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The Future of Extra Care Housing: Findings from The ECHO Project


These presentations report on independent research funded by the NIHR School for Social Care Research. The views expressed in these presentations are those of the research team and not necessarily those of the NIHR School for Social Care Research or the Department of Health/NIHR.
The ECHO Project Sample

• 4 ECH schemes located in 2 local authorities (a unitary authority and a County council, 2-tier authority), 1 of which is a dementia specialist scheme.

• Each scheme visited on 4 occasions.

• Residents interviewed 4 times across 20 months (51 residents took part in 164 interviews).

• Managers of schemes (7) and local commissioners (2) interviewed at the beginning and end of the study.

• Care and support workers (20) interviewed once.
Residents Managing their Changing Care Needs in Extra Care Housing

Ellie Johnson, Liz Mills, and Linda Mein
Avoiding Ageing and Decline

Delaying the onset of care needs by ‘keeping busy’
Keeping Busy

‘[The activities are] better here [than when I lived in a house], because it’s so very regular... Okay, you do your gardening; the WI once a month – but here, there’s things every day ... The accessibility’s brilliant. And also ... it is on the premises here and it does make a lot of difference’.

Site D, Resident 2

‘They have art and craft, if there is anything going on I go, but it isn’t very often, you don’t get much activity here, not very much...They’ve got nothing here, only Bingo, apart from that, there’s nothing. And it’s not much of a life is it really?’

Site A, Resident 2
Keeping Busy

Facilitated by:

• ECH scheme having a full activities programme.
• On-site facilities, activities staff, material resources.
• Residents being able to self-organise, either as individuals or as a group.
• Resident having good mobility.
• Resident having links to the external community.

Impeded by:

• Reduced mobility, disability or illness.
• Poor building design, inaccessibility.
• Lack of organised activities.
• Staff shortages and absences.
• Poor transport links.
• Poor ‘balance of care’ in scheme.
Resisting Dependency

Avoiding formal care until absolutely necessary
Avoiding Formal Care by:

Adapting

‘I cook for myself... Well I say cook for myself, I get most of them from Iceland. Meals for one. Beautiful, I can fill the freezer full of five or six meals and it’s only about seven quid ...The food [in the restaurant here] was great. I have no problem with the food it is just the fact that I like my one bit of independence that’s getting my own meal when I want it’. Site D, Resident 12

Relying on Each Other

‘Do you know a lady in my little flats Thursday, she brought me round a cream rice pudding, she knew I weren’t eating and she said “try this” ... I know they’re always pleased to see me [in the lounge] and if I don’t go down there I get phone calls to see if I’m alright and the lady in that flat up there said that I could ring her at night or day it doesn’t matter what time, now there’s not many people that say that is there?’ Site B, Resident 2
Difficulties in Avoiding Formal Care:

‘Of course when she [care worker] came in, she said, “The only thing is you’ve got to have five hours care a week.” I said, “Five hours care.” I said, “I don’t need care.” I said, “I can look after myself.” Well she said, “Well that’s the new ruling that has been brought in, so there’s no option, you know.”’

Site B, Resident 3
Resisting Dependency

Impeded by:

• ECH scheme requiring residents to receive formal care provision, regardless of need.
• Resident lacking a support network (inside and outside of scheme).
• Health and safety concerns and regulations.
• Lack of material and financial resources.

Facilitated by:

• Resident is able to receive informal care or support from friends/family members.
• Resident has access to and knowledge of [assistive] technologies and aids.
• Residents being able and willing to help and support each other.
• ECH scheme having a formal volunteering scheme.
Maintaining Control

Managing the timing and content of care provision
Managing the Timing and Content of Care

‘I get up and I shower and I do that myself. They won’t do that, no, way - phew. I got to be a little bit worse than I am to do that you know. ...They’ve given me cream to rub on my bottom but they said, these carers that come in, gotta look at my bottom, I don’t want to show my bottom, oh no! ... One said last night “I’ve got to rub cream in”, I said “no you haven’t I’ve rubbed cream in” [laugh]... I’m not solely in their hands yet!’

