



**Northumbria
University**
NEWCASTLE



**Primary research with practitioners
and people with lived experience –
to understand the role of home
adaptations in improving later life**

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About the authors' organisation

Northumbria University, Newcastle, is a research-rich, business-focussed, professional university with a global reputation for academic excellence. Our research looks at shaping interventions that have impacts on a health, educational, behavioural, economic and social basis, at local, national and international levels. Northumbria is in the top quartile in the UK for its research power in Allied Health Professions and Nursing. More than 80% of research activity in this area is rated as world leading or internationally excellent.



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Executive summary

Introduction

Background

In the UK, more than 90% of those aged 65 and over continue to live at home. Many older people, including those living alone, experience independent and fulfilling lives. However, research shows that ageing is associated with greater risk of living with higher levels of disease and disability, including long-term conditions such as diabetes, mobility limitations, experiencing social isolation, mental ill health and falls. In the UK, 60% of older people are living in large homes, sometimes through choice, but sometimes because of a lack of suitable 'moving on' options. At least 3 million people over 65 are estimated as receiving public funded services, such as home care, community alarm or telecare services and home improvement and/or housing related support services. Some 2 million older people are said to currently need, but not receive, any care services.

Adapting the home to changing need is known to support older people to stay at home, even with limited mobility or long-term health conditions. Commissioned by the Centre for Ageing Better, the most recent, comprehensive review of the international literature on home adaptations (Powell et al., 2017), finds strong evidence that minor home adaptations, such as grab rails or lighting adjustments, are an effective and cost-effective intervention for preventing falls and injuries. The review also highlights how minor adaptations work best when combined with necessary repairs and home improvements, such as removing trip and falls hazards. Furthermore, involving the individual, and their family members and carers in home adaptation decisions, is more likely to result in better outcomes. There is less robust evidence about the effectiveness of major adaptations, such as an external ramp or a stair lift, but there is some evidence to suggest that they can support people in some circumstances. There is also not much known about older people's decision making and overall experiences of acquiring, and living with, home adaptations.

The Centre for Ageing Better commissioned qualitative research to understand motivations for and barriers to acquiring home adaptations and their impact on quality of life. The research was led by a team from Northumbria University, in partnership with Newcastle City Council, North Tyneside Council, Newcastle University and Elders Council of Newcastle.

Methodology

Phenomenology, a research approach focusing on experiences from the first-person point of view (Swanson-Kauffman and Schonwald, 1988), guided the qualitative research. Data were collected from two local authority sites (Newcastle City Council, North Tyneside Council). A non-representative sampling profile captured diversity and included: age range (65-74, 75-84, 85+), gender, ethnicity, house type and tenure, household composition, minor or major home adaptation and its funding source. The study also gathered 'lived working experiences' of a range of practitioners seeking best outcomes for home adaptations' users.

Strand One: Participant Lived Experiences, a two-phased approach

Phase One – Six older adults (three from each site) used a wearable still camera over a one-day period within their own home. The wearable camera automatically captured taken for granted, everyday use of, and interaction with, home adaptations. The images were reviewed and confidentially discussed with each participant, during a semi-structured interview carried out in participants' homes.

Phase Two – A further 24 participants took part in a home-based, qualitative interview (12 from each site) to explore the range of impacts of home adaptations on the lives of older people.

Strand Two: Practitioner Experiences

Four focus groups (two at each study site {n= 8-13}) were carried out with a total of 39 practitioners, with discussion guided by emerging findings from the wearable camera data. A range of professionals, contractors, suppliers and those from signposting agencies and charities in touch with older people, participated.

Key findings and recommendations

Throughout the report, findings are reported on from within a common home adaptations journey, from triggers to access, and from installation to outcomes. Here we firstly report our key findings from within this journey. We then offer our recommendations. Whilst these are specific to the context and location of our study, some are likely to have implications for other locations.

Key findings

Triggers

1. **The decision to adapt the home was often made when the person was already struggling.** Common triggers included: following a crisis, such as an injurious fall; a gradual realisation that long-established coping strategies, such as using doors and furniture to deal with increasing unsteadiness or dizziness, were in themselves, becoming hazardous; shrinking use of the home; and family and friends showing carer or worry strain.
2. **Participants delayed installing adaptations.** Participants and practitioners recognised that delaying securing home adaptations was partly because of their clinical appearance and negative associations with vulnerability and loss of independence.

