation since November 2007, the pilot received funding in the first instance for two years.

The Atlantic Philanthropies established the following immediate, medium and long term outcomes for the advocacy project:

### **Immediate Outcomes**

- A replicable model of dementia advocacy will have been established to the point where they are fit to be commissioned by statutory authorities and should, therefore, be sustainable over a four year period.

### **Medium Term Outcomes**

- People with dementia and their carers will have confident access to an independent advocacy service, which respects their involvement and views, and delivers clear outcomes in relation to health and social care.
- Accountability of health and social care providers will be reinforced and supported through access of people with dementia and carers to independent advocacy.
- The agreed advocacy model for working with people with dementia will be reviewed and further developed for use by practitioners in allied fields and for policy makers.

### **Long Term Outcomes**

- Health and social services providers will actively involve people with dementia in decisions about their care.

- People with dementia and carers will be confident that there is an independent, effective advocacy service which works to resolve their health and social care problems.
- The Human Rights of people with dementia will be demonstrably supported.

In referring to the Advocacy Programme, Alzheimer's Society states that it is:

*'...based on a person-centred approach, with a focus on human rights is central to the advocacy work. A distinct feature of the programme is its independence from the statutory services or any external agency which may be involved with a person with dementia. This approach enables the advocates to work exclusively to support the person with dementia, with no conflicts of interest or outside influence (Alzheimer's Society NI 2010 p. 3).'*

The aims and objectives of the advocacy service are:

1. To provide an independent advocacy service for people with dementia in compliance with relevant advocacy standards.
2. To empower people with dementia to speak on behalf of themselves where possible, or to represent the views of the person with dementia alongside them to ensure their views are taken into consideration.
3. To keep the person with dementia central to the advocacy process, and to respect their wishes, feelings and instructions, irrespective of age, gender, race, religion, culture, language, physical or mental health or sexual orientation.
4. To promote the rights and dignity of people with dementia, and adhere to the principles outlined in the Human Rights Act (Human Rights Act 1998).
5. To work in partnership with relatives and carers, other professionals and agencies to ensure that the views of the person with dementia are taken into consideration. At all times the advocates are independent.
6. To highlight emerging themes from the advocacy cases to relevant government agencies and key stakeholders to address important issues that affect people with dementia.



## Structure

Initiated in 2007, the programme initially recruited an advocacy manager employed full-time. Two part-time advocates were employed in 2008, followed by a 32 hr per week advocate funded by the Western Health Board in 2009. Part of the programme's remit was also the recruitment of volunteer advocates. Volunteer recruitment began in April 2009, recruiting volunteers from a variety of backgrounds. As of May 2011, the programme has 12 volunteer advocates on its books, with five of them being actively involved in open cases. As with the volunteer advocates, the paid staff possess a range of qualifications and transferable skills. Understanding that it would be difficult to recruit people with dementia advocacy experience due to the lack of work in this area in Northern Ireland, the advocacy manager aimed to attract individuals with a range of other skills and then complete a training needs analysis for those appointed.

There is currently no formal advocacy qualification in Northern Ireland. However, the paid advocates have all attended training, including training provided by the Dementia Advocacy Network in London. The training covered issues such as, communication, instructed/non-instructed advocacy, the use of talking mats, human rights, awareness of elder abuse (mandatory), health and safety. Training is signposted by the Advocacy Manager. Regarding the volunteer advocates, training has been provided by the Advocacy Manager. In 2010, the programme also developed guidelines for the volunteer advocates. An advisory panel of key stakeholders from the Health and Social Care sector was appointed and meets quarterly to act as a 'sounding board' for the project.

*There is currently no formal advocacy qualification in Northern Ireland.*

From 2007 Alzheimer's Society was also part of a Comic Relief-funded, four organisation partnership, 'Uniting Against Elder Abuse'. Their role in this was to provide advocacy for people with dementia at risk of or experiencing elder abuse. From 2009 Comic Relief extended the funding for a further two years to a partnership between Age NI and Alzheimer's Society.

## **Funding**

The funding for the programme was initiated by The Atlantic Philanthropies (AP) who in 2007 awarded Alzheimer's Society with a grant of £250,000 to develop programmes of advocacy for people with dementia. In November 2009, funding from The AP was renewed. The AP funding was provided under the provisions of decreasing funding on an annual basis.

AP has a particular interest in dementia, and has funded a range of other programmes and projects which look at dementia, such as an increased awareness and advocacy. For AP it is important that older and vulnerable people are provided with 'a stronger voice' with people, where necessary, acting on their behalf.

In 2009 funding was also granted from the Western Health Board to cover the costs of one advocacy worker over a two year period. This funding is due to end in August 2011 and any funding beyond this date is not guaranteed.