Site B, Resident 2

‘They [the care workers] come in at eight o’clock to get me into my night clothes ready for bed. I don’t go to bed at that time but that’s my time and I’m sitting watching television by then’.

Site C, Resident 1
Maintaining Control

Facilitated by:
- Resident being aware of how to make changes to their care provision / who to talk to about their care needs.
- Care provision being organised to allow for flexibility and change.
- Positive relationships between residents and care staff.

Impeded by:
- Staff shortages.
- A lack of care provision at night.
- Care organised into inflexible ‘runs’.
- Difficulties with requesting re-assessments or increased payments from the local authority.
Thank You

For more information please email: Eleanor.Johnson@Bristol.ac.uk or visit the ECHO Project website: http://www.bristol.ac.uk/sps/research/projects/current/echo/
Organising Care Work in Extra Care Housing

Ailsa Cameron
Sample

• 20 care workers (5 from each site).
• 15 worked as care workers/ assistants or support workers, 3 team leaders (1 of the social club), 1 deputy manager and 1 activities champion.
• The 3 team leaders & deputy manager worked full time, the remainder part time. Contracted hours ranged from 10 to 30 per week.
• 6 participants had worked in their current role for < 12 months, 6 for between 1 & 5 years, 8 for 5+ years.
• All participants, except the team leader of the social club, carried out direct care with residents.
• Sites A & B are located in area 1 and C & D in area 2.
What we are interested in

• Perspectives on what they do
• Training and preparation
• How their work was organised
• How they experienced their work
• Opportunities and challenges
Perspectives on ECH & what care workers do

‘Basically, the work I feel I do here is we assist vulnerable adults to have more of an independent life here, so by doing small tasks for them like helping them to make their food, their personal care, just making their lives a lot easier.’

Site B, Care Worker 2

‘I like the idea of ECH, like I said I worked in a care home, didn’t like it, but here .... I like the kind of accommodation, I think its still you know promotes independence, the people can still do quite a lot for themselves ..... you work with their hobbies and all that and then you create activities so yeah it’s quite a lot that can be done and they can have fulfilled lives.’

Site A, Care Worker 1
Perspectives on what care workers do

‘...getting people up and washed and dressed, showered or bathed in the morning, make breakfast, choice um obviously put clean clothes on of choice whatever they want to wear um always give them the choice and obviously making sure their wellbeing is alright.’

Site D, Care Worker 1

‘You’ve got their care plan to refer to, but, you can go in and they’ll go, yeah I’ll have my breakfast, and I’ll have a wash first ... It could tell us if we’ve got a flat to clean, or if we’re doing personal care or shopping or ...’

Site A, Care Worker 5

‘I do a little bit of everything. Personal care, housework, help with their medication. Sometimes I feel like a general dogsbody ... what we do is try and obviously help the person live as independently as we can.’

Site B, Care Worker 1
Training

‘Yeah, [name of provider], I’ve had lots of training through them. I went on a week’s training course, got the induction program, .. I’ve had my medication training, I’ve got training courses coming up, there’s the e-learning system which is you know, your health and safety, safeguarding, adults, children, nutrition, you know, so the training is second to none really.’ Site C, Care Worker 4

‘Also we’ve got quite a few people with dementia which we’ve done dementia training but it’s still nice just to do a little bit more.’ Site B, Care Worker 1

‘I would like to do end of life [training] as well .... I’ve done it so I know I can do it but I would like to have more training.’ Site A, Care Worker 1
Support
‘They [organisation] are so family orientated ... they really understand that we all got normal lives at home ... just a great company.’ Site A, Care Worker

‘and we’re treated good as well [by] the management and all the other staff, it’s lovely to work here, it is really nice.’ Site B, Care Worker

‘And I’m happy here. And I get all the support I need you know, if I’ve a problem or if something’s troubling me, I know that my manager is there for me and I know my team leader’s there for me.’ Site C, Care Worker

‘Erm, it’s just a fun company to work for. Yeah they really look after their staff.’ Site D, Care Worker

@ECHOProject123
The challenges faced - the changing resident profile

‘There are people that are on different, as I class, brackets of care. You will have some low people that may just need a bit of cream put on or a bit of shopping done or stuff like that and then you’ve got your very high care packages that come in that, you do everything for them so that’s their personal care, their shopping, their house work and everything .... I would say from the time I’ve worked here .... it feels like it’s getting progressively higher care...’