Access

3. Sources of information and advice on the role of home adaptations mostly came from friends, family and, to a lesser extent, signposting agencies, such as age-related or disease-specific charities and home improvement teams. There was some consensus amongst older people and practitioners that formal services, including healthcare and housing, largely became involved at a point of deterioration in health or mobility.
4. Practitioners and participants had difficulty navigating the system. Common barriers to accessing home adaptations included participant uncertainty about their financial and health-related eligibility, as well as general lack of awareness of local authority services and processes.
5. Some participants experienced access and installation delays, particularly those who were unable to self-fund, with some experiencing significant delays. Completing application forms and waiting for a decision and an installation date, was frustrating and unnecessarily prolonged the use of inappropriate and temporary coping strategies. A number of participants were willing to accept significant time delays, as long as they eventually received the adaptation they required, highlighting the extent to which the adaptations were valued.
6. Practitioners expressed frustration with assessment and installation 'bottlenecks' and there was strong agreement that these were due to lack of resources, such as not having enough staff to process referrals and grants, or contractors to carry out adaptations, rather than insufficient Disabled Facilities Grant (DFG) funding.
7. Some people chose to 'go it alone' as a direct result of delays. There were concerns that 'bottlenecks' may not only leave an already compromised person in a potentially vulnerable and deteriorating state but that some people might inappropriately 'go it alone', including buying second hand and disreputable adaptations not suitable for their needs.

Installation

8. Participants benefited from contractors who communicated clearly, regularly and in a personable manner, fulfilled their agreed obligations, took on the concerns of clients and tailored adaptations to meet individuals' needs.

Outcomes

9. Many participants acknowledged that it took time to adjust to using their home adaptations, from learning to trust 'gadgets' (such as stair lifts) and adopting new routines (charging the stair lift), to changing pre-adaptation behaviour. For a minority of participants, home adaptations did not achieve their aim, or led to negative consequences.
10. There were very positive expressions of 'getting back to normal', reclaiming home spaces, such as the first floor or the garage and generally fitting back into everyday life. The restoration of small, subtle, routines was appreciated as life affirming, 'a boon', and 'a life-saver'.
11. Several participants reported fewer falls after adaptations had been installed.
12. Participants also discussed secondary outcomes including home adaptations preventing unwanted relocation; exit and entry adaptations enabling more social contact; reducing worry and carer strain for family and formal carers; and in some cases, no longer needing or reducing care services.
13. Practitioners generally agreed that Central Government guidance on home adaptation services monitoring and evaluation could be improved upon. There was also recognition that there is a need for a multi-disciplinary, cross-sector, integrated approach to outcome monitoring and reporting.

Recommendations:

- There is an urgent need for positive messaging about home adaptations, for example, offering a 'Facilitating Independence Grant', as opposed to a 'Disabled Facilities Grant' (DFG). This needs to include a wider understanding of the adaptations themselves and the benefits of adapting the home. Older people need to be at the heart of this process.
- Some people are delaying installation, partly due to the clinical appearance of products and negative associations. There needs to be more focus on retailers and designers to get attractive products into the mainstream retail market.
- Adaptation services need to work with signposting agencies and health services to simplify the home adaptation processes. This includes providing up-to-date information of locally available home adaptations services, saying how long the process might take and highlighting potential exit points, e.g. ineligibility for funding support. For those individuals growing older without family support, (e.g. people ageing without children), this recommendation is an urgent priority.

- Increases to the DFG budget need simultaneous increases in funding to aspects of the adaptation processes, such as administration and contractors. Successful and timely distribution of this funding is dependent upon other resources. We need to learn from other areas that are using their funding in a smarter and more innovative way.
- When installing adaptations, contractors should adopt a personalised approach to the individuals' wants and needs. This is to ensure that the adaptation is meeting both the functional and emotional needs of the individual.
- Central Government needs to provide better guidance on home adaptation outcome measures. Such metrics need to be based on robust evidence of what services can achieve as well as policy goals. Local services should have the flexibility to achieve such outcomes according to local need and local context.

Background

In the UK as elsewhere, the population is ageing with growing pressures on health and social care services. Numbers of older people continue to increase, particularly those over 80 years. By 2037 there are projected to be 1.42 million more UK households headed by someone aged 85 or over (DCLG, 2012). Ageing is associated with higher levels of disease and disability, including long-term conditions, such as diabetes (Salisbury et al., 2011); an increasingly sedentary lifestyle, sometimes associated with falls and fear of falling (Hrobonova, Breeze & Fletcher; Woodcock, Franco, Orsini & Roberts 2011); experiencing loneliness and social isolation and mental ill health (Cornwell & Waite, 2009). At least 3 million people over 65 are estimated as receiving public funded services, such as home care, community alarm or telecare services and home improvement and/or housing related support services (Age UK, 2017). It is also estimated that some 2 million older people currently need, but do not receive, any care services.