## **Dementia, Communication and Advocacy**

Dementia "describes a group of symptoms associated with a progressive decline of brain functions." (Luengo-Fernandez, Leal and Gray 2010 p. 6). There is evidence which shows that people with dementia can express themselves, give a preference and impart accurate, reliable information (Whitlatch and Feinberg, 2005). For some people, they may require another person to help them vocalise their views. In such a situation, an advocate – a person who "speaks out about people's views, wishes and rights" (Cantley et al 2003 p. 6) may be a useful resource for the person with dementia.

Advocacy can therefore be a tool for upholding the human rights of the older population. The Northern Ireland Human Rights Commission's has investigated a number of cases involving older people. Its report *Enhancing the Rights of Older People in Northern Ireland* (Northern Ireland Human Rights Commission 2001) covers a range of policy areas including social care, health, transport, income levels, housing, education and employment. The report found that laws, policies and practices still discriminate against older people in many areas. Respecting and acting on behalf of an older person with dementia can help to ensure that people are not discriminated against and that their views are always kept to the forefront.

Possible changes to mental health legislation may increase the credibility and importance of advocacy. The Bamford Review (Bamford 2005) recommended changes to mental health legislation as well as calling for the introduction of mental capacity legislation. The Review's recommendations have been accepted by the Northern Ireland Executive. The lead principle of the legislation will be a respect for the autonomy of the individual, although provision will be made for proxy decision making where capacity is impaired.

*Independent advocacy should be available to people with dementia in order to support them in decision making, their families and carers and health and social care professionals who work with them (DHSSPS 2010 p. 32).*

The Bamford Action Plan 2009-2010 (DHSSPI 2008) included a commitment to develop a dementia services strategy. The resulting draft strategy, *'Improving Dementia Services in Northern Ireland - A Regional Strategy'* (DHSSPS 2010), circulated for formal consultation in 2010, includes the statements that:

- Independent information, support, and advocacy should be offered at the point of diagnosis (DHSSPS 2010 p. 26) and that;
- Independent advocacy should be available to people with dementia in order to support them in decision making, their families and carers and health and social care professionals who work with them (DHSSPS 2010 p. 32).

There are many "models" of advocacy. The person with dementia may speak for themselves and therefore be seen as a "self advocate". Or the person with dementia can speak for a peer and "peer advocate" for someone on the basis that they have a shared set of experiences. "Volunteer Advocates" are unpaid and work in a one-to-one relationship with their clients as do "Paid Advocates" who advocate, as the name implies, on a remunerated basis (Cantley et al 2003 pp 8 - 9).

The advocacy role may take one of two forms:

- **Instructed Advocacy** occurs where "the advocate is clearly instructed by the service user and works to an agenda set out through a process of negotiation between the two parties." (Henderson 2007. p. 9)

- **Non-instructed advocacy** occurs where the advocate “takes affirmative action with or on behalf of a person who is unable to give a clear indication of their views or wishes in a specific situation” (Henderson 2006 cited in Henderson 2007 p. 7).

This report reviews an advocacy project which uses a combination of independent paid and volunteer advocates.

## 2. Methodology

The data was obtained by interviewing paid and volunteer advocates, the Advocacy Manager and Alzheimer's Society Director for Northern Ireland, stakeholders who are a part of the stakeholder group, clients and family members, health professionals and the funders (Atlantic Philanthropies). There has also been examination of a small sub-set of project documentation. The project was carried out over a 12 week period.

- **Sample**

The evaluation used a non-random sample to obtain information from a variety of sources with the advocacy staff acting as the *gatekeepers* for the information which was obtained. Although randomization would be preferable in order to eliminate selection bias, this option was impractical within the short time frame of the study. In a future study however, conducted over a longer time frame, it would be preferable to select informants randomly. Such an approach would not violate the obligation of the advocates to protect those clients who either did not have the capacity to participate or did not wish to participate.

The advocates and advocacy manager selected:

- Clients from their case load who could communicate their experience of advocacy to the researcher during one visit (as only one visit was feasible due to the time scale of the study)
- Family members who would be willing to participate in a telephone conversation or to complete a postal questionnaire where their relative could not do so on a single visit; Family members were excluded by the advocacy staff from inclusion in the study where a) the person with dementia had died, b) where several visits would be needed in order to gain an accurate impression of the project's involvement with the client and/or family and c) where a family member had previously taken part in another research study conducted by different evaluators.

- Paid and volunteer advocates.
- Health care professionals who had worked with or referred to the service.
- A sample of anonymous advocacy client records for each advocate (including a volunteer).