Site B, Acting Senior Carer
The challenges faced - the organisation of care

‘It’s a sheet called a run with carers’ names at the top, times down the side and then flat numbers and times.’  
Site B, Care Assistant

‘No you get a run every morning or afternoon, you get a run what you’re doing and one day you could be up this building next the new building.’  
Site D, Support Worker

‘When you come in in the morning, you come in and you’ll pick up your [.....] rota and it will give you your times and what residents you’re going to visit that day.’  
Site C, Support Worker
Limitations of the organisation of care

‘You do get stressed sometimes when it’s, when sometimes you’ve got to rush. You have got to stick to your times.’

Site A, Care Worker

‘It’s back-to-back, especially if you have the handset. We have 15 minutes leeway but the residents have to have their time as well. If you need the toilet that’s 5 minutes and then you’re 5 minutes late. It would be good to have 5 minutes in between…’

Site B, Care Assistant
Impact of the organisation of care as ‘runs’

‘It depends on their care package, because we are set boundaries and time limits and so obviously we’ve got to keep within that time frame but if we go over, then we’re going to have to explain what we did with that extra time for that to be carried on to go into their care package so it all depends.’

Site C, Care Worker

‘I want them to do like they would at home …. Whereas here, it feels like they’re being industrialised if you know what I’m trying to say. They’ve got to fit into the routine of the business which is, sometimes is not a good thing if that makes sense.’

Site B, Care Worker

“This time business thing for me is quite …. difficult because I want to spend more time talking to them and chat, but ... it [doesn’t] allow.”

Site C, Care Worker
Favours as a compensatory strategy

‘And another lady, she’s so tiny she bought an apron and she was swimming in it so I took it home and took it up... I took it up for her. Things like that yeah. When one of our ladies was in hospital I went to see her a couple of times. Took her washing in, washed it, took it back’.

Site A, Care Worker

‘sometimes ... if they’re running low on groceries or shopping and that and I know I’m going to nip there and I’ve got enough to carry I might bring a pint of milk.’

Site B, Care Assistant

‘I wouldn’t do us a favour because that’s not how the business should work and I strongly believe in that because it’s not about me being kind, but it’s not fair you know I’m kind of charging one person for the shopping but for the other one I will do for free and then [name of organisation] pays me for that and I think you know where is the equality yeah’.

Site A, Team Leader

@ECHOProject123
Conclusions

Care workers:

• enjoyed their work, felt well prepared, but showed different levels of understanding of the role of ECH, particularly in relation to key policy goals.

• noticed that their settings were accepting residents with more complex needs and reported this was impacting their work.

• told us their working patterns were structured around ‘time/task’ & this was a source of frustration/ concern for some.

Taken together, these pressures could undermine the original aims and aspirations for ECH.
Thank You

For more information please email: A.Cameron@Bristol.ac.uk or visit the ECHO Project website: http://www.bristol.ac.uk/sps/research/projects/current/echo/
Living with Dementia in Extra Care Housing

Teresa Atkinson
THERE'S NO PLACE LIKE HOME
Home....
Home.....
Where are people with dementia living?

70% per cent of care home residents are living with dementia.

15-35% of people living in Extra Care Housing have dementia

Fix Dementia Care: NHS and Care Homes 2016
The Housing and Dementia Research Consortium, 2012
What do people with dementia struggle with?

- Sight problems/visual perception
- Orientation/getting lost
- Visual distortion/hallucinations
- Cognitive overload
- Familiarity
- Social interaction/isolation
- Mobility/walking
- Outdoors
- Understanding their world
- Co-morbidity
What can ECH offer people living with dementia?