More than 90% of those aged 65 and over remain in their own home in the UK (ONS, 2011) and many can and do lead independent and fulfilling lives. However, 'staying put' does not necessarily mean that the home is suitable for changing need. It is estimated that there are 1.8 million disabled people with an accessible housing need (Department for Work and Pensions, 2014), and a household survey, carried out in 2014, found that 59% of disabled people within the UK, who are 65 and over, say that they will need accessible housing features in the next five years (DCLG, 2016). Many older homes were not built to modern accessibility standards. It is estimated that 60% of older people are living in large homes, sometimes through choice but also potentially because of a lack of suitable 'moving on' options. There seems to be little affordable housing being built in locations with nearby facilities or good transport links, to enable people to move to properties that are more accessible (Powell et al., 2017). Whilst there is some interest in home share, co-housing and brokering schemes, the latter helping the owner move into a more suitable rented property while letting their own family home, these alternative later life, stay at home, housing options are still very much in the minority (Shared Lives Plus, 2018; UK Cohousing, 2018).

From within this context, the Centre for Ageing Better commissioned both a review of the evidence of the efficacy of home adaptations (Powell et al., 2017), and qualitative research on the lived experiences of home adaptations for people aged 65 and over. Overall, the review presents evidence of how adapting the home can increase the usability of the home environment, promoting and potentially prolonging, independent living and better quality of later life. The review also points to adaptations making it easier for domiciliary formal and informal support to be put in place when needed and ideally enabling comfortably 'staying put', through to end of life.

In particular, Powell et al.'s (2017) review provides strong evidence for minor home adaptations, such as grab rails or lighting adjustments, to be effective and cost-effective interventions for preventing falls and injuries. It also highlights how minor adaptations work best when combined with necessary repairs and home improvements, such as removing trip and falls hazards and also, that involving the individual and their family members and carers in home adaptation decisions, is more likely to result in better outcomes. There is less robust evidence about the effectiveness of major adaptations, such as an external ramp or a stair lift, but there is some evidence to suggest that they can support people in some circumstances. Critically not much is known about older people's decision-making and overall experiences of acquiring and living with home adaptations.

This report sets out the findings from commissioned qualitative research that begins to address this gap. It focuses on understanding motivations for, and barriers to, acquiring home adaptations and their impact on quality of life from the point of view of older people. The study also gathered 'lived working experiences' of a range of practitioners seeking best outcomes for home adaptations' users. The research was led by a team from Northumbria University, in partnership with Newcastle City Council, North Tyneside Council, Newcastle University and Elders Council of Newcastle.

Lived Experiences of Home Adaptations

Project Partners

Project partners have established working relationships. Both Newcastle and Northumbria Universities are active in ageing research including focusing on health, housing and social care and as such, have strong links to each other, to Newcastle and North Tyneside Councils (introduced below) and very established relationships with the Elders Council of Newcastle. The latter is involved in shaping Newcastle to be a great city in which to grow old. Elders Council are also well connected to and have regular contact with service commissioners, providers and policy-makers.

Project Site

The research was conducted in two significant and contiguous local authorities in the North East of England: North Tyneside and Newcastle.

Despite their geographical proximity, the two boroughs of Tyne and Wear exhibit considerable differences in terms of both their populations and their respective processes and structures. The proportion of people aged 65 and over is lower in Newcastle (14.3%) than in England (17.7%), whereas North Tyneside has a higher proportion (19.3%) (ONS, 2016). The populations also differ in relation to their ethnic composition, with 18% of Newcastle residents describing themselves as other than white British, compared to only 5% in North Tyneside (ONS, 2012). Newcastle is also more deprived, ranked 53rd in England based on

average scores used in the Indices of Multiple Deprivation, against a rank of 130th for North Tyneside (Communities and Local Government {CLG}, 2015). The same dataset shows that 26% of Lower Super Output Areas in Newcastle fall within the most deprived 10% nationally for income deprivation affecting older people (IDAOPI), whereas only 11% of those in North Tyneside fall within this group (CLG, 2015). The local authority areas also differ with regard to the number of falls experienced by the very oldest people. In 2014/15, Newcastle was found to experience 5,338 emergency hospital admissions for injuries due to falls in persons aged 80+ per 100,000 population, which is broadly in line with the figure for England, but considerably lower than the 6,154 recorded for North Tyneside (Public Health England, 2017).

