University of Worcester
Association for Dementia Studies

University of Worcester
Institute of Health and Society
Henwick Grove, Worcester, WR2 6AJ
www.worcester.ac.uk/dementia

HDRC membership event, 16th June 2015

Advantages and disadvantages of different models of Housing with Care schemes for people living with dementia

Dr Julie Barrett

25th June 2015

Acknowledgements

The HDRC steering group would like to thank all of the people who took part in the membership workshop reported in this document (16th June 2015) for giving up their time and sharing their views, knowledge and learning.

Address for correspondence

Association for Dementia Studies

University of Worcester

Henwick Grove

Worcester

WR2 6AJ

Tel: +44 (0) 1905 542531

Email: j.barrett@worc.ac.uk

Table of Contents

Introduction and background

Workshop theme

One of the outcomes of the 2014 HDRC workshop was a list of the consortium's priority research themes. The top priority theme was: the advantages and disadvantages of different models of Housing with Care schemes for people living with dementia (Barrett, 2014).

There is very little research evidence relating to the advantages and disadvantages of different models of Housing with Care schemes in terms of outcomes for people living with dementia and their families. It has been shown that significantly implementing the Enriched Opportunities Programme in an integrated model of Housing with Care can significantly enhance the quality of life of residents with dementia, as demonstrated by the cluster randomised control trial (RCT) study across 10 ExtraCare Charitable Trust schemes (Brooker et al, 2011). This approach has now been implemented in all ECCT schemes. Looking specifically at separated model schemes, the housing provider Housing&Care21 assessed the value of their six "Dementia Wing" schemes in 2014 (Housing&Care21, unpublished research presented at the HDRC membership event, June 2015). No comparison was made with the provider's more numerous integrated schemes. Interviews were conducted with the schemes' care managers and several key decision makers in the business. They found that such schemes were: stigmatising and labelling; prevented integration and community support; put the condition first, the person second; and there were Deprivation of Liberty issues. Recommendations included: moving away from dementia wings and promoting integrated schemes; reviewing whether dementia wings are depriving people of liberty; treat each person individually; apartments should be age and dementia friendly; review all schemes to assess dementia friendliness; if dementia wings are used, they should be different enough to warrant their existence; consider having a communal part of the building. Despite the limitations of this study, the findings were used as an evidence base for a policy document on use of dementia wings.

2015 Workshop

On 16th June 2015 the HDRC steering group organised a workshop for HDRC members, chaired by Dr Simon Evans (Principal Researcher, Association for Dementia Studies, University of Worcester) in order to share knowledge and learning relating to the HDRC's top priority research theme and increase understanding among members.

In addition to the eight steering group members and two guest speakers, 22 members and friends of the HDRC attended, representing 19 different organisations, including: housing

providers and commissioners, academics, architects and consultants. Attendees had a broad spectrum of experience, expertise and interest relating to accommodation and care for people with dementia.

Aims

Key aims for the workshop were the sharing and understanding of the outcomes of different scheme models from around the world for people living with dementia and the development of a set of advantages and disadvantages for different models, based on the participants' views, experience and observation. The output from the workshop would then provide experience-based evidence to use in the development of a research proposal to more extensively explore this important theme for the sector.

The workshop

Presentations

At the 2015 membership event, delegates were given a presentations relating to the workshop theme:

The HDRC's top research priority – Julie Barrett, HDRC Research Coordinator

Do we know what works when caring for people living with dementia in Extra Care housing? – Vanessa Pritchard-Wilkes, Housing&Care21

Innovation in Housing, Design and Community Integration: Lessons from Europe and Worldwide – Tracy Paine, Belong and Damian Utton, Pozzoni Architects.

Hogeweyk – the "Dementia village" – Michael Spellman, The ExtraCare Charitable Trust.

