

The Cherry Orchard Pilot Project: “Patient Participation and Advocacy in Long-Stay Care Setting”

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Focus of Presentation

- What is Advocacy?
- Need for advocacy in residential care
- Aims of Cherry Orchard Advocacy Group
- Evaluation Framework
- Approach Taken
- Outcomes

What is Advocacy?

Advocacy usually has the aim of empowering service users both in the content of their decisions (e.g. ensuring the person has the appropriate information to make an informed choice, valuing the person's own goals and choices) and in enabling them in the process of expressing that choice and achieving their goals.

Atkinson and MacPherson, 2001

Types of Advocacy

- One-to-one OR Group-based:
 - Self-advocacy
 - Peer advocacy
 - Professional
 - Citizen/Volunteer

Principles of Advocacy

Advocacy should be:

- results-based
- independently provided
- confidential
- empowering
- accessible
- operating in the best interests of the client
- provided by a trained advocate

Rationale for Advocacy Service

- Quality of Long Term Care Services varies and often does not meet the needs of service-users
 - *Draft National Standards for Residential Care Settings for Older People, 2006*
- Growing emphasis on Social Model of Care
- Profile of residents in long-stay care settings

Project's Aims and Objectives

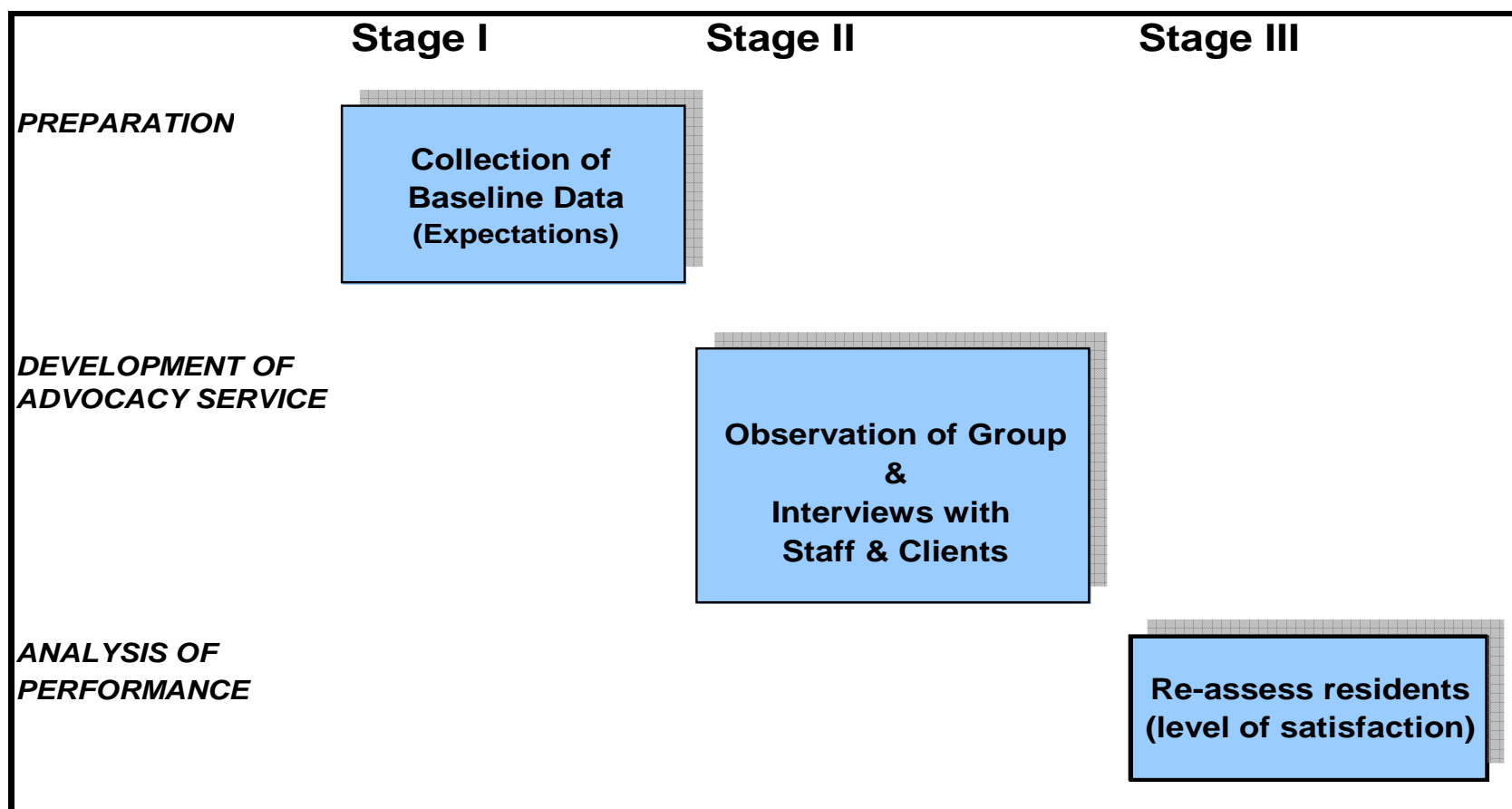
- Aim:

To establish a resident's advocacy group within the Hospital

- Objectives:

- To promote a “social” model of care
- To empower clients to make decisions, to request facilities or services and to identify gaps in the service
- To promote feeling of self-worth and confidence
- To achieve a climate of health awareness and optimum quality of life in Cherry Orchard Hospital

Evaluation Approach: Overview



Proposed Approach

- Phase 1: Collection of Baseline Data
 - Ascertain perceptions, experiences of participation and expectations within the members of the group
- Phase 2: Observation of Advocacy Service
 - Assess if project working towards common objectives, adheres to principles of advocacy, identify themes
- Phase 3: Interviews with Staff
 - Views on progress being made
 - Hopes for the project
 - Main challenges and how these are being overcome
 - Includes those involved and not involved in project

Proposed Approach (cont'd)

- Phase 4: Re-Interview Clients
 - Ascertain level of satisfaction with Advocacy Group
- Phase 5: Analysis of Results
 - Strengths and weakness
 - What issues are residents concerned with?
 - How is advocacy group helping to resolve the problems?

Field research activity to date

- 12 Advocacy Groups
- 3 Management Meetings, 1 Steering Group Meeting
- 1 Focus group with relatives
- 12 one to one interviews with participants:
 - 7 females, 5 males. 25-86 years old
- 14 one to one interviews with staff
 - 12 females, 2 males
 - 3 not involved

Advocacy Group: Process

- Meets on a monthly basis
- Small but cosy room
- 12 meetings have taken place to date
- Minutes are given to each member prior to meeting
- Group consists of twelve patients representing each ward, one volunteer, two social workers who facilitate the meetings and secretary who takes minutes
- Reps. from group meet hospital management quarterly

Views on the Project



Residents' Views on the Project

- Some scepticism at first
“We’re not going to make that much of a difference”
– Advocacy Group Member
- The group itself is seen as something meaningful to do
- high level of curiosity and enjoyment in taking part -
- The group identifies a purpose to bring about changes
– “it is not just to talk”. Residents feel happy they are seeing some positive results so far
- Most feel project will benefit all residents
- Group of view project *reinforces* high quality of life
- For most participants in advocacy group is a new experience with some concerns re confidentiality

Staff Views on the Project

- Before the initiative the patient's opinions/voice had been taken into account but in a "non official way" and depending on patient capacity.
- Project is a good idea and likely to make a difference in the future, mixed views on the results so far
- Different meanings of "advocacy"
 - It gives patients more of a say and more confidence
 - It makes staff more aware of patients needs

Staff Views on the Project (cont'd)

- **Mixed views and concerns regarding:**
 - Representation and feedback process
 - Keeping momentum going (for staff and residents)
 - High expectations of residents
 - People with cognitive impairment needs

Relatives' Views

- Mixed opinions re QoL and Care in Hospital, generally relatives are happy with Hospital
- Relatives wish to be consulted to a greater extent
- More activities and outings are needed.
- Some concerns about privacy, dignity and independence (wheelchair access,...)
- Agree that Residents need a charter of Rights

Outcomes of the Group

*What changes has
the group brought
about so far?*



Outcomes: What changes have been affected by the group?

- Opportunity for socialisation
- Opportunity for patients to have a voice
- The challenge to change “systemic” problems
- Staff being more conscious of residents views and priorities
- Comprehensive list of QOL issues compiled by group
- Suggestion boxes on all units
- A once off Focus group for relatives
- Potential for representative participation in hospital initiatives
- Staff reduction in personal mobile phone use in residential units
- Greater awareness of patient needs amongst staff where English is not first language
- Identification of a technical fault in hot food trolley system



Conclusions

- Advocacy must be a “long term commitment”
- Importance of “practicalities”, focussed agenda and planned action
- Multidisciplinary team participation and strong leadership is required
- Management involvement must be guaranteed
- Clarification of advocate role and representative feedback
- Resident representatives are empowered:
 - Forum for voicing “legitimate” concerns
 - Gain information on what is happening in hospital, mixed experiences depending on the Ward
- Moving the hospital from a “medical” model of care to a more comprehensive and holistic model

Themes/Observations

- A work in Progress
- Advocacy and its meanings
- Representation of others
- Facilitation

Recommendations

- Choose model that suits needs and profile of clients
- Independent, appropriately trained advocate
- Ensure client confidentiality
- Training for staff on empowerment and advocacy in a multi-cultural context
- Keep staff interested on long term basis
- Assist patient representatives with feedback and representation
- Make group accessible to all who want to take part but a separate advocacy service for residents with dementia
- Make sure project can bring about results