<b>Group</b>	<b>Number Contacted</b>	<b>Number Interviewed</b>
<b>Clients</b>	4	2
<b>Family Members</b>	15 (9 phone, 6 postal)	10 (7 telephone, 3 postal)
<b>Advocates</b>	3	3
<b>Volunteer Advocates</b>	10	3
<b>Health Professionals</b>	10	6
<b>Alzheimer's Society Advocacy Manager</b>	1	1
<b>Alzheimer's Society Director for Northern Ireland</b>	1	1
<b>Atlantic Philanthropies</b>	1	1
<b>Stakeholder Group</b>	6	6

1. Table of those contacted for interview and interviewed

## **Method**

### **Focus Groups and Face to Face Interviews**

Where possible, interviewees were contacted and face to face interviews arranged. Focus groups took place with advocates and volunteers; this created a shared space where discussion about the programme could take place freely. One to one interviews in the presence of an advocate were conducted with clients. Interviews were also conducted with some family members, the Advocacy Manager, the Northern Ireland Director of Alzheimer's Society, the local co-ordinator for The Atlantic Philanthropies in Northern Ireland and stakeholders from the stakeholder group. Where consent was given, interviews were audio recorded and transcribed.

## **Telephone Interviews**

Interviews were conducted by telephone where it proved difficult, due to time and geographical constraints, to arrange a face to face interview. At the beginning of the interview, the researcher explained the purpose of the evaluation and gave assurances about interviewee anonymity. The researcher used a semi structured interview schedule to structure the conversation whilst taking account of additional information which the informant wanted to supply. Each interview was of 25 – 30 minutes duration. Of the 9 family members who consented to be interviewed, 7 people were contacted and interviewed by telephone representing 80% of possible telephone contacts. All health professionals were interviewed by phone.

## **Postal Questionnaire**

A postal questionnaire was designed and administered to family members did not participate in a telephone interview. A postal questionnaire was disseminated to 6 family members by the Advocacy Manager. Of the 6 questionnaires which were disseminated, 3 (50%) replied.

## **Advocacy Client Records**

These are completed by the advocacy manager at point of referral and are used by advocates when engaging with clients. They include biographical details and a diarised detail of meetings. Nine anonymised “advocacy client records” were made available so that the researcher was in a position to examine the referral source, the nature of the case, the advocacy process and any outcomes.

## **CharityLog**

Demographic data was obtained by extracting data from the Project’s CharityLog (Watts 2011). CharityLog is a web-based database management system.

CharityLog could benefit the project by making it easier to extract data in relation to a particular case, to conduct supervision with reference to data which is drawn down from a central repository and to generate summary statistics and outcome information.

During the evaluation period, the data was in the process of being migrated from an MS Access database system to CharityLog. The demographic data was extracted from CharityLog and provides a summary of the characteristics of the client group, common referral points and the size of the advocacy caseload and is a 'snapshot' of the demographic data at a particular point in time<sup>1</sup>.

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<sup>1</sup> Source: summary based on anonymised data supplied by the project to researcher 28/03/11.



### 3. Demographic Results

#### The Clients

- Between June 2008 and 1<sup>st</sup> April 2011, the advocacy project had 146 clients of which 87 (60%) were female and 59 (40%) male.
- There were 99 ‘closed’ cases and 47 ‘active’ cases.
- The approximate mean age of the clients was 77 years<sup>2</sup>.
- Advocacy Project cases were distributed across the Health and Social Care Trusts as follows:



- According to the Dementia Register<sup>3</sup> (McVeigh 2011):
  - 24% of all cases in Northern Ireland are in the Belfast area whereas 15% of the project’s caseload are in this area.
  - 18% of all cases in N. Ireland are in the Southern Trust area whereas 8% of the project’s cases are in this area.

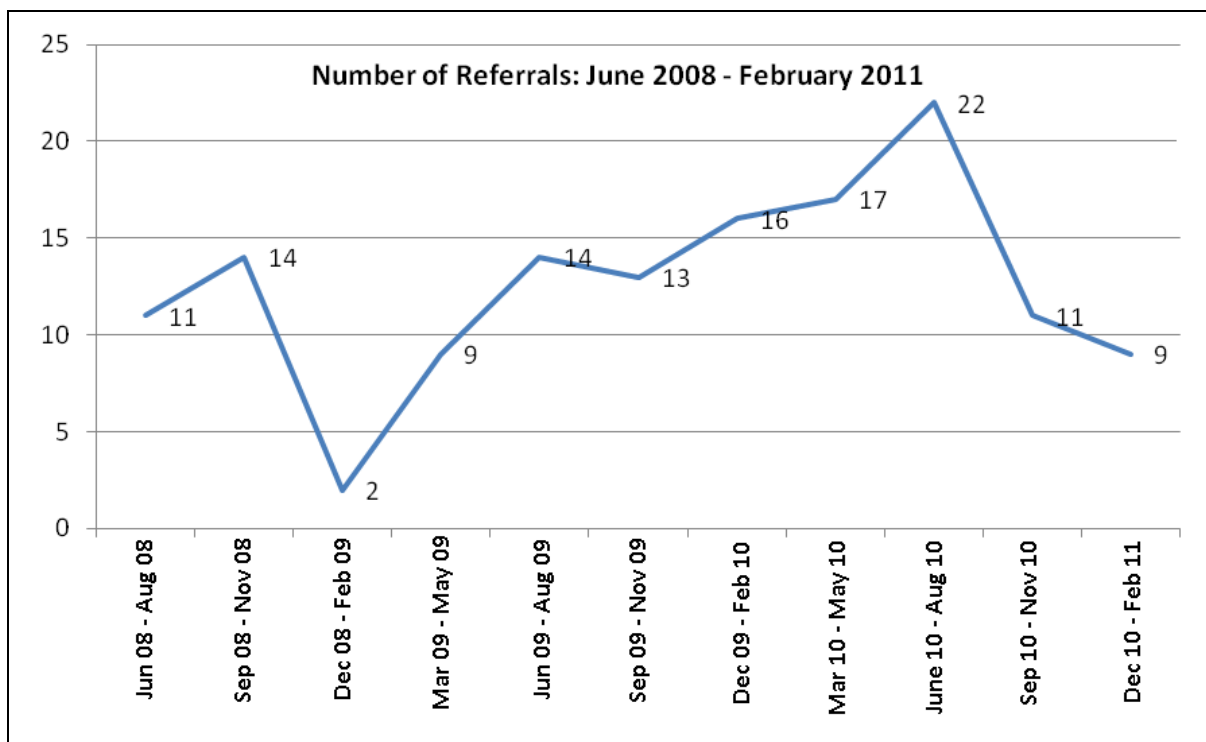
<sup>2</sup> Grouped data was supplied by the project with clients being allocated to one of ten age bands. Where a client’s age was listed as falling within a particular band, their age was taken to be that of the mid-point for that band.

