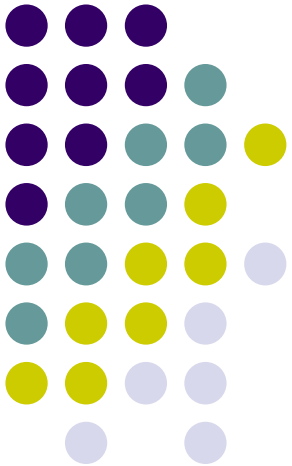
# Brú Chaoimhín Advocacy Group

## ‘The unifying voice of residents with and without dementia’

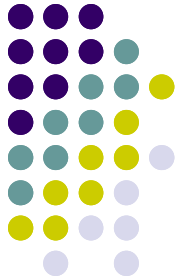


**Presented by**

**Sarah Marsh**

*National Council on Ageing & Older People Conference, Tullamore 2006*

# What is Advocacy?



"It is concerned with the balance of power between the client as a member of a minority or other disenfranchised group and the larger society. From the advocates' point of view the client's problems are not seen as psychological or personal deficits but rather as stemming or arising from discrimination as regards social and economic opportunities. Therefore, techniques of intervention, rather than focusing solely on the relief of individual clients, should challenge those inequalities within the system which contribute to or cause difficulties for the….person" (Phillipson, 1993)

# What is Advocacy?

Advocacy literally means towards a voice

It involves ‘making the case for someone or for a group of people or helping them to represent their own views, usually to defend their rights or to promote their interests. The concept has special relevance to people who are disadvantaged in some way, and as a consequence are less able to speak for themselves’

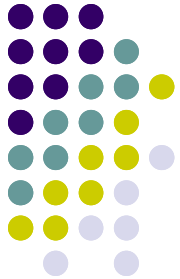
(p. 5, Killeen, 1996)

# Advocacy

“ Hearing the voice of the service user is pivotal in planning, commissioning and monitoring of services”

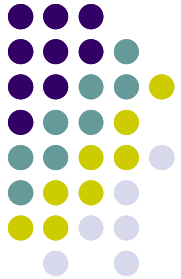
(Leadbetter, 2002, p204)

# Guiding Principles of Advocacy



- Always act in the clients interests
- Always act in accordance with the clients wishes and instructions, where possible
- Ensure the client feels in control of the process
- Provide the client with the necessary information to empower him/her to make an informed decision
- Carry out instructions with diligence, competence, and confidentiality
- Advise and support without persuasion

# Three Types of Advocacy

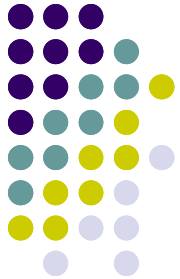


- **Self-Advocacy**

  The right to participate in your own life and the life of your community as an equal citizen and human being. Being allowed name, blame, and claim if you have a grievance and the right to due process.

  All older persons should be given a voice and a space to communicate their message and a presence physically where decisions are made for and about them.

# Three types of Advocacy contd.



- **Group-Advocacy**

  A group of self-advocates who meet to support each other and work to effect change with the assistance of a trained facilitator.

- **Professional-Advocacy**

  An independent professional, such as a social worker, who is paid, named, and trained to advocate on behalf of an older person.

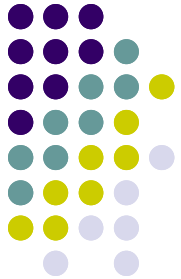
# Who can be an advocate?

Anyone can become an advocate but all advocates require training, information on rights and entitlements, and experience.

Advocates must have the following skills;

- Interview techniques/listening skills
- The ability to empathise, empower, negotiate, re-frame, and represent clients views accurately
- Group work facilitation skills
- The ability to identify problems and be willing to work with older people on issues that require on-going work

# Brú Chaoimhín Advocacy Group



**Aims and Objectives**

(i) Improve resident's quality of life

(ii) Hear the views and listen to residents

(iii) Manage and steer group discussions in a way that facilitates all group members

(iv) Hear people in a supportive way

(v) Assist residents in gaining access to the things they want

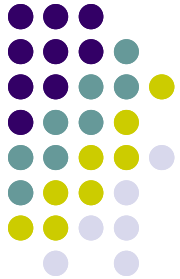
(vi) Create a self-directing group

(vii) Focus on present issues and recent problems

(viii) Include people with mild cognitive impairment and people with other disabilities

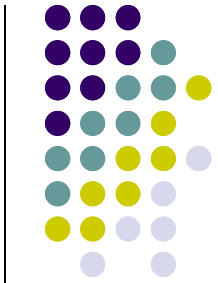
(ix) Establish a model of advocacy that has positive effects for residents and results in attainable actions/outcomes