In addition, there is a key difference in the management of the local authority housing stock between the two areas, with Newcastle using Arms-Length Management Organisation (ALMO) "Your Homes Newcastle" and North Tyneside using in-house management. Critically, the two areas also operate different methods of facilitating adaptations. Referrals for minor adaptations in North Tyneside are processed by the "Select and Direct" service that allows fast, telephone-based assessments for minor adaptations to be installed. Requests for more complex adaptations are referred to the community Occupational Therapy team for assessment of their needs and how best to meet them. Clients' individual circumstances and current tenure will then determine how the adaptations are funded, either from the housing revenue account, via a DFG, or self-funding. Newcastle has established a Home Improvement Agency (Care and Repair Newcastle) both as a mechanism for streamlining and improving the DFG processes, but also to provide a wider range of support services. It has also introduced the online tool "My Equipment Newcastle" to enable users to make a self-assessment for minor adaptations.

Structure of the Report

In the next section we outline our Methodology, data collection with older people (participants) and practitioners and data analysis. We then present project findings, starting with practitioner experiences. To give meaning to the lived experiences of home adaptations and incorporating our wearable camera data and images, we then detail two participant case studies. The case studies follow a common participant journey, from triggers for considering home adaptations, to accessing information and appropriate services, to financial and needs assessments, to installation and finally, to adapting to and living with, the adaptation, including perceived challenges and benefits. For our 30 participants, there was wide variation throughout this adaptation journey. To capture the richness of this variation we conclude by presenting our overall data from within a 'Contexts and Capabilities' model.

Our final section offers a discussion of our key findings, their implications for future lived experiences of home adaptations and the role of policy and practice. We conclude the report with our recommendations.

Methodology

The aim of this project was to explore the role of home adaptations in improving later life by exploring the lived experiences of practitioners and older people. This section highlights the methodology and methods used, sampling and recruitment, ethical issues, data collection and data analysis.

Methodology and method

To understand motivations for, and barriers to, acquiring home adaptations and their impact on quality of life, an in-depth exploration of the meanings given to human experiences in the research context (van Manen, 1997) was needed. Phenomenology's focus on understanding and describing lived experiences made it appropriate for addressing the stated aim (Swanson-Kauffman and Schonwald, 1988). This also allowed the research to gather 'lived working experiences' of a range of practitioners seeking outcomes for home adaptation users. In order to address the project's aims, a two-strand approach was used and data was collected from two different local authority sites to ensure breadth of participant experience and service provision.

Strand One: participant lived experiences

To capture the views of older people in receipt of home adaptations a two-phase approach was used. Phase One involved using a wearable camera (Autographer, OMG Life). This small, light (58g) camera has a 136-degree wide-angle lens, and can be either worn on a lanyard, resting on the user's chest or clipped onto clothing. It automatically captures at least one image every 30 seconds, without user interaction. Due to the position of the camera, it captures activity, social participation, and health-related behaviours, as well as use of assistive devices, adaptive behaviours, and home adaptations (Wilson, Jones, Schofield & Martin 2016). The wearable camera allowed insight into daily functioning that could not otherwise be captured.

Ten older adults (five per site) were targeted to utilise the wearable camera over a one-day period. Users were shown how to use the camera, and were given written, illustrated instructions of how to do so. Images were uploaded onto a laptop and were reviewed as a 'slideshow' with each participant enabling reflection on their home adaptations within an in-depth semi-structured interview. This data allowed participants to reflect on taken for granted, everyday use of and interaction with, home adaptations. The data also refined and validated the research questions and interview topic guide to inform subsequent interviews through participant experiences.

Ten further face-to-face semi-structured interviews were then targeted to take place at each site to capture the range of impacts of home adaptations on the lives of older people. Interviews were carried out in participants' homes to be both convenient for those involved and allow the environment itself to act as prompt for discussion.

Strand Two: practitioner experiences

The perspectives of practitioners were collected via four focus groups, two at each study site. These occurred alongside stage two data collection to ensure they were informed by the wearable camera data collection findings. The focus groups were multi-disciplinary and featured a range of professionals/suppliers and informal key contacts. This approach was chosen instead of one-to-one semi-structured interviews to maximise participation and enable diversity of different approaches to inform discussion and facilitate reflection and comparison. Multi-disciplinary focus groups, as opposed to uni-disciplinary, were chosen as the provision of home adaptations services were seen to cross a range of disciplinary boundaries, and this provided the ability to reflect and appreciate integrated working. This was deemed to be more significant than the potential downside of practitioners from individual disciplines feeling unable to discuss their relationship with others while they were present.