Deprivation of liberty – implications for different HWC models – Sue Garwood, Housing LIN Dementia Lead

The presentation slides from the event are available on the HDRC website at: https://housingdementiaresearch.wordpress.com/hdrc-workshop-2015/

Group discussions

Delegates were asked to consider and discuss, in their table groups, what they thought were the advantages and disadvantages of different models of housing with care in terms of outcomes for people living with dementia, their family carers and scheme staff. There were 5 table groups, each with a member of the HDRC steering group acting as discussion facilitator and note taker. The groups were allowed 1 hour for discussion. To focus the discussion and make reporting easier the groups were asked to come up with their top three advantages and top three disadvantages for each of the following models:

- **Integrated:** People with dementia live in apartments "Pepper potted" amongst other residents in the scheme.
- **Separated:** People with dementia are clustered together within a separate self-contained area of the scheme (e.g. a wing or floor).
- **Specialist /dedicated:** A scheme where only (or mainly) people with dementia live

- **Hybrid / other:** A combination of different provisions e.g. the Belong model which combines independent living (Housing with Care) and specialist households (Care homes).

The HDRC steering group and delegates acknowledged that the four models under discussion were by no means the only models that can be considered to be Housing with Care, however, in the time allowed it was not possible to discuss every model and variation of model.

The delegates were provided with a handout containing suggestions for points that they might like to consider during their discussion:

- Outcomes for people with dementia
  - Benefits and drawbacks for people with dementia.
  - The degree to which their needs are being met in terms of facilities and activities, care provided, staff skills, services accessed, building design, use of assistive technology, balancing autonomy and safeguarding, deprivation of liberty issues, home-for-life issues, policies and procedures, etc.
  - Quality of life, emotional and social wellbeing and overall living experience.
- Benefits and issues for other occupants.
- Benefits and challenges for staff.
- The CQC “mum test” (is it good enough for my mum? / consider whether these are services that you would be happy for someone you love and care for to use).

Results

Cross cutting issues

Two of the discussion groups felt that there were factors influencing the outcomes for people living with dementia that cut across all models of Housing with Care. They suggested the following:

- Whatever the scheme model, the important factor is good quality person centred care and support
- Staff training – staff need to be well trained in dementia care. The success of a scheme depends very much on how well the staff are trained and supported.
- The location of the scheme.
- The tenure.
- Choice and suitability: the fact that there are different models provides choice – the model that works well for some individuals living with dementia may not work well for others.

Advantages and disadvantages of different models

Table 1 gives the advantages of each of the four models that emerged from the discussions and Table 2 gives the disadvantages, categorised for ease of comparison.

Table 1: Advantages of different models of Housing with Care schemes

Issue:	Integrated	Separated	Specialist / dedicated	Hybrid
Social environment	• Provides a diverse community. • Greater feeling of community. • Gives people living with dementia dignity. • Possibly less likelihood of stigmatisation of dementia. • There is the potential for peer support, befriending, etc. • There is a reduced risk of social isolation greater likelihood of social inclusion for residents living with dementia. • There is a reduced risk of challenging situations being exacerbated.	• May be easier to manage "sundowner" issues	• The design of the built and social environment can be dementia friendly. • Tend to be smaller schemes which can have a safe, homely environment for people living with dementia. • Staff and residents can get to know each other well.	• Works for people at different stages of dementia. • If a person needs to move to less independent living, they remain in the same scheme / enabling them to retain a connection with the scheme community as a whole. • Offering day care facilities may provide the opportunity for people to more easily make the transition of moving into the scheme e.g. they will be familiar with the environment and may have pre-existing relationships with some staff and residents.
Built environment	• If dementia develops while the individual is living in the scheme and is settled, there is no need to move building or apartment and they will continue to be able to orientate and navigate around the building.	• It is easier to tailor the environment and customise facilities for people with dementia if they are living in a separate area.	• The design of the built and social environment can be dementia friendly. • Tend to be smaller schemes which can have a safe, homely environment for people living with dementia.	• If a person needs to move to less independent living, they remain in the same scheme / village which will make it easier for them to continue to orientate and navigate within the scheme.
Residents without dementia / family		• May be more preferable and acceptable for those without dementia and their families.		• May present a more attractive, "normal" environment to visitors.