<sup>3</sup> “Data refers to the total register size at 31 March 2011. The data is obtained from the Quality and Outcome Framework – a system to remunerate GPs for providing good quality care to their patients.”

Proportion of people with dementia by Trust Area		
Trust Area	Dementia Register (NI)	Advocacy Project
Belfast	24%	15%
Northern	22%	30%
South Eastern	21%	17%
Southern	18%	8%
Western	16%	28%

**Table 2: Proportion of People with Dementia by Trust Area**

- The top two referral sources were from Social Workers (29%) and Family (21%) with Residential Home Managers accounting for 10% of referrals<sup>4</sup>.
- By dividing the thirty three month period between June 2008 and February 2011 into eleven quarters, the graph below details the number of referrals during each 3 month time period:



- Advocacy staff ran fourteen workshops for Trusts, private care homes and UNISON members between January and March 2010 (Cinnamond 2011). The timing and

<sup>4</sup> Percentages are an estimate because clients may be referred from multiple sources. 'N' will therefore be greater than 146.

number of these workshops may explain the increase in referrals leading up to August 2010.

- Although staff were not directly promoting the project from April 2010 onwards, because they had not secured funding, the increase in referrals between April and August 2010 may show that there is a time lag between promotional events and increases in referrals. Moreover, in the absence of regular promotional events, referrals may decline which is what may have occurred after August 2010.
- There has been a decline in the number of referrals from a peak of 22 during June 2010 – August 2010 to 9 in Dec 10 - Feb 2011.

### **The Advocates' Caseload**

- The caseloads of the three paid advocates accounted for 110 (76%)<sup>5</sup> of the total caseload. The mean number of cases for this group was 37, range 28 – 51.
- There were 12 volunteer advocates who cumulatively account for 33 (23%) of the caseload. The mean number of cases for this group was 2.8, range 1 – 10.
- 96 (60%) of cases were classified as cases where advocacy was used to address a 'living arrangement' issue. 19 (12%) of cases involved "Access to Resources" issues and 16 (10%) of cases addressed "Relationship" issues.<sup>6</sup>

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<sup>5</sup> Percentage estimated.

<sup>6</sup> Percentage is an estimate because a case may involve the attempt to resolve more than one issue. 'N' will therefore be greater than 146.

## 4. Experience of Using the Advocacy Service

The following section explores the perceptions of those who have had personal contact with the advocacy service; either as clients, family members of clients or in a professional capacity in the health sector.

### Clients

Two clients were interviewed (one male and one female). Before each interview, the appropriate advocate gave a brief description to the researcher of the case together with the nature of their involvement. Each interview was conducted informally with the researcher asking the clients a number of questions from a pre-prepared Topic Guide. (The questions were adapted for each client in order to take account of the background information supplied by the advocate). Both interviews were conducted in the advocate's presence as the client had not met the researcher before and the researcher wanted to use the advocate's presence as a visual cue to encourage the client to give pertinent answers. Verbal consent was obtained by the appropriate advocate before the interview and the researcher asked for verbal consent again before beginning the interview. One interviewee gave verbal consent for the session to be digitally recorded.<sup>7</sup>

A visit was also arranged with two further clients. The researcher visited the clients' homes when requested to do so but, on arrival, both clients were indisposed. Because of the time limited nature of the study, revisiting both clients was deemed to be impractical.<sup>8</sup>

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<sup>7</sup> Written consent forms were not used because consent with this client group is an ongoing rather than a one-off phenomenon. Cambridge and Forester-Jones (2003) caution against the use of formalized consent processes where a person's ability to comprehend may fluctuate on a daily basis.