Sampling and recruitment

Strand One: participant lived experiences

Following consultation with partners, a sampling profile was set up to capture the range of issues reflected in both participating sites. Specific criteria were as follows:

- Age range (65-74, 75-84, 85+)
- Gender
- Ethnicity
- House type (e.g. terrace, semi-detached, detached, bungalow, etc.)
- Tenure
- Household composition
- Funding source for adaptation
- Adaptation size (e.g. minor adaptations up to £1,000 / major adaptations £1,000+)

These sampling criteria were given to local authority and other partners to collate potential participants. Local authority records were focused around funding sources, so this was used to generate contacts and then the services/research team used a purposive sampling approach to capture a breadth of backgrounds for the sample. Additional services and groups, such as Newcastle Elders Council and other voluntary organisations (e.g. Newcastle Society for Blind People; Deaflink; BME groups), were used as gatekeepers to recruit those who seek support and/or resources through self, community (e.g. faith group), family or other means.

Prospective participants identified by local authorities were contacted by those services, using an information script provided by the research team, in the first instance to ensure that they were interested to take part in the study and have their details circulated with the research team. Those identified through partner organisations were asked to complete a short expression of interest forms. All prospective participants were then contacted by a member of the research team to discuss participation, before receiving a copy of the participant information sheet (see Appendices 1-3) in the post. Having been allowed to consider this for seven days, they were then contacted again to confirm their intention to take part and book an appointment. All participants took part in one-to-one, face-to-face semi-structured interviews, which were utilised to allow greater depth of understanding and tease out the experiences of home adaptations.

Although a full sample was collected across both sites (n=30) (see participant breakdown table below), only six participants (three at each site) agreed to use the wearable camera. Despite being offered detailed information and reassurance to the contrary, a number of participants felt wary of the intrusion associated with wearing a camera and preferred to take part in one-to-one interviews, which were more familiar to them. However, it was felt by the research team that existing wearable camera data was strong enough that data saturation had been reached for this phase, and additional participants were included in Phase Two as a result.

		Site one	Site two
Wearable camera use	Camera	3	3
	Non-camera	12	12
Age	65-74	5	2
	75-84	7	8
	85+	3	5
Gender	Male	8	5
	Female	7	10
Ethnicity	White British	15	13
	Other	0	2
House Type	Bungalow	5	0
	Semi-detached	6	7
	Terrace	2	6
	Flat	2	2
Tenure	Social rent (local authority)	5	2
	Social rent (housing association)	1	1
	Owner occupier	7	10
	Private rent	2	2
Household composition	1	9	9
	2	4	5
	3	2	1
Funding source	DFG	2	2
	Local Authority (Non-DFG)	3	7
	Mixed	3	0
	Self	7	4
Adaptation Level	Minor	9	4
	Major	6	11

Strand Two: practitioner experiences

Recruitment of practitioners focused on individuals who were involved in part of the process of residents receiving home adaptations. This included advice and representation services, local authorities, NHS staff and private companies in order to capture a wide range of perspectives. Practitioners were recruited via local authority partners or through contacts at relevant organisations, either previously held or sought out by the research team. Potential participants were provided with an information sheet upon invitation to take part, which set out the background to the research and what the focus group would entail.

	Site one	Site two
Advice/Representation	0	6
Contracts/Technical/Installation/Manufacturing	5	2
Health Improvement	0	1
Home Improvement	2	2
Housing	0	1
Nursing	1	1
Occupational Assessment and Therapy	10	4
Rehabilitation	0	3

Data collection

Strand One data collection took place between August 2017 and November 2017. As stated above, Phase One participants were asked to wear a wearable camera for a one-day period, before being visited to review the images and take part in a one-to-one interview with a researcher. Phase Two participants took part in one-to-one interviews (see Appendices 4-5 for interview schedules). Strand Two data was collected via multi-disciplinary focus groups, which took place in September and October 2017.

Ethics and governance

Ethical approval to carry out this primary research was received from Northumbria University, Health and Life Sciences research ethics subcommittee. The Economic and Social Research Council's 2015 Framework for Research Ethics, including principles of good practice in relation to, participant and researcher risks and their mitigation, participant consent, data protection, storage, and retention, were also followed. All participants were given participant information sheets at least one week in advance of being asked to confirm participation, and agreed to the informed consent procedure before taking part.

