

1 Introduction

Many intellectually disabled people live in inappropriate and unsafe housing in the UK (MENCAP, 2022). Many may also be autistic or have physical disabilities, presenting with complex needs such as over-sensitivity to environmental stimulus (visual, tactile, auditory), isolation, poorer health, poverty and abuse (Simplican, 2019). The lack of choice and control in terms of dwelling, affordability and the requirement for home modifications to support their ongoing needs are all contributing factors to poorer health outcomes (NHS, 2017).



2. Study aim

To understand how occupational therapists contribute to the design of homes of intellectually disabled people, to help them live better lives.

Patient and Public Involvement (PPI) was sought as the needs and priorities of disabled people have not always been included in research and in the provision of services (NIHR, 2024; Atkin et al., 2020). The study was carried out in collaboration with Team Springwell, Sussex Partnership NHS foundation Trust (SPFT). They are the Experts-by-Experience (EbEs) in this study.

3. Meet team Springwell...



SCAN ME

Sussex Partnership NHS Foundation Trust

A Collaborative Research Journey with Experts-by-Experience (EbE) on: The Occupational Therapy Contribution to Good Home Environment Design For People with Intellectual Disabilities.



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4. Method in approaching this collaborative research as a process and principle

4.1. The research collaboration process so far...

1. BUILDING RELATIONS

Familiarised with Springwell members, interests & projects.

Gauged capacity of & interest from group.

Exploratory conversations.

All this, took time.

2 GRANT FUNDING TO

Compensate Springwell & their facilitator.

Support meaningful engagement from EbE: a shift from PPI to co-researchers.

Fund accessible communication process.

3. PLANNING & DESIGNING

Obtained consent from EbEs.

Used accessible means to communicate.

Co-created interview questions & schedule.

4. ETHICAL CONSIDERATIONS

Included people who the research seeks to benefit.

Liaised with SPFT facilitator before any co-production activities commenced.

Safeguarding & policies (consent, MCA (2005), confidentiality).

5. INTERVIEW PROCESS

Access to space & technology.

Reasonable adjustments to support EbE involvement.

EbE co-led interviews with own questions.

Considered risks: fatigue and time optimisation for everyone.

4.2. Research design: 13 Semi- structured interviews conducted online.

The data will be analysed using reflexive thematic analysis (Braun & Clarke, 2022)

5. Results of the process

- Conditions were set where EbEs felt able to contribute with authority e.g. meetings were held in their space with familiar support structures and a known facilitator.
- Providing safe opportunities for all to be involved by managing dynamic Interactions and power tensions in-situ.
- Technology was critical to share information, and scheduling and conducting of interviews.
- Involvement from EbEs lived experiences brought a different perspective with focus on disability rights, human rights and training of occupational therapists.

6. Discussion

- Conditions of funding and institutional support underpinned this research.
- The collaborative working of the study was shaped by managing social and accessibility requirements (e.g. communication, funding & institutional support required to establish working relations & group norms) and in understanding the role of EbEs as co-researchers.
- Need for continual reflection from co-researchers to support the emotional safety of Springwell members, valuing them as contributors and colleagues; and ensuring their views were prioritised intentionally (Fraser-Barbour et al., 2023).

7. Next steps....

Knowledge transfer and exchange (HSE, 2021)

- **Data analysis:** findings will be discussed with EbEs to review their understanding and agreement before publication.
- **Dissemination:** support Springwell to contribute (speak or audiovisual record) for a conference presentation.
- **Foster further collaboration** - to develop guidance for intellectually disabled people in research (funding required).



8. Limitations

- Timing challenges to grant funding meant Springwell were not equally involved at the beginning in shaping the initial concept design and proposals.
- Grant funding also placed boundaries on time and type of EbE involvement.

9. Implications & conclusion

- The involvement of intellectually disabled people as co-researchers should occur from the beginning, but is a challenge when funding only flows after grants are awarded.
- Ensuring a culture of safety and empowerment was essential for continued involvement.
- Utilising technology (to meet/interview) and providing accessible communication methods was integral.
- The co-researching and trust-building process takes time. It continues to be shaped and negotiated as the research evolves.

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Ethical approval:

University of Brighton Cross-School Research Ethic Committee. Ref: 2023-12383-Yong The occupational therapy contribution to good home environment design to support the participation and wellbeing of people with intellectual disabilities.

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