<sup>8</sup> The evaluation was conducted over a 12 week period. Interviews with clients at times and locations which were convenient for them took place on days 24, 37 and 51. Because of a) the time lag between beginning the study and meeting clients and b) the need to collect other data, the decision was made to restrict interviews with clients to one visit only.

### **Client ‘A’**

Client ‘A’ could talk meaningfully about those issues which concerned her. These issues included problems with her own home and dissatisfaction with her current accommodation. Client ‘A’ was unable to describe how the advocate had helped her but, from observation of client- advocate interactions, it was clear that the client was happy for the advocate to raise issues on her behalf. Moreover, observation of client-advocate interactions would suggest that the capacity of the client was being monitored and that descriptions of the advocate’s involvement with the case were given which satisfied the client’s desire to know how her case was progressing and how certain issues might be resolved.

### **Client ‘B’**

Client ‘B’ was able to describe how the advocate had advised him in relation to accommodation issues. Client ‘B’ was very complementary about the impact of the advocate’s involvement and seemed certain that her involvement led to positive outcomes which would not otherwise have occurred.

*“She’ll be calling to see me an odd day - she couldn’t do enough.”*

Client ‘B’ also referred to the frequency of the advocate’s visits and described the advocate as a “good listener”. Observation of client-advocate interactions showed the advocate updating the client on any progress to date and asking for the client’s advice on how to proceed.

## **Family Members**

Face to face, phone interviews and postal questionnaires were undertaken with ten family members. The opinions of family members about the service were largely positive with 9 (90%) of family members rating the service as “excellent” and all questioned said that they would “definitely recommend it”.

Family members were asked what they thought the advocate did on behalf of their relative. The results are presented in the following table:

***90% of family members rated the service as “excellent” and all questioned said that they would “definitely recommend it”.***

Theme	Frequency
Encouraged relative to make decisions	4
Helped to resolve accommodation issues	2
Signposted to resources	1
Made it possible for client to personalise living space	1
Arranged meetings	1
No response	1
<b>Total</b>	<b>10</b>

**Table 3: What Family Members think Advocates do on behalf of their relative**

The fact that the family members were very clear about what the advocate did for their relative demonstrates that advocates performed distinct functions. Neither advocates nor family members confused the nature of the advocacy service with a befriending service or one providing direct practical assistance.

One of the family members described the role of the advocate as enabling their relative to make decisions and commented that, prior to the advocate’s involvement, the relative:

*...felt that people were making decisions about her (the client) without including her.*

Family members were asked about the positive aspects of the service and 7 of the 10 respondents thought that the “independence” of the service was its most positive feature.

*...they are understanding, neutral and available.*

None disliked the service although one person thought that the demand for advocacy services exceeded the supply of available advocates. This perception of “demand exceeding supply” was also the view of the respondent who completed the postal questionnaire.

2 of the 10 respondents explicitly mentioned the advocates’ espousal of their clients’ wishes as a positive feature of the project in situations where providers were perceived to be offering unsatisfactory solutions.

*...the advocate pointed out to the client that he could discharge himself...*

When asked about the more negative aspects of the service, one family member felt that the project didn't have:

*...sufficient staff to deal with problems quickly.*

A second family member said that they didn't like the fact that:

*The project has not been confirmed or rubber stamped yet as being so important and necessary.*

Changes that family members thought could be made to the programme were that 3 (43%) of the 10 respondents thought that the linkages between statutory services and the project needed to improve with one of the three reporting that statutory workers did not have adequate knowledge about the advocacy service.

One respondent also felt that contact with the service would be more beneficial before the client and family have reached a crisis point but there was no consensus among the respondents about how this situation could be rectified.

Three respondents thought that the advocacy service need to be "marketed" to potential professionals, users and family members and referred to the possible use of leaflets and the targeting of specific contact points like GP Surgeries and supermarkets. There was however no consensus among family members on the best method of publicizing the advocacy project.

Two respondents described how the advocate used alternative communication methods to communicate with clients with verbal communication difficulties. Using methods of this type is an indicator of good practice because it lessens the possibility of proxy decision-making where the advocate makes decisions for the client.

Although it was only possible to interview two clients, the testimony of family members supports the view that the advocates have had a positive impact on improving clients' lives by helping them to make decisions about accommodation and by enabling them in other areas of their lives.

## Health Professionals

In all, ten health professionals were contacted and six were interviewed. These ranged from a social worker, a nurse case manager, a community nurse, a care home manager and two team leaders in hospitals. They were spread between Antrim, Armagh, Fermanagh and Tyrone.