Due to the potentially sensitive nature of the data, participants were fully informed about the wearable camera before use, and followed pre-existing guidance specifically for use with wearable cameras (Kelly, et al., 2013). The respect and privacy of participants and third parties was ensured throughout. Participants were informed that they were able to either remove the camera, turn off the camera, or use the fitted privacy button to pause recording, at any time they do not wish to record. They also had the opportunity to browse, and delete, any images before the research team viewed them. Participants were advised to inform third parties of its presence when entering their home, and if third parties did not wish to be recorded on the wearable camera, the participant was to remove the device. Also, due to the potentially sensitive nature of some home adaptations (such as those relating to personal hygiene, including wet rooms), participants were specifically advised to remove the device at all inappropriate times. All data was encrypted and stored on a password-protected computer. Participants provided consent if any non-identifiable images were distributed further than the research team. Any identifiable images were entirely confidential.

Data analysis

Wearable camera images showing home adaptations were extracted from the dataset and coded using Content Analysis. These then acted as a source of data for analysis, and the themes were a prompt for subsequent interviews. Face-to-face interviews and focus groups were transcribed verbatim before being entered into NVivo qualitative analysis software. Data was analysed using open and axial coding as individual categories (i.e. as individual locations, within each strand) by multiple members of the research team, before interim findings were drawn together to identify overarching themes and issues. Open and axial coding were used to break data down into individual themes, before being drawn together to stress the similarities between categories.

Following analysis by the project team, two member-checking events with a range of stakeholders were carried out to test and refine the emerging themes and recommendations and add additional rigour to the process. Full details of these events can be found in Appendix seven and Appendix eight.

Findings introduction: The participant journey

Interim data from the camera interviews informed the development of topic guides for the remaining face-to-face interviews with other participants and practitioner focus groups. It illustrates a chronological journey most participants experienced when accessing home adaptations. This included four distinct phases, each of which is discussed in more detail subsequently. These were:

- Triggers: the decision that a housing adaptation was required to support functioning
- Access: the process of identifying appropriate adaptations and the services/funding required to deliver them
- Installation: the process of actually receiving the adaptation
- Outcomes: the perceived and experienced benefits of receiving the adaptation

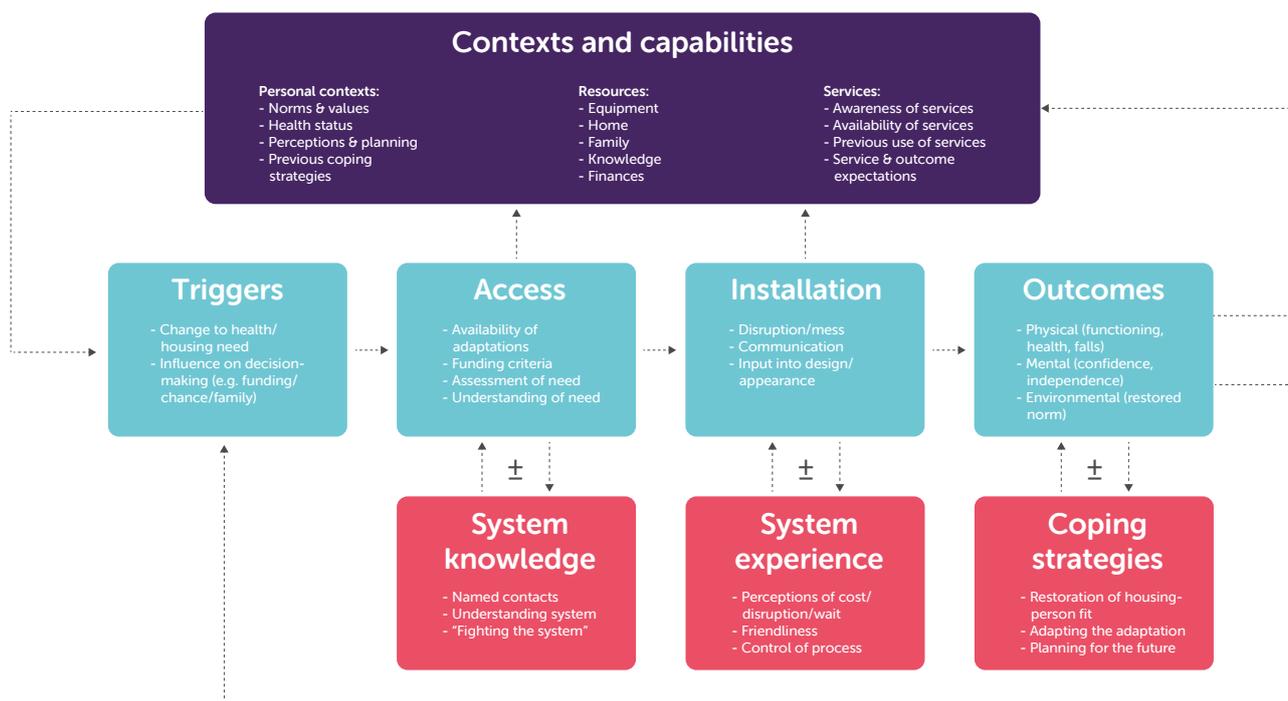
However, what was immediately noticeable was the wide variation in the participants' experiences of this journey. In going through each stage, it was clear that a complex array of contextual factors was playing a significant role in influencing the process on every level, from when the adaptation was deemed necessary, through how it was accessed, and how it was valued and integrated into the person's home environment. These factors were individual to each participant, and included the resources, knowledge and experience they brought to the journey (such as financial resources, their desires and priorities for their home, access to understanding of adaptations and many more). These factors influenced how the adaptation itself could be integrated into their own view of normality within the home. Thus, although not a clear aspect of the home adaptations journey on a surface level, it was important to capture these contexts as key determinants at each stage.