• Innovative design (Torrington, 2006; Utton, 2009)

• Potential to promote a good quality of life for people living with dementia (Evans & Means, 2006)

• Can maximise dignity & independence

But

• Limitations of ECH in supporting people with advanced dementia (Evans et al, 2007; King, 2003)

•Extent to which ECH provides an alternative to residential care (Darton et al, 2012)
Extra Care Case Study Sites

• A – Integrated. Same housing & care provider. Over 55’s. Registered specialism: dementia

• B – Integrated. Same housing & care provider. Over 55’s.

• C – ECH for people living with dementia. Different housing & care provider. Over 55’s. Re-provision of former care home

Independence & Control

‘Well, for a start off, you’re still yourself and that’ what I like, you know, they’re not coming round and saying you’ve gotta.....they don’t but if you ask them anything you want them to do they’ll do it.’ (Resident Site C)

‘If you’ve got someone with dementia yeah, we will promote independence and I think that’s what we need to focus to promote it, but it’s not that “Oh if she’s here lets expect her to be independent” because that’s not how it works. They sometimes can do only small things – let them do those small things, if they cannot do the big ones help them and let’s see how we go’. (Staff)

They make the bed for me and draw the curtains back and they get my breakfast for me here, not over at the café and they come in each meal time and then they come in at 8 o’clock and get me into my night clothes ready for bed. I don’t go to bed at that time but that’s my time and I’m sitting watching television by then. (Resident Site C)
Independence & Control

‘When I was in the old house, it was residential and we were cared for. Here it’s dementia, and it’s like living in your own flat, your independent in your own flat and they have quarter hour slots to look after you. As I say I don’t see anybody all day until half past seven when they come and give me a quarter of an hour. Now to me that’s no way of looking after people, BUT, that is the system now, it’s changed. You see perhaps I ought to move and go somewhere where it’s residential I don’t know, but I’m a bit too old to be bothered.’ (Resident Site C)

‘You’re tied and limited. If I wanted to have a reasonable life really I would need to leave here so that I could be independent. I could come and go and go to a pub and have a pint or two at night or whatever and just wander back home a short distance. I haven’t got it. I haven’t got that situation.’ (Resident site C)
Complexities & Co-morbidity

‘One of my residents that I look after had dementia. She has diabetes as well. It can be quite challenging depending on her mood. I’ve got to basically, when I work a morning shift, I have to get her up in the morning. I have to ensure that she’s having her food which can be quite challenging at times because sometimes she just might not want to or she can kind of go off track with her attention so that can be quite challenging at times getting her to take her medication. And keeping her on track ‘cause when she’s doing stuff she can have her medicine in her hand for one second and then the next second she’ll completely forget what she’s doing and she can put things in randomly places and, so yeah. I would probably say she’s one of my most challenging but most enjoyable at the same time if you know what I’m trying to say so.’ (Care Staff)

We also like to be flexible with temporary (changes in care), so one scheme they said, “We just happen to have five people with quite difficult dementia and we need to get some extra staff in temporarily.” So we gave them a block of money for a period of about three months to do that.’

(Commissioner)
‘You’ve got to go out of the building and across up into there on the local roads and make your way here, there and anywhere you can get to buy. You can’t go to the shops or nothing. They haven’t got any!’ (Resident C)

‘Yes, and try to walk up to the local Co-op or something like that, but I don’t know how far it is. Well, it’s not far up the road. I’ve been in the car and seen it but I don’t just know quite how long it would take me so I’m a bit nervous about risking going up there.’ (Resident C)

‘Even the building makes it, you know lonely I think. Say this place now, I come through that door, that’s the main entrance and all I have here to go is just this. That’s supposed to be kitchen isn’t it, kitchen, living room, one bedroom’. (Resident C)

‘We wanted it to look more dementia friendly than perhaps was acceptable to private buyers coming in. So we have had to compromise on stuff like that to try and mitigate some of that risk, which is fine; we accept that that is a competitive dialogue process, we have to accept that they are the experts.’ (Commissioner)
Awareness, Understanding & Stigma

