The Development of Sheltered Housing for People with Dementia in Ireland

Workshop: 11 November 2011
Purpose of the workshop

• Raise awareness of the range of housing models that have been developed elsewhere for people with dementia.
• Present preliminary research findings.
• Get feedback from key stakeholders.
• Generate discussion and debate about supported sheltered housing particularly with respect to future service development possibilities.
PhD research in the Living with Dementia Programme

A qualitative study exploring the factors that influenced the development of 3 supported sheltered housing schemes for people with dementia in Ireland.

• What factors made service development possible?
• What challenges had to be addressed?
• What is required in order to sustain and replicate them in the Irish context?
Research Focus

• The development of services/the development process and influences on it.

• NOT an evaluation of this service model.

• NOT a comparative analysis

• NOT looking at costs or outcomes

• NOT recording people’s experience of working or residing in the schemes
Rationale for the study

The identified schemes used in the study are unusual in the Irish context where nursing home/nursing care is the dominant long term care model.

This contrasts with the situation in other countries in Northern Europe, UK and North America where housing approaches/models of long term care for vulnerable older people, including and especially for people with dementia, are being prioritised in policy and practice.

How and why did they develop when they did against a background that, if not hostile, was also not conducive to the development of alternative care models for older people? What are the critical factors?
Principles underpinning the study

Belief that older people with dementia should have a range of choices with respect to the way in which their long term care needs are met.

They should have access to the most appropriate service in most appropriate setting.

The range of available services should demonstrate respect for individual needs and preferences.
Methodology

Qualitative research using a case studies approach

3 case study sheltered housing schemes (two in Dublin developed by the same voluntary housing association and one in Cork area) are distinguished by the fact that they were planned to support people with dependency needs, including dementia, as opposed to those sheltered housing schemes that have developed support services over time, mainly in response to the increasing needs of ageing tenants.

(2 minor case studies are also included)
Case study methods

- Review of available records/documentation
- Semi-structured interviews with 45 key stakeholders which were recorded and transcribed

*Key stakeholders: 3 groups*

1) People who were directly involved in the development and/or commissioning of the case study schemes.
2) National or regional decision-makers/policy makers from the housing sector, related health and social services and/or dementia services.
3) A limited number of individuals involved in the planning of the schemes that did not progress as planned.
Theoretical framework

• Change management theory
The development of the case study schemes represents the introduction of change, a different way of doing things, a new model of long term care. Specifically, the schemes do not employ nurse managers or nursing staff. They offer accommodation and social care and support. This represents a radical departure from traditional practice in the Irish context.
Preliminary Findings: what factors made development possible?

I. Individual champions

Health Boards

‘If it has the interest of the top of an organisation, it happens.’

‘[Senior manager] engaged with local health board managers and the Councils and [housing association] to try to push these developments along.’

[Senior Manager]’... was a personality who drove change and had a very charismatic way of bringing a lot of people with him. People and their personalities were fundamental to driving this through.’

[Senior Manager] was there at the time...so maybe within the [health boards] you have that model that works-you have one champion.’
Individual champions

Housing

• ‘This was very new and I think it is about the personalities involved. [Housing officer] really took it on and wanted to become involved with it.’

• [There was]’...buy-in from our own people inside responsible for voluntary housing...I think [housing officer] had a lot of respect for [housing association], had a look at what they could do and thought, let’s do it.’

• ‘...there were some very receptive officials in the Department at the time...’

• [Official] ‘... was very supportive and open to new models. Described as ‘positive and powerful’.

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Individual champions

Housing associations

(Dublin) ‘She’s very forthright in her ethos and she’s also very charismatic...If it’s anybody who has spearheaded a whole different ethos by herself, she’s done it and she’s inspired loads of other people.’

‘... an energetic person...who could sell sand to the Arabs.’

(Cork) ‘One dynamic visionary woman [is] really carrying this...’