The Capabilities Model (Sen, 1985; 1999; 2004) was used as a theoretical framework to provide an understanding of this context. This model argues that unlike other, more hierarchical or psychologically focused models, wellbeing and quality of life should be considered within the boundaries of what a person is able to achieve, rather than via a standardised set of outcomes. As such, in this context, the physical and psychological outcomes experienced as a result of housing adaptations, defined as 'functionings and utility' within the model, are best understood within the contexts of the resources and immediate personal factors which are available to them. Thus, the range of decisions available to them in relation to how housing adaptations can be used within their individual context, or their capability set, are largely dependent on these personal factors. As a result,

the experiences of triggers, access, installation and outcome varied greatly, for example, from a participant with resources such as a background in architecture or a family member working as a property developer, to those with no knowledge of housing adaptations and no experience of accessing them in the past.

While this approach was clearly beneficial in understanding the lived experiences of each participant, it also offers benefits to services and providers by illustrating how each stage of the housing adaptations journey offers an opportunity to engage with and increase participant capabilities in the future. Thus, information about how adaptations can be of benefit, experiences of installation and value placed on outcomes, all hold the ability to feed back into the participants' capabilities and create additional resources moving forward. Thus, if further changes are experienced, and the process begins again, the benefits of this journey and how the previous adaptation is being used to help the participant can be maximised.

Figure one illustrates a model of how the participant journey can be understood in this context, using three tiers. The first is the overarching influence of contexts and capabilities. The second is the housing adaptation journey as experienced by participants, and the third are the opportunities offered to increase utility and resources for each process, which can be fed back into the participants' contexts.



Data will now be presented to illustrate this process in detail, including the overarching significance of contexts and capabilities alongside each stage of the participant journey. Participant quotations will be used to provide detail on individual points, with practitioners identified by role and participants with a simple code (the suffix "a" will be used where data has not been provided by the participant themselves, but a carer or family member present).

Findings 1:

Practitioner experiences

Triggers

Referral

Across the two sites there were common referral routes to home adaptation assessment. These included, GP, Social Care Direct, Community and Voluntary Sector, Care Agencies, and Family / Self.

"A lot of the referrals come through from the care agencies. That are going in to see that person to provide care and the older person themselves has not been aware that there's been something wrong or... They need..."

(NHS Nurse, Focus Group 3)

"Or that we encounter are people who are... Lose their sight later in life. And they will start to struggle with everyday tasks and lose confidence. So, we are often asked about lighting and can that be changed or improved to help them in the kitchen, for example."

(Vision Charity, Focus Group 3)

There were also common triggers for referral.

"For us, it can be everything from getting out of bed, on and off the toilet, in and out of the house. Yes, bathing is a big one. The stairs."

(Occupation Therapist, Focus Group 1)

"Loss of confidence following falls, which may need some adaptations and some equipment."

(NHS Nurse, Focus Group 3)

There was some recognition that, even for professionals, navigating a route through to acquiring the right adaptation at the right time and from within an individual's entitlements, can be challenging.