‘When I first moved in here three and a half years ago I didn’t even know what it was about. I didn’t even know there were dementia people here. I must have taken me a good year to understand why they were here. And then ever since then I’ve been asking questions about them as well. I still don’t understand. So it’s very … it’s difficult living here, especially when you haven’t got dementia yourself because some of those dementia people tell you off and they’re very aggressive with it. And because I don’t understand their condition it’s very hard to understand why they’re telling you off for no reason at all, sort of thing.’ (Resident Site A)

‘There are activities here which I am not interested in. They have a café downstairs where the dementia people have their meal, and they play Bingo every Saturday. They do a racing sort of game every now and then but I’m not interested in those sort of things because the dementia people go to them and it is pointless going to any activity with them when they ignore you.’ (Resident Site A)
Opportunities for social interaction

‘I’ve got more social contact because I’ve got all these people around me now in the same boat as me so to speak.’ (Resident Site C)

‘Most days I go down (to the lounge) but I don’t spend a long time. Because I don’t think there’s much going on, they don’t have much activity.’ (Resident Site C)

Because I’m sort of lonely up here, sort of by myself most of the time and err ...Yes, I don’t seem to have any visitors. Yes, I couldn’t cope, I wouldn’t say I wouldn’t but I couldn’t cope with a lot of people coming in and out.’ (Resident Site C)
Are we getting it right for people with dementia?

There has been little in the way of formal research about different housing models and the outcomes that they can deliver compared to residential care or nursing care, both in terms of quality of life for people with dementia and in terms of lifetime cost of care.

However, what is clear is that there is no single model of housing that works for everyone with dementia and at every stage.

‘Cost and capacity, with quality coming a poor third. We place people in poor care quality because we have no choice, particularly around dementia. There is a particular niche there that is not enough.’ (Commissioner)

Dementia Care (2015) Housing options for people with dementia
Thoughts…..

• ECH can provide a home for life for people living with dementia?

• ECH can provide a QoL for people living with dementia?

• Specialist vs integrated?
Thank You

For more information please email Teresa Atkinson (t.Atkinson@worc.ac.uk) or Simon Evans (Simon.evans@worc.ac.uk)

or visit the following websites:
http://www.bristol.ac.uk/sps/research/projects/current/echo/
www.worcester.ac.uk/dementia
Commissioning Extra Care Housing

Robin Darton and Randall Smith
The ECHO Project

• 2 year project, October 2015–September 2017
• 2 local authorities:
  • City, unitary authority (Area 1)
  • County council, 2-tier authority (Area 2)
• Interviews with commissioners of adult social care in extra care housing:
  • February 2016
  • April 2017
Financial Pressures

• Changing capital funding regimes

• Changes to local authority funding arrangements

• Uncertainties arising from proposed rent/benefit changes for supported housing:
  • 1% reduction in social rents from April 2016, delayed to April 2017
  • Local Housing Allowance cap on social rent; delayed for 1 year; then to 2019/20; then amended in October 2017 to flexible funding model (‘Sheltered Rent’) to be introduced in 2020

• Planned scheme put on hold (Area 2), but not yet seen impact in Area 1 (recognised future risk)
Key Drivers (Commissioners’ Reports)

• For commissioners:
  • Cost
  • Capacity
  • (Quality)

• For providers:
  • Cost
  • Workforce/recruitment
  • National Living Wage/National Minimum Wage
  • Competition from other employers
Contracting for Care & Support

• Area 1:
  • Combined care and support contract from April 2016
  • Variable hourly rates for social care, increased from previously negotiated rate, but removed uplift for weekends and bank holidays
  • Balance: 5–15 hours (40%); 15+ (40%); variable for unpredictable needs (20%)

• Area 2:
  • No change in arrangements between 2016 and 2017
  • Local authority contract with housing provider
  • Housing provider contract with onsite care provider (on approved list)
  • Separate contracts for care and contribution to core
  • Set hourly rate for care (increased for NMW), and higher for spot purchase (incentive to use onsite provider)
  • Balance: up to 7 hours (low); 7¾–14 (medium); 14¾+ (high) (Weighted to high)
Contracting Issues

