

‘Let me speak, help me be heard’

The ‘Let Me Speak, Help Me Be Heard’ project is an independent advocacy service for people with dementia. It is managed by Alzheimer’s Society, Northern Ireland and funded by The Atlantic Philanthropies.

The advocacy service is for people who are living with any form of dementia. It aims to help individuals with dementia to make their own views and wishes known. The service works in partnership with relatives and carers, other professionals and agencies to ensure that the views of the person with dementia are taken into consideration.

Funding for the project was provided by the Atlantic Philanthropies in 2007 and renewed in 2010. The project also successfully tendered for funding for advocacy from the Western Health and Social Care Trust for a two year period beginning in 2009.

The project objectives include the following:

- To provide an independent advocacy service for people with dementia in compliance with relevant advocacy standards.
- To keep the person with dementia central to the advocacy process, and to respect their wishes, feelings and instructions.
- 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).
- To highlight emerging themes from the advocacy cases to relevant government agencies and key stakeholders to address important issues that affect people with dementia.

In February 2011 The Institute for Conflict Research and Praxis Care were commissioned to conduct a 3 month evaluation of Alzheimer’s Society advocacy service for people with dementia. Some of the key issues are as follows:

Key Issues

The draft report ‘Improving Dementia Services in Northern Ireland - A Regional Strategy’ (2010) states that: ‘Independent information, support, and advocacy should be offered at the point of diagnosis’ and that ‘Independent advocacy should be available to people with dementia in order to support them in decision making...’ The Let Me Speak, Help Me Be Heard’ project is well placed to address these needs.

The advocacy role may take one of two forms: **Instructed Advocacy** - 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.’ or **Non-instructed advocacy** - 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.’ The current service utilises both forms of advocacy, using paid and volunteer advocates.

The lack of availability of advocacy training in Northern Ireland has meant that the project has had to source training in England alongside developing in-house training materials. The advocates would welcome an opportunity for a formal advocacy qualification to be developed in Northern Ireland.

Evaluation

The data was obtained by interviewing paid and volunteer advocates, the Advocacy Manager and Alzheimer’s Society Director for Northern Ireland, members of the stakeholder group, clients, family

members, health professionals and funders. Project documentation was also reviewed.

Advocates deal with a wide range of issues including delayed discharge from hospital, family conflict, finances, transition points, unusual choices, support from social services, care plans, enabling a person to speak at a review or to speak on their behalf and financial abuse.

Views from family members indicated that the advocates 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. 90% of family members rated the service as "excellent" and all questioned said that they would "definitely recommend it".

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

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.

Referrals were made across the 5 Health and Social Care Trusts, with the majority coming from the Northern and Western areas.

Publicity and awareness raising is an ongoing activity and attempts are continuously made to target possible areas of referral.

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Leading the
fight against
dementia



The Last Word

"She'll be calling to see me an odd day - she couldn't do enough."

(Alzheimer's Society client)

"...(the advocates) are understanding, neutral and available."

(Family member)

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

(Statutory Professional)

"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."

(Action for Advocacy)