‘She has had to be so persistent...she’s passionate about the dignity of older people. She really is.’ ‘Phenomenal dedication really against considerable odds.’
Individual Champions who

• Believed in the model and communicated this to others in their organisation.

‘It provided accommodation with care within a domestic type of setting which enabled individuals to maintain their daily living skills and continue as best they could with their chosen lifestyle and what they were used to doing at home.’

• Were willing to take risks in order to progress these developments

‘[Senior Health Board Manager] was the type who would run with new ideas, taking chances.’
‘Another thing I admire about ___I know that she has taken risks...[in order to develop the service]’
II. Partnership approach [Dublin case]

‘...by attending meetings, we began to know people. The establishment of relationships became a very important function because you were not dealing with an anonymous person in an anonymous authority...Also both sides were getting a greater understanding of [each others’] problems.’

‘A triangle of trust developed...The reason it worked in the end with all the minefields was mutual trust.’
III. Identification of a problem or problems that needed to be solved: housing perspective

‘We saw a gap...we were providing housing but the care element wasn’t there. People needed more than we could give them’. ‘It addressed our concerns about tenants who can no longer manage in one of our sheltered housing schemes.’

‘We found after a few years that many people who went in as able bodied became non-able bodied and needed a lot of help. People with dementia and other health problems.’

‘People who became higher dependent and had to move out of housing...for a local authority that causes problems.’

Other issues: challenge and costs involved of managing very vulnerable residents
Identification of Problem that needed to be solved: Health Board perspective

Shortage of public long stay beds and also few private nursing homes in the area at the time. Lack of capital funding to build new public units.

‘The acute hospitals, particularly in this area, were chock a block with people who needed residential care and were no longer able to go home. Now that coupled with the demand and the need for people in the community who were living alone and also needed supports.’

‘There was an awareness of the general dearth of services for people with dementia...backlog of need in that particular area, where people were reasonably healthy but suffered from dementia. That would have been known to the PHNs.’
Identification of a problem that needed to be solved: Health Board perspective

‘...we had people with dementia all over the place. I’d get calls at 5 o’clock on Friday evening... This man is missing and we had nothing for them...you had this constant row with people and families in acute distress, absolutely acute distress...’

‘We had the idea, from visiting people in hospital that a lot of people in long stay wards really didn’t need to be there. That they could be back in the community if there were supports.’

‘...there had been lots of problems in trying to get dependent older people placed in residential care...’

[There was a need ]‘...to bring some equality to people for a basic standard of accommodation.’ Lack of accommodation for older people who didn’t fit neatly into boxes and who were vulnerable.
IV. Availability of Capital Funding

Capital Assistance Scheme (CAS): funding allocated to build/buy/convert premises

• Dublin: CAS funding provided most of the funding for building two units. The health board had sites available; the land was sold to the local authority and the funding used to top up capital funding to develop the day centres.

• Cork: CAS funding used to buy and convert an old building.

IV. Revenue funding more problematic
V. Related factors (not exhaustive)

- Consultants’ support (Cork and Dublin)
- Health board service managers efforts to resolve post-commissioning problems (MOPs, GM, DONs)
- Awareness of a growing elderly population in the community
- Social housing was becoming a housing priority at the time
- Nobody really objects to housing for older people – easy to sell. Deserving client group.
- Track record of Dublin housing provider: possible to visit services they had already developed elsewhere
- Disquiet about existing long stay care services at the time (pre-HIQA)
Preliminary Findings: Challenges involved in development of the case study schemes

I. Revenue funding

• Lack of dedicated funding/defined budget line in health boards (now HSE) to cover care costs
• Need to negotiate to get discretionary funding
• No individual statutory entitlement to community supports.

*No policy defining either health board or local authority responsibility for supported sheltered housing.
Revenue funding

In the absence of dedicated revenue funding

Cork: cobbled together from rents, fundraising and a bank overdraft. Some time before any funding was secured from the local authority or from the health board. Ultimately payment for bed nights for homeless people was secured from l.a. and Section 39 funding from health board.

