

Ageing in place with Down's syndrome
and dementia: An ethnographic account
in a small group home setting.

Sam Quinn

University of the West of Scotland
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In this presentation I will...

- Explain the link between Down's syndrome and dementia
- Define what 'ageing in place' means
- Outline the aims of my study
- Briefly explain how I collected and analysed my data
- Give a summary of the findings

Link between Down's syndrome and dementia

- Life expectancies 
- Number of people with DS and dementia 
- Earlier onset; average age **54**.

Over **2,000** people
with a learning
disability in Scotland
live in group home
accommodation.



Ageing in Place:
A model of care
where people are
helped to stay in
their home as
long as possible.

Ageing in Place Model

- First applied by Janicki and Dalton (1999).
- Common in many small group home settings.
- Help somebody to stay at home as a condition progresses by providing support when and where it is needed.



Key knowledge gaps

- Research does not tell us if ‘ageing in place’ is an appropriate model for people with Down’s syndrome and dementia in a small group home.
- Lack of understanding of how living with a person with a learning disability and dementia affects co-residents who do not have dementia.
- Lack of evidence for use of dementia friendly environments with people with learning disabilities and dementia

Aim and Objectives

Aim

The aim of my study was to investigate multiple perspectives of ageing in place with Down's syndrome and dementia in a learning disability group home.

Objectives:

1. To observe **multiple perspectives** (people with dementia, staff and managers, family and co-residents) of living with dementia in a learning disability group home.
2. To understand the role that the **physical environment** plays in ageing in place in a learning disability group home.
3. To understand the role **organisational culture** plays in ageing in place for people with learning disabilities and dementia.

Study setting and Sample

A small group home in Scotland for people with learning disabilities that uses the ageing in place model.

Sample	Number (n=)
Residents with Down's syndrome and a diagnosis of dementia	6
Co-residents who did not have dementia	8
Staff members	15 (approx.)
Family members	8
Total	37

What is an ethnography?

- Takes the view that best way to understand something is to experience it.
- Researcher joins as a member of a specific culture or group.
- Usually takes a long period of time.



Study Design and Multi-Methods

Method	Quantity
Participant observation notes	8 Months
Semi-structured interviews with family	8
Focus group with staff members	1
Access to residents medical records	14

Data Analysis

- My data was analysed using thematic analysis and Nvivo software.

Staff and Family Views

- Strong staff and family support for ‘ageing in place’ through the entire dementia journey.
- Familiarity of environment and people seen as key strength of ageing in place.
- Only seen as inappropriate in cases of severe ill health, where treatment could not be provided onsite.

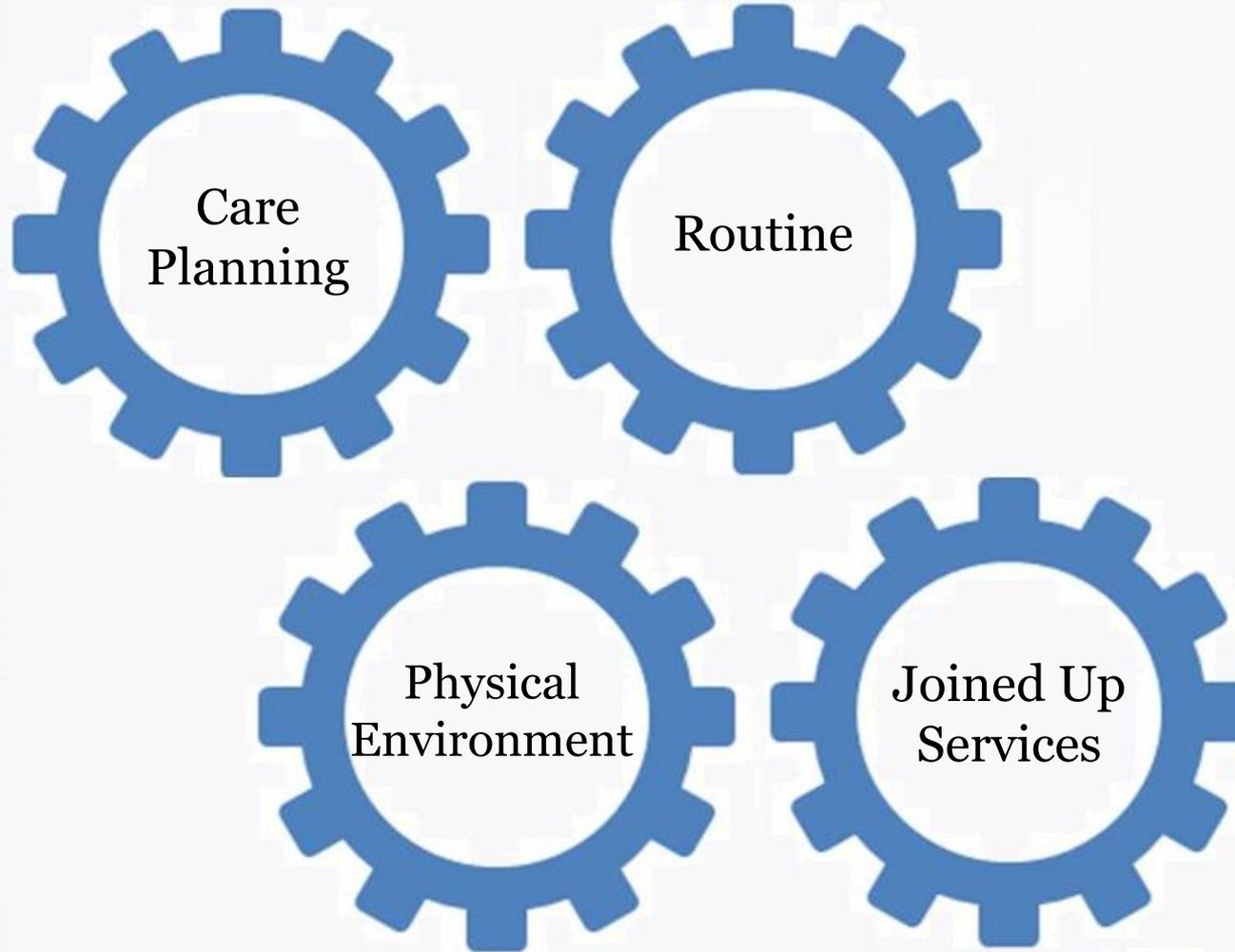
Co-residents

“Interviewer: how does that relationship work? between residents who have dementia and those who don’t have dementia...”

Staff member: Because they’ve all been together for so long, they don’t label each other, they don’t know that that person has dementia, that’s just Catherine or that’s just John and I think that’s the beauty of this house.”

- Staff focus group

The Mechanics of Ageing in place



Personalising Interventions

“I ran to her room and found her totally unresponsive... no amount of talking or touching her was going to help. So the GP was called and I remained in her room to await him.

I chattered away to her and suggested putting on her music... After only a few seconds her hand started to move to the music and she opened her eyes. Within a few minutes she was bright and smiling.”

-Account written by manager

Personalising Interventions 2

“We put on a DVD of Rangers greatest wins and he said “We won!” when he saw them lift the cup. He also said “There you go” when Rangers scored.

It was amazing to see him so responsive and able to recognise what was going on and interacting with things around him.”

- Observation notes

Thank you for listening

Contact me:

Email: Samuel.quinn@uws.ac.uk

Tel: 07877 946161

Any Questions?

