



“Let me speak, help me be heard”:

***an evaluation of an advocacy service for
people living with dementia in
Northern Ireland.***

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History of the Project

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.



What is advocacy?

The advocacy role may take one of two forms:

Instructed Advocacy

Non-instructed advocacy



Aims

- 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).



The Evaluation

- Terms of Reference
 - To elicit the:
 - experience of using the advocacy service for people with dementia, families and carers.
 - views of people who made referrals to the advocacy service.
 - views of professionals who have worked with the advocacy service.



Methods

- Interviews;
- Questionnaires;
- Focus Groups;
- Sample of Advocacy Referral Forms;
- Examination of demographic data extracted from Charity Log.
- Analysis
 - 'quantitative': summary statistics
 - 'qualitative': identification of themes using 'Framework'.



Methodological Issues

Consent: written and/or verbal;

Sampling methods;

Research Issues for the Future

Different type of design;

Examination of specific features of the project.



Data Collection

Group	No Contacted	No Interviewed
Clients	4	2
Family Members	15	10
Advocates	3	3
Volunteer Advocates	10	3
Health Professionals	10	6
Alzheimer's Society Advocacy Manager	1	1
Alzheimer's Society Director (NI)	1	1
Atlantic Philanthropies	1	1
Stakeholder Group	6	6



- Key Findings

The Clients

Client 'A'

- Client 'A' could talk meaningfully about issues
- These issues included problems with own home and dissatisfaction with current accommodation.
- Observation shows that the client is happy for the advocate to raise issues on her behalf.



Client 'B'

- Client 'B' described how the advocate advised him in relation to accommodation issues.
- Client 'B' seemed certain that advocate's involvement led to positive outcomes which would not otherwise have occurred.
- The advocate updated the client on any progress to date and asked for the client's advice on how to proceed.



Family Members

- 9 of 10 family members rated the service as “excellent” and all of these said that they would “definitely recommend it”
- 7 of the 10 family members thought that the “independence” of the service was its most positive feature.

Family Members: Perceptions of advocate's role

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
Total	10



Health Professionals

Noted the positive and professional service provided by the advocates.

Service is client centred.

Service provides quick responses and regular updates.



Other Issues

- Advocacy qualifications
- Volunteer advocacy.

The Future

- Mental Capacity legislation
- Care Homes