Issue:	Integrated	Separated	Specialist / dedicated	Hybrid
Interaction with the outside community	• A community hub allows the outside local community in and interaction between people of all ages, opportunities for community building and pursuing interests outside the scheme. • Greater integration with the local community reduces stigma within that community towards the scheme.	• There can be interaction with the local community, if it is done carefully.		• Usually have community hubs. • May present a more attractive, "normal" environment to the outside community.
Staying in place / end of life issues	• If dementia develops while the individual is living in the scheme and is settled, there is no need to move building or apartment, resulting in fewer moves and more control over the population balance.		• Residents more likely to stay until end of life.	• High level of flexibility, meeting people's needs as they change (person-centred) and enabling people to progress in the same setting and stay for longer. • Can be a home for life.
Family carers	• May be more support for family carers.			
Staff / person centred care		• It is easier to target resources effectively and have specialist staff working in the area for people with dementia.	• More personalised and targeted care planning, delivery and risk management due to staff being better trained in dementia care. Staff can develop specialist skills and expertise resulting in higher quality care for people at all stages of dementia until end of life. • Staff and residents can get to know each other well.	• High level of flexibility, meeting people's needs as they change (person-centred) and enabling people to progress in the same setting and stay for longer.

Issue:	Integrated	Separated	Specialist / dedicated	Hybrid
Cost of build				
Revenue costs including for occupants		• Could be a cheaper option in terms of how the care offer is structured e.g. a more specialist service could be offered in a designated area of the scheme.		
Deprivation of liberty	• There is less risk of DoL issues that could result in registration as a care home.			• There is less risk of DoL issues and the housing elements being seen by the CQC as a care home.
Couples	• Couples (where one is living with dementia and the other is not) can stay together and age together, with appropriate, flexible care for both.			• Couples, where one of them has dementia, can remain living close together even if the person with dementia needs to move across to the care home within the hybrid development.

Table 2: Disadvantages of different models of Housing with Care schemes

Issue:	Integrated	Separated	Specialist / dedicated	Hybrid
Social environment	• There may be less motivation by the provider to make the community 'dementia friendly' – dementia perhaps being an 'add on' or 'paid lip service to' rather than a core service.	• More "institutionalised" model. • How do you ensure the dementia area is always full? • Greater risk of social isolation from the scheme community for the residents with dementia. • The dementia 'wing'/'unit' may create a focal point for stigma or a dementia ghetto, a "them and us" attitude.		• People may perceive themselves as being in a hierarchy. • There is a risk of the care home parts of the scheme being stigmatised and – unless mitigated – this could lead to a 'that's where you end up' attitude.
Built environment	• There may be less motivation by the provider to make the building and interior design 'dementia friendly' • The size and scale of the building may be challenging for people living with dementia.	• Adaptations for people living with dementia may be safety focussed rather than quality of life focussed e.g. bars on windows.		
Residents without dementia / family	• People with and without dementia living alongside each other may cause friction due to issues such as problems eating together, noise levels and lack of understanding from other residents towards people living with dementia. • People without dementia may have certain expectations about living at the scheme, which may not include living alongside people with dementia. This may be more of an issue for those who own their apartment.	• The dementia 'wing'/'unit' may create a focal point for stigma or a dementia ghetto, a "them and us" attitude.	• Families may be deterred by the perception of stigmatisation.	

Issue:	Integrated	Separated	Specialist / dedicated	Hybrid
Interaction with the outside community		• Greater risk of social isolation from the outside community for the residents with dementia.	• The potential for stigma for the scheme in the surrounding community, unless mitigated by management.	
Staying in place / end of life issues	• What happens when the dementia progresses? It may not be a home for life.			• Moves, although they happen within the same place, they may be more inevitable, a person working their way through the building as they age.
Family carers				
Staff / person centred care	• It is difficult for staff to respond to the diverse needs of individuals. • May be more difficult to keep an eye on people as their dementia develops and they are prone to go out and get lost.	• More "institutionalised" model. • Possible higher likelihood of task focussed or 'farmyard' care in the dementia area.	• May create greater demands on staff.	
Cost of build	• There may be cost implications for the building design.			• Tend to be large. The availability and cost of the amount of land required can create a high initial build investment and means that it may be more financially viable to build out of urban areas.
Revenue costs including for occupants			• Can be an expensive option compared to other models.	• May be expensive option for residents if no public subsidy.
Deprivation of liberty		• There is a greater potential for DoL issues and CQc wanting to register as a care home.	• There is a greater potential for DoL issues and CQC wanting to register as a care home	