All interviewees stressed that they had had a positive experience of using the service and would be happy to use the service again or recommend it to other health professionals.

The number of referrals was varied, ranging from one to twelve. The length of time spent on a case was difficult to estimate, from several weeks to over a year with two cases still ongoing. Cases tended to be about family conflicts around certain issues including; independent living – staying in hospital/homes or living at home and finances.

Health professionals tended to have a good understanding of the role of the advocate. It was described as:

- ✓ *Speaking on behalf of the client.*
- ✓ *Speaking for people who might not be able to speak for themselves.*
- ✓ *Looking at their situation, being objective.*

It was noted that nurses, care assistants and social workers also have a role as advocates but three people acknowledged that the independence of Alzheimer's service from the Health Trusts was crucial and that advocates were there solely for the client and so are useful in complex cases.

Respondents noted the professional nature of the advocates and that they were well-presented and confidently able to assess clients and present information and explain situations to families. One person felt that the fact the advocates did not get too close to patients was positive and kept the service professional.

Positive comments which were made about the service were that it was patient centred and as such could give the service user a sense of empowerment, the fact that there was a broad remit and could be contacted about most matters and

***Health Professionals noted the professional nature of the advocates and that they were well-presented and confidently able to assess clients and present information and explain situations to families.***



that this was a support to the health professionals themselves, also that there was usually a quick response and regular updates.

There were very few negative comments about the service, mainly around the issue of the understanding of an advocate's job and promotion of the service. One respondent noted that the advocate may not always be able to be around immediately and there may be some time between visits but that as they don't work on site this is inevitable. There may also need to be some work done around informing other staff on the role of the advocate as many health professionals already feel themselves to be advocates and as such cannot see the need for an independent advocate.

Everyone felt that the service was definitely needed in the long-term:

*It is beneficial to clients that their rights are identified and acknowledged.*

*Particularly in the light of a dementia strategy in which advocacy is crucial.*

Several interviewees also felt that a statutory duty to provide advocacy would help provide the service to a wider base of clients and also provide a more cohesive, joined-up service as more health professionals would be aware of it, although others felt that this would lack independence and that the service should really only be for those who need it.

## **5. Organisation of the Advocacy Programme**

This section details how the programme is organised from the work of the volunteer and paid advocates to the promotion of the service and training for staff.

### **Models**

The advocacy service currently uses a hybrid paid advocate/volunteer model although the paid advocates manage the majority of cases. (see Demographic Results). The use of volunteers in a project of this type is a useful resource; however, making effective use of people who have other commitments on their time raises a number of difficulties.

One of the undoubted strengths of the service is the perceived independence of its paid staff – a feature about which there was almost unanimous comment amongst those family members who took part in the study. Although one could argue that standing outside of the statutory sector would preclude the advocacy project from statutory referrals because of the possible perception that the advocate's are "*quality assuring*" the work of statutory staff, the evidence does not support this view. Examination of the sample of Advocacy Client Records indicates that five of the seven referrals were made by either a Social Worker or a Community Psychiatric Nurse (CPN).

### **Position of Advocacy within Alzheimer's Society**

Alzheimer's Society is in a key position to offer this service, its presence in the sector, independent status, knowledge and contacts can promote and support the service whilst giving it credibility. However, advocacy is not considered a core service of the Alzheimer's Society and the programme is funded by an outside source.

Advocates and volunteers felt that although Alzheimer's Society has influence and standing within the health sector there is a lack of understanding of the role of advocacy within some sectors of the Society and as such this restricts the promotion of the work from Alzheimer's Society itself.

This also means that although advocacy staff are included in updates their role is not part of Alzheimer's Society core services and they do not feel their service is well understood.

## **The Role of Advocates**

Alzheimer's Society in Northern Ireland currently have three paid advocates, one full time, one 32 hrs per week and one half-time. All advocates have had previous experience in similar positions, one had worked as a head teacher, one was a qualified social worker and the other had a background in general nursing and a Master's degree in health promotion. All are female.

Interestingly, two of the advocates had previous family experience of dementia (also one volunteer spoken to) and the support given by Alzheimer's Society had brought awareness and an interest in working in this area. All advocates had a strong belief in the importance of advocacy and their role.

Advocates work alone although have constant support from the Advocacy Manager and also from each other and will normally discuss difficult cases informally together. They have regular email and phone contact.

Although there is support from within the team, support from Alzheimer's Society in general may be less consistent. This may be due to a lack of understanding of the role of an advocate in general and also from the fact that the service is not core to the society.

The role of the advocate is not to befriend a client. They must obtain consent and the client must have some understanding that the advocate is working for them and supporting their views. This can be difficult to get across based on the level of dementia and often there is a reliance on non-verbal communication such as picture books and talking mats. There is also the possibility of using family members and people close to the client such as friends and religious leaders to gauge from their previous behaviour what they would wish. However, this form of non-instructed advocacy is problematic as the true wishes of the client may not be represented. Moreover, non-instructed advocacy is only used when all other options have been exhausted.

