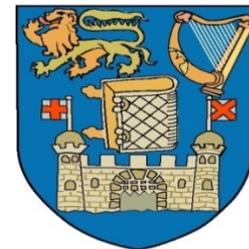


# Alternative Care Settings for People with Dementia



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## Housing with Care

- Defined as self-contained accommodation for an age specific group that usually includes the provision of individualised care, meals prepared on the premises, availability of care and support staff 24/7 and communal facilities. (Croucher et al 2006:11)

# HWC ethos

- Promotion of independence and empowerment of residents
- Emphasis on privacy and dignity
- Care and support in a homelike environment

# PhD research on the development of HWC for people with dementia in Ireland

Five voluntary HWC developments used as case studies - all planned to support older people with high dependency needs including PWD

- 1 was never built
- 1 closed only months after opening
- 3 continue to operate

# Research methodology

## Qualitative research

1) Site visits 2) review of available documentation

3) In-depth semi-structured interviews with 43 stakeholders including:

- Decision-makers and service managers from the HSE
- Local authority housing managers
- Voluntary housing association managers
- 'Experts' with knowledge/experience/interest in the topic

# Study Rationale

- HWC development for people with dementia is the trend in many other countries in northern Europe and North America (including the UK) but has not developed in Ireland.
- Are we different in Ireland or are we at a different stage in service development?

# Research questions

- What factors facilitate HWC development in Ireland?
- What factors create barriers to HWC development?
- What is the climate for future HWC development?

## Research findings

### Factors that facilitated HWC development

- Capital funding
- Champions from the housing and health sectors
- Available land
- Pressure on acute hospitals, HSE community services and housing services
- Concern about the unmet needs of older people

# Factors that created barriers

## I. Lack of revenue funding

- No dedicated budget
- Fair Deal restrictions
- No statutory entitlement

Related factors: location, lack of service take up

## Factors that created barriers

### II. Resistance to the HWC model

- No nurses on site and not regulated
- Perceived risks to older people
- Home for life issue
- Professional self interest: unclear roles, increased caseloads, lack of financial incentives, fears about personal accountability

## Climate for future HWC development

- Inauspicious economic climate
- New capital funding challenges
- Long term care funding structures are biased in favour of nursing home care
- Eligibility and charges system limits access to services and the generation of revenue for HWC providers
- Continued reservations about perceived risks to residents

## Climate for future HWC development

- The introduction of regulation was believed to be a serious barrier to both the sustainability of existing HWC services for people with dementia and the further development of HWC services for people with high dependency needs including PWD.

# Findings re: HWC regulation

1. Widespread belief that regulation is needed
  - It acknowledges good work
  - Gives reassurance to families and residents
  - Protects potentially vulnerable older residents by enforcing standards
  - Helps to define HWC services and the limits of service capacity
  - Contributes to better accountability
  - Increases confidence in the model

## Findings re: HWC regulation (2)

II. Voluntary housing providers and some in the HSE had serious reservations about the impact of the introduction of regulation.

- Belief that regulation will increase costs
  - Cost of bringing facilities up to standard
  - Registration charges

## Findings re: HWC regulation (3)

- Concern that regulation will reduce service flexibility by rigidly defining what HWC providers must and must not do if they accept responsibility for vulnerable older people.
- Fear that regulation will make it difficult to achieve HWC service objectives by prioritising health and safety issues over quality of life for residents

## Findings re: HWC regulation (4)

- Concern that regulation will limit HWC providers' ability to create an environment in which to provide individualised care and promote the independence of residents.

# Findings: Impact of regulation on HWC for people with dementia

- I. Regulation seen as a particular threat to dementia specific HWC services
  - Existing budget constraints/Costs already high
  - Fear that regulation will make people with dementia more vulnerable to being refused admission. (O'Connell Court example)

# US and UK literature: implications of HWC regulation

Study findings are consistent with the international literature on HWC regulation that focuses on concerns about:

- Increased costs
- Reduced service flexibility
- Whether regulation will make services more institutional and less domestic and homely

(Oldman 2000, Golant and Hyde 2008)

- Particular concerns about the restrictive influence of regulation on the admission and retention of people with cognitive impairment and other high dependency needs because of the priority placed on physical health and safety over quality of life.

Manthorpe et al observe that

‘an overly cautious approach to risk is disempowering for people with dementia...can prevent them from doing things that most people take for granted...and also act as a barrier to offering people with dementia a full choice of services and support...’ (2010:6)

They argue for a 'risk enablement' approach to the delivery of services for people with dementia.

- They and others suggest that attempts to minimise or eliminate risk result in forgoing benefits and restricting freedom, which undermines a person's autonomy and well-being.

# Issues arising

- The challenge is how to achieve the right balance between protection and independence.
- What is an acceptable level of risk?
- Need for regulations that are sensitive and proportional.