# Background to Brú Chaoimhín



- Brú Chaoimhin is a large public nursing home in the Liberties, Dublin. There are currently 95 residents aged 65 and over with an estimated 83% having a cognitive impairment.
- 68 residents have a disability (termed frail elderly)
- Day centre accommodates 54 community dwelling older people and 50 residents
- Referrals to Brú Chaoimhin usually due to medical reasons but also due to accommodation needs, loneliness, and/or alcoholism

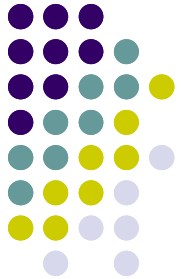
# Background to Brú Chaoimhín



- An Advocacy pilot was conducted between October 2004 and January 2005. This was evaluated by Ms Emer Begley, a PhD Student TCD.

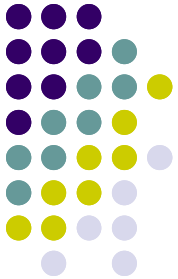
- Established as Residents' Council in January 2005.

# Advocating for People with Dementia



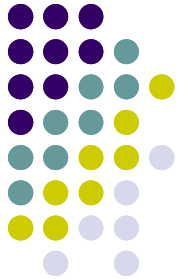
- An aim, from the outset, was to facilitate a mixed Advocacy Group that included people with cognitive impairments and those without due to the high number of people with memory problems
- People with dementia are one of the most vulnerable groups in society
- People with dementia are often excluded from services
- Difficult to hear the voices of people with dementia
- Staff were asked to identify candidates with cognitive impairments for participation in the group

# Why did we do Advocacy with People with Dementia?



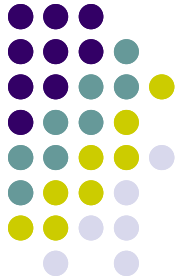
- Inclusionary – all residents are part of the Brú Chaoimhin **community.**
- To investigate if people with dementia can contribute and benefit from being involved in such groups.
- Service evaluation – improve practice development and inform staff
- Move away from ‘caring for carers’ approach.
- Challenge the myth that dementia is a death that leaves the body behind.
- Challenge ageism and discrimination.
- To build confidence, **empower**, **enable**, and increase **independence**
- People with dementia may be vulnerable to forms of abuse.

# Facilitating Advocacy with People with Dementia



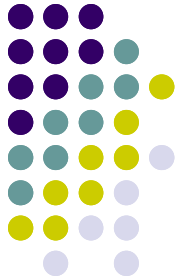
- In order to communicate and understand meaning, the advocate must get to know the person.
- The process is slow, trust needs to be built.
- Explanations need to be clear, short and repeated as necessary. Cue cards, written information and body language are useful.
- Be prepared to go over the same issues many times if necessary. There are days when residents may not have any obvious issues, this doesn't mean they haven't got something to say!
- Environment – temperature, seating, accessibility, flip charts, remove any unwanted stimuli.
- Small numbers, balanced for personality types.
- Take up individual cases as needed (not everyone wants to talk in a group).
- Awareness and knowledge of dementia is important.

# Methodology



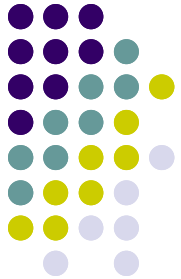
- Facilitated by Brú Chaoimhín Social Worker and observed by TCD student
- Group referrals made by staff members and face-to-face assessments carried out by facilitator/social worker
- Ten Advocacy Group members (1 community dwelling member, 4 members with cognitive impairments)
- Informed verbal consent gained from all group members
- Sessions lasted approximately one-hour
- Agenda set by group members from the out-set

# Themes Discussed



| | |
|---|---|
| **Week one** | Introductions/explanations & ‘reinstate bingo’ |
| **Week two** | **Activities** & smoking ban/outdoor area |
| **Week three** | Activities list & OT presentation |
| **Week four** | Hairdresser/activities & waking times |
| **Week five** | Smoking ban & reminiscence (spontaneous) |
| **Week six** | Group social & reminiscence |
| **Week seven** | **Questions & answers with Director of Nursing** |
| **Week eight** | Student social worker presentation on entitlements |
| **Week nine** | **Leaflet** on comfort money following last weeks presentation |
| **Week ten** | Social & close of group |

# Themes Discussed



## Activities

Different activities and varying levels of activity were carried out on the different wards. “Doing the same thing every day is monotonous”.