Advocates have mixed experiences of dealing with family members and health professionals. Occasionally, family members who work in healthcare may refer a client themselves, on some occasions there have been hostile reactions from the family to the advocate. There is a

similar mixed reaction from health care professionals. Although those we spoke with were very positive about advocacy, some advocates have had ambivalent relationships with some health workers who feel that they are being challenged or undermined in their own role as advocates.

Advocates deal with a wide range of issues including delayed discharge from hospital, family conflict, finances, transition points, unusual choices (for example, hoarding), support from social services, care plans, enabling a person to speak at a review or to speak on their behalf and financial abuse. The wide range of issues covered shows the need for this service and the fact that there was no similar service four years ago, shows how crucial the Alzheimer's programme is.

### **Advocacy Client Records**

All nine sampled documents contained descriptions of the case in legible handwriting with information being arranged chronologically by the date of a visit or when something was done on behalf of the client. The documents were sufficient to enable the reader, in the majority of cases, to identify the reason for referral to the service and to confirm that the advocates identified themselves to the client on the initial visit, described their role, teased out the nature of the issue and made efforts to bring the case to a successful resolution.

However, the sample includes five styles of form with the content being arranged in subtly different ways which can make it difficult to navigate through the document and/or rapidly retrieve specific pieces of information. This has been identified and is being addressed by the migration to CharityLog.

The 'diary' entries completed by the advocates ranged from brief details being provided to detailed text regarding the case. A more standardised format for completing diary entries, perhaps including keywords or phrases, could give more coherence to the forms.

## **The Role of Volunteers**

Volunteer advocates were recruited in April 2009. There was a high response to advertisements for volunteers (almost 100 responses) and a high level of experience, skills and qualifications in those who applied. 22 volunteers were recruited and there are currently 12 active volunteers with 5 volunteers working on open cases. 3 volunteers were spoken to in a focus group for this research. Volunteers receive peer support from the paid advocates and have found them to be very helpful and always available. Paid advocates also noted that using volunteers helped to give more of a gender balance to the project.

### **Volunteer A**

Volunteer A is a solicitor. He was interested in doing volunteer work to use his skills in another capacity and try something different in his spare time.

He completed the initial induction and training with Alzheimer's Society and to date has been involved in one case. This involved several visits to a client of 1-2 hours and several phone calls. The case was settled quite quickly, (in a few weeks) and he has had no other cases since.

Although finding the experience positive and worthwhile, he noted that he would be reluctant to take on more complex cases without further training. However, taking time off work without the guarantee of further cases would make him reluctant.

### **Volunteer B**

Volunteer B is retired. She previously held a managerial position within the health care sector. She wanted to get involved in volunteering as she had recently retired and had time to 'give something back' and this service was a good fit with her previous experience.

She has had 4 cases to date. Two have been relatively simple and settled over the phone or with a few short visits. The other two were more protracted, involving longer visits and more contact with health care professionals taking between four and nine months. She feels that she is allocated more complex cases because of her wide experience and knowledge in this area.

She has been deeply involved with the advocacy service and as well as attending training and workshops, has also attended and helped out at conferences the Alzheimer's Society has been involved in.

The above examples show the high calibre of skills and knowledge that the volunteers possess. Unfortunately, so far some volunteers have been under-utilised, with most volunteers having on average 2.8 cases each to date.

Although the project is keen to use volunteers it may be that they were recruited too early before the project had time to become grounded and gain a steady number of referrals. Additionally, the use of volunteers may not be pragmatic as advocates have to meet when it is suitable for the client, which may be difficult with a work schedule or other commitments.

Despite the fact that volunteers can provide a wider skills base they may not prove to be a cost benefit to the advocacy service. The time involved in recruitment and training of volunteers may cost more to the service than the work they are able to do. Nevertheless, volunteers are an important part of the project; it may be that there needs to be more analysis into how they are used.

## **Training**

Training is an area of concern for advocacy in Northern Ireland. Unlike England and Wales where an independent advocacy qualification has been developed and funded by the Department of Health and the south of Ireland where training was also developed by the Department of Health, there are no accredited or statutory qualifications in Northern Ireland. Training for independent advocacy is now accredited by City and Guilds; however, due to the cost of the course and travel associated, it prohibits advocates in Alzheimer's Society from taking a course in England or Ireland. This qualification is also based on the legislation in England and Wales and needs to be adapted to Northern Ireland legislation.

Training for advocates is of an ad hoc nature, training sessions have been developed and co-ordinated by the Advocacy Manager and advocates have also been on training courses in London provided by the Dementia Advocacy Network and Action for Advocacy. Advocates have received training in communication with clients, instructed and non-instructed advocacy, human rights, safeguarding vulnerable adults, talking mats and health and safety. Talking Mats training was provided by the Dementia Services Development Centre which has an office in Belfast.