Issue:	Integrated	Separated	Specialist / dedicated	Hybrid
Couples		• Not great for couples who want to live together in same apartment depending on criteria for allocating properties	• Not an option for couples if they wish to stay together and one of them has dementia, unless the scheme specifically targets couples.	
Other			• Housing providers are not keen to create these types of schemes.	•

Conclusions

The purpose of the workshop was not to determine which Housing with Care model the HDRC members consider to 'work best' for people living with dementia, rather, the aim was to generate a set of advantages and disadvantages of different models in order to begin to build an evidence base for larger scale targeted research.

Nevertheless, some comparisons between the models can be made from the points generated by the workshop attendees in Tables 1 and 2. It can be seen in Table 1 that, according to the attendees, the separated model has no advantages over other models in terms of the social environment. However, the integrated model was considered to be at a disadvantage in terms of the built environment in that it may be less likely than other models to have dementia friendly design features and this, combined with the tendency for integrated schemes to be relatively large, can make it difficult for people with dementia to orientate and navigate in the scheme.

It was felt that separated models schemes may be preferable to people without dementia and their families. However, while it was suggested that integrated schemes may perpetuate friction between residents with and without dementia and resentment towards residents with dementia, it was also felt that the 'dementia wing' in separated schemes may create a focal point for dementia stigmatisation, a "dementia ghetto" as it were. It was also felt that such stigmatisation of the whole scheme may occur for specialist schemes within the local outside community.

Interaction with the outside community was considered a potential benefit of integrated and hybrid schemes, which may be more likely to have community hubs, while people living with dementia in separated and specialist schemes may suffer from social isolation and stigma from the outside community.

Due to the fact that specialist schemes and the dementia areas in separated schemes may be more likely to have specially trained dementia staff, it was felt that these models could provide more targeted, personalised care, whereas it may be difficult for staff in integrated schemes to respond to the diverse needs of the residents.

People living with dementia were thought to be more likely to stay in specialist and hybrid schemes until end of life. Integrated and hybrid models were considered more expensive to build, whereas specialist and hybrid models were considered to be an expensive option in terms of revenue costs (including cost to residents). Separated and specialist models were felt to have a greater potential for the occurrence of Deprivation of Liberty issues and perhaps run

a greater risk of being seen by the Care Quality commission as providing “accommodation together with nursing or personal care” and registerable as a care home. Integrated schemes had the advantage over other schemes for couples where one of them is living with dementia in that they can stay together and age together with appropriate, flexible care for both.

Two of the discussion groups felt that, whatever the model of the Housing with Care scheme, successful outcomes for people living with dementia depended on factors such as good quality person-centred care and support, well trained and well supported staff and the location of the scheme. Also, there is no one size fits all – the model that works well for one person living with dementia may not work well for another. It was considered that there are examples that work well or less well across all the models, depending on how dementia-friendly all the different facets outlined in the discussion group briefing are.

The HDRC plans to use the output from this workshop to support the development of a proposal for a research project to gather more in depth evidence relating to this theme that will enable housing providers, commissioners and service users (people living with dementia and their family carers) to make more informed decisions.

References

Barrett, J., 2014. *HDRC membership workshop: The HDRC what next? Shaping research and informing decisions*. Housing and Dementia Research Consortium Report. https://housingdementiaresearch.wordpress.com/publications/

Brooker D., Argyle, E., Clancy, D. & Scally A., 2011. Enriched Opportunities Programme: A cluster randomised controlled trial of a new approach to living with dementia and other mental health issues in ExtraCare housing schemes and villages. *Aging and Mental Health*, 15(8), 1008-1017.

Housing&Care21, unpublished research presented at the HDRC membership event, June 2015