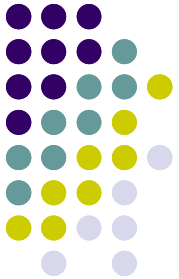
## Actions taken

List of activities drawn up and forwarded to Director of Nursing.
Requests that more activities be introduced.

## Results

Establishment of Activities Committee where Occupational Therapist assesses residents ability to participate in activities.
More residents attending the day centre.
Increased number of activities on wards.

# Themes Discussed condt.



**Smoking Ban**

Brú Chaoimhin not exempt for smoking ban. Outdoor facilities seen as inappropriate. Non-smokers also supported the re-introduction of the smoking room.

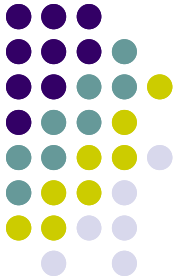
**Actions taken**

Letter sent to Director of Nursing.

**Results**

Director of Nursing addressed the group but management not willing to change position on this issue. Group wished this issue to be taken further.

# Themes discussed condt.



**Entitlements and Information**

Group members asked for information on their pension entitlements, also access and information on equipment provision and availability.

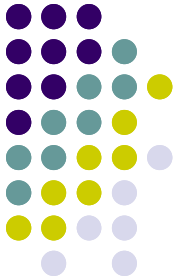
**Actions taken**

Social work student made a presentation on pension entitlements and comfort monies. The Occupational Therapist gave a presentation to the group on assistive aids, devices, and equipment.

**Results**

A leaflet on pension entitlements has been produced by the group to be disseminated throughout the home.

# Themes Discussed contd.



## Bed and waking times

Discrepancies with the time residents were woken in the morning.

Group members felt that in some cases residents were required to get out of bed too early.

## Actions taken

Letter sent to Director of Nursing about this issue.

## Results

Survey of staff about waking and bed times.

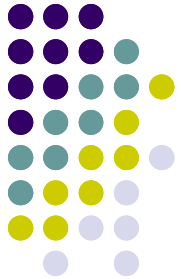
Residents able to stay up as late as they wish.

Rota system for residents with specific needs.

# Factors that Effected outcomes

- **Group members**
  - MDT assessment
  - group dynamics
  - probability sampling
- **Facilitator**
  - trained in advocacy
  - creating appropriate atmosphere
- **Staff**
  - high levels of staff co-operation
  - referrals
  - transport of group members
- **Environment**
  - conducive for group discussion
  - disability friendly;
- **Researcher**
  - presence of non-staff or group member

# Summary of Outcomes

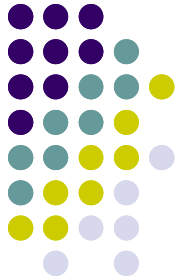


- **Material outcomes**
  - Increased activities
  - More residents going to day centre
  - Activities committee
  - Residents committee
- **Professional outcomes**
  - Supporting psychosocial practice
  - Challenges instutionalisation
  - Cost effective
  - Highly feasible
- **Personal outcomes**
  - Empowering, enabling, supporting autonomy and independence
  - Fosters good relations (between residents and between residents and staff)
  - Facilitates communication

# Facilitation

- Ensure everyone's voice is heard
- Assure confidentiality
- Gain majority consensus on all actions to be taken - majority rule
- Keep explanations short and concise, particularly if there are people with dementia in the group
- Gain co-operation from staff members
- Control the group in a non-threatening diplomatic way
- Be vigilant in recognizing any group member experiencing distress or discomfort
- Create a relaxed and secure environment (providing tea and coffee can create a more conversational atmosphere)
- Facilitation requires two staff members

# How Clients Helped Themselves



- Without prompting, one member made notes during each session to support her memory and bring ideas to the next meeting.
- Supportive environment - members respecting each other (group dynamics).
- Consensus.
- Overall good will and interest.

# What did we learn?

Benefits:

- Group advocacy is possible with people with dementia.
- Giving people the opportunity, without doing harm, is the most important factor in advocacy with people with dementia.
- Benefits to group members, other residents, the facilitator and to Brú Chaoimhín.
- Residents did gain access to much of what they requested.
- Self-directing group.

# What did we learn?

Challenges:

- Be prepared that it may not be a success.
- Didn’t suit all people/residents – one size does not fit all!
- Multi-disciplinary assessments before commencing group.
- Finding a suitable space.
- Adapting techniques to suit the group.
- Group dynamics.

# Recommendations

- Combination of peer and professional advocacy useful.
- Further development of advocacy models for people with dementia.
- Knowledge of advocacy theory is essential (see reading list).

**JUST TRY IT!**