• Area 1:
  • No financial eligibility criteria enabled wealthy to take up social rented housing, so added
  • Provision in contract for use of Direct Payment, but tends not to be used

• Area 2:
  • Free to use Direct Payment for choice of provider, but guided to onsite provider
  • Some concerns about several providers entering premises
  • Insufficient staff onsite if provider does not want to expand (not usually an issue)
  • Managing vacancies and balancing needs – changes in suitability while on waiting list
Adjusting to Changes in Care Needs

• Area 1:
  • Temporary changes: ±10% adjustment to commissioned service allowed in contract
  • Permanent: reassessment
  • Providers able to refer reduced needs to adult social care system, and in discussion about extending to increases

• Area 2:
  • Temporary changes: purchase weekly number of hours, so flexibility within week, more difficult from week-to-week
  • Permanent: reassessment
Commissioning & Developing Provision

• Area 1:
  • Provision of affordable units on target, but shortfall of extra care for private sale, and members require check on estimates
  • Assessment of demand complicated because choice to move
  • Housing Department view of what is affordable housing
  • Competition for land for general needs housing etc
  • Arrangement with neighbouring authority

• Area 2:
  • Shortfall in private provision compared with strategy
  • Investor preferences for private developments in some districts
  • Need to review number expected to benefit
  • Concern that low income residents priced out of extra care, and residential care will be only option
  • Prevention emphasised by Care Act, but no funding available
Discussion

• Assessment of need – Housing White Paper requirement to plan to meet needs and stimulate market (Cm 9352)
• Shortfall in private extra care provision
• Costs (NLW/NMW) pressures and recruitment
• Direct Payments – dominance of onsite provider
• Forms of provision – communal space (HAPPI 2)
• Impact of government announcements and changes on provider confidence
Thank You

For more information please email Robin Darton (R.A.Darton@kent.ac.uk) or Randall Smith (Randall.Smith@bristol.ac.uk) or visit the ECHO Project website: http://www.bristol.ac.uk/sps/research/projects/current/echo/
What is the Future for Extra Care Housing?

Simon Evans
History

• History of extra care housing
• Core characteristics
• Broad, evolving model
• Benefits and popularity
• Demand and supply
A Brief History of Extra Care Housing

• Emerged in 1980’s as Very Sheltered Housing
• 2008 – 935 schemes providing 39,000 units, 25% for sale
• 5,000 ECH units were built in 2016, 48% for sale with an average price of £260,000
• 5% of people aged 65 and over live in sheltered, ECH and private retirement housing; 0.5% live in ECH.
• 50,000 units of ECH in total
Core Characteristics?

• a focus on supporting independent living in self-contained accommodation (which can be for rent, shared ownership or sale);
• the availability of 24-hour care;
• design of the built environment to enable ageing in place/a home for life;
• the maintenance of ‘balanced communities’ in terms of levels of care need (including people living with dementia and other long-term conditions);
• access to a range of communal amenities such as restaurants, shops and social activities (which are often open to people living in the wider community).
Benefits of ECH

• Independence
• Security
• Social interaction
• Health and wellbeing
• Costs – fewer moves to rescare, reduced NHS and ASC costs.
Drivers for ECH

• Demographic change

• Policy drivers - downsizing, personalisation, integration, independence, etc.

• Localisation – community hubs

• Economic savings – findings from ECCT study:
Key Challenges for ECH

• Austerity e.g. welfare cuts like Housing Allowance

• Changes to the model
  • Diversification of provision - Public and private
  • (Un)Balanced communities

• Demand and supply

• Awareness – policy/decision makers, professionals, public
Some Questions for Discussion

• Who is Extra Care Housing for?

• Is the ECH model changing and does it matter?

• How can supply be increased?

• Public / Private Bifurcation – is it an issue?

• Should ECH be seen as an alternative to residential care?