Although training is signposted and advocates and volunteers are encouraged to take part in all training and instruction that is available, there is a sense that there is a lack of consistency with regard to training opportunities in Northern Ireland and as such advocates feel there is a perception that their credibility is diluted. Advocates would like further prospects to gain formal qualifications in advocacy to improve the service provided and also to give the service further credibility.

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## **Promotion and Awareness**

The advocacy service has been promoted in several ways; through talks and workshops with health professionals, the creation of leaflets aimed at families and self-referrals and some media exposure.

The knowledge and visibility of Alzheimer's Society brand is one of the key strengths in promoting the service. Volunteers remarked that they felt they had more credibility and were more recognised as representatives of Alzheimer's Society when they visited clients.

Presentations have been made to health professionals, between January and March 2010, 14 half-day workshops were held across Northern Ireland and targeted Trusts as well as independent healthcare providers such as private nursing homes. Additionally, a full day workshop was held for UNISON members.

Leaflets have been created and distributed throughout care homes and hospitals, staff noted that these leaflets had been picked up by family members and clients and the first self-referral took place in May 2011.

Publicity and awareness raising is an ongoing activity and attempts are continuously made within the project to target possible areas of referral. Some health care professionals commented that with so many presentations it is difficult to remember each one individually. Additionally, staff who may attend these presentations do not carry the same weight as managers and as such it may be more difficult to make advocacy a priority throughout a home or hospital without targeting higher levels of management.

It may be useful at this time to evaluate the reach of publicity through follow up and feedback from health care staff on presentations and with clients and family on leaflets in order to feed into a strategic approach to marketing the programme.



## 6. Conclusions

Throughout the evaluation, health professionals, family members and the researcher who have observed advocates work with clients noted the professional nature and high standard of work done by advocates. Clients interviewed stated they were happy for advocates to act on their behalf and advocates and volunteers have reported the strong and continuing levels of support by management. The core part of the programme, providing advocacy to clients who have dementia is clearly meeting its objectives and is an empowering and effective service. In fact during the evaluation the project underwent a quality assurance assessment by Action for Advocacy which found that:

***The core part of the programme, providing advocacy to clients who have dementia is clearly meeting its objectives and is an empowering and effective service.***

*In a field where there is a considerable risk of becoming the advocate for the carer, this service has managed to retain a passionate commitment to be there to make the views and wishes of the individual known, to make sure they are wholly considered in decisions about their life. Case file and interviews showed a remarkable clarity that the loyalty of the advocacy service is to the service user. Despite the need to work appropriately with carers at times, the clarity of focus and role of advocates was consistent and impressive (Action*

*for Advocacy 2011 p. 3).*

## 9. Recommendations

### Referrals

1. Continue to take measures to increase the number of referrals from the Belfast Health Trusts as this is where the highest numbers of people with dementia are.
2. Increase the number of referrals from Nursing Homes by continuing with the programme of presentations to Nursing Home staff meetings and conferences.
3. Continue to target managers where uptake of the service has been poor in order to consider how one might foster relationships with workers in that area and maintain contact where existing relationships have been successful.

### Publicity

4. Continue to offer presentations in suitable day centres, memory clinics and old age psychiatry facilities where this is possible given the project's capacity to deliver presentations.
5. Continuously review the marketing strategy which is being used at specific time points and adapt where necessary.
6. Provide training for all advocates in the application of appropriate communication tools.
7. Continue to follow up and get feedback on presentations and leaflets, especially in the area of the understanding of advocacy and what it means to the work of health professionals.

### Recording of Work

8. Because of the time consuming nature of advocacy work, the number of cases can *appear* low although the *volume* of work is high. It is therefore imperative that the project captures information which shows how intensively advocates work with particular clients. The service should:

- a. Consider how to capture evidence of the clients' experiences and satisfaction with the service.
  - b. Develop a quantitative measure of the work carried out by each advocate in order to show how intensively advocates work with individual clients. Such a measure could be "number of hours worked per week per client".
9. Monitoring could also extend to practitioner's assessment of their own work – perhaps by using 'reflective diaries' – so that the advocates can really hone in on what distinguishes their work from other professionals who may also self-identify as advocates although not working exclusively in an advocacy role. Reflection is a currently a key part of supervision.
  10. Examine specific rather than generic outcomes on a rolling basis so that it is possible to collect in-depth information on a particular aspect of the advocacy project.
  11. Use observational techniques to study the advocacy process in real time and explore other creative ways to verbally communicate with people with dementia.

### **Volunteer Advocates**

12. Explore with volunteers what skills they would like to contribute to the project as well as working as advocates.
13. Further explore the potential for volunteer advocacy being involved in specific, time bound pieces of work e.g. assisting in the RQIA inspections.
14. Develop a database of volunteer availability times – perhaps reviewed on a monthly basis - could be useful to ensure that there is always someone available to meet clients.

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