Dublin: rents + Delayed Discharge Initiative funding, funding from the national budget for sheltered housing and from local health board budgets. Knock-on effects.
Challenges

II. Charges to residents/tenants

• No policy re: charges for care and support services
• No statutory basis for it
• DOE requirement that applicants must be on l.a. waiting list.
• Implications of Fair Deal
• Situation of homeowners
• Differential rent system
Challenges

III. Lack of understanding of the model

‘Nobody knew what it meant when people said there was no nursing...people didn’t get that.’

‘The hardest thing to get across was that this was people’s home.’

‘...they still saw it as the old Council model of sheltered housing...’

‘The social model was unknown in Ireland...where there is a dominance of the medical model...’

‘There is confusion about what we were. Are you fish or fowl?’

‘Supported sheltered housing doesn’t fit into the [health services] system...’

‘So to get staff to see that these are not patients, these are people. Moving them away from that whole mindset...’
Challenges

IV. Resistance to the model

• ‘The prevailing belief, including among families, is that nurses were necessary.’

• ‘The model was met with scepticism...Dementia care has been traditionally shaped and driven and populated by nursing and medical practice, and this was a move away from that.’

• ‘People were threatened by it; they feel it will require more work and money...Fear that if people are de-institutionalised, the level of community supports that would be required would be more than the [health services] can deliver. Nursing home care is neater, packaging people off...’
Challenges

V. Difficulty in accessing community support services (PHN service, GP service, others)

- Lack of clarity around PHN role
- Concerns about increased workloads
- Lack of financial incentive for GPs + shortage of GPs (Dublin)
- No statutory entitlement to Community Services
Interrelatedness of the challenges presented and knock-on effects (Dublin)

- Acute beds blocked. Lack of understanding of the model. Lack of appropriate referrals. Lack of dedicated revenue funding.
- Decision to use DDI funding to meet revenue costs
- Inappropriate admissions from acute hospitals
  - Very limited access to GP services. Inexperienced staff. Limited access to other community services.
- Negative Repercussions
  - Significant Minority of A&E Admissions
  - Strained relationships/negative reputation for the service

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V. Challenges: inter-agency relationships

• Health Board and Local Authority had different agendas

‘We had a difficulty in that...the health board wanted to take a list of people that were blocking beds and they weren’t necessarily people that would be in need in housing.’

And different expectations were also a factor.

• Housing Association expected/were assured that community services would be available when they were not.

• Belief that HA promised more than they could deliver

• Care costs were higher than anticipated
Preliminary Findings: Sustaining existing supported sheltered housing services for people with dementia

- Budget cuts
- Regulation: increasing focus on risk and safety

Some evidence that the case study schemes are moving towards delivering services to people with lower dependency needs than was originally planned.
Preliminary Findings: Future development of supported sheltered housing

‘[The case study schemes] prove that it is possible.’

That was then, this is now.

• Economic recession affecting health and housing budgets
• CAS scheme severely limited: new leasing scheme
• Rapidly escalating Fair Deal budget
• Stigma about dementia, low profile of dementia in the health services. Evidence of ageism in society.
Preliminary Findings: future development

The evidence suggests that focus needs to be on

• Review of existing services
• Current funding structures that ‘...do not support individual choice.’
• Finding ways to foster partnership/coordination between housing and health, statutory and voluntary/community
• Customer participation/customer orientation
• Acceptance that transitions are inevitable in the lifetime cycle and that we have to plan for them (at micro and macro level)
With respect to the planning and development of services for people with dementia in particular, the evidence suggests that the focus should be on

- Allowing for risk and managing it within a system of regulation/inspection
- Changing how we think about care and how it is delivered. How do we want our own care needs to be met? We know what people do not want.
- More effectively advocating on behalf of people with dementia and challenge the status quo
Thank you