“That we’ve got people round the table that all work in a similar field, albeit different offshoots of it. And all of us have got different criteria. All of us have got different mechanisms for how we... Who we refer to and how. And then all the funding is different. And then the equipment that you put in is different. So, if we’re having this conversation as professionals round the table, look at the quagmire that it must be for the public. To try and negotiate the system.”

(Health Improvement Officer, Public Health, Focus Group 3)

Adaptations are not always the first course of action.

“I suppose it’s anything that stops somebody doing the things that they want to do within their own homes. So, that’s not always an adaptation as we know. And we do have a process that we go through, that if equipment won’t meet those needs, then we might proceed to an adaptation. There are all sorts of, sort of, avenues that we need to go through first. Before we reach the adaptation stage.”

(Community Occupational Therapist, Focus Group 1)

Access

In terms of access, whilst some people self-referred, there was agreement across the two sites that there is a general lack of awareness of how to access home adaptations.

“People actually don’t know that these services are out there. And also how to access them. You don’t get taught, at any point in your life, how to become an older person. It just sort of happens, [. . .] you know, if you have a child, you’ve got your health visitor and they explain what you’re supposed to do. You become old and no-one is there telling you.”

(Age related Charity, Focus Group 1)

“I think they’ve gone round the houses, haven’t they? Trying to find somebody to help them. That’s something that comes across quite easily and they’re not aware of what we can provide from our role.”

(Occupation Therapist, Focus Group 2)

Community and voluntary organisations may act as signposting agencies.

“And our organisation is one of them that gets contacted. [. . .] You know, people ring up and they’re just wanting advice - so we can, like, tell them about Social Care Direct, which gets them on that first step to where they need to be.”

(Vision Charity, Focus Group 3)

Whilst practitioners also noted that the advent of ICT enabled communication might better inform the public, there was also some concern about this creating a mismatch between lay and professional understanding of need.

“People are more informed by the media but may not understand what’s really required. Sometimes the referrals that come in, or the requests, are very prescriptive. We need a stair lift. We need a level access shower. No, what you need is an assessment for difficulty with the stairs. Or difficult bathing.”

(Occupational Therapist, Focus Group 2)

Assessment

In terms of assessment, from both sites and across different sectors, there was lots of discussion about adaptations grant eligibility.

“So, there’s the means tested budget through the home improvement agency for... For owner occupiers, license holders,[. . .]. Our local authority actually fit the adaptations themselves. And pay for them, 100%”

(Home Improvement Officer, Focus Group 3)

“If someone was self-funding, we would be making sure that they were getting all the benefits that they’re entitled to, to help them to pay for any adaptations. We’d also be looking at other sources of money and help with installing the... the equipment.”

(Age related Charity, Focus Group 1)

As this focus group discussion extract illustrates, there was practitioner understanding of why some people might feel eligibility is an unfair process.

“It is. And feeling, you know, “we’ve worked so hard, we’ve tried so hard, now Mr Bloggs next door is getting his for nothing and he’s never done anything. And we’ve worked hard and we’re going to have to pay”. So, I do think sometimes people disengage with the process out of that sense of outrage.”

(NHS Nurse, Focus Group 2)

“If you’re a council tenant?”

(Interviewer, Focus Group 2)

"You're not financially assessed. So that you could have your half a million in the bank and still get your adaptation for free."

(Occupational Therapist, Focus Group 2)

"Or it's a so-called minor adaptation, which is a certain value where, you know, we go up to £600 or £700 or £800 and just... There's no assessment. If it's over that, and it's private property or non-council property, you have an assessment."

(Home Improvement Officer, Focus Group 2)

Reasonable and practical action was considered to be fair.

"I definitely think the reasonable and practical is a big thing, because if somebody has difficulty with stairs, or has difficulty accessing the toilet, often their expectation in a more normal environment is to have an additional toilet downstairs. [. . .] If you're having difficulty getting to the toilet, the stairs are the problem. So, putting an additional toilet in isn't going to solve the problem of the stairs."

(Occupational Therapist, Focus Group 4)

Although there were also discussions about the criteria for what is fair and equitable. For example, grab rails tend to be offered for one point of entry/exit to the home and practically, this is usually at the front entrance. This meets a functional need to be able to come and go. However, there are emotional needs.

"Because you can only get grab rails on the front of the property, currently funded. And I think for people who want to use their garden and things like that, that is actually really beneficial for people in the long term. That they're able to get out and go in their garden."

(Private Housing Manager, Focus Group 3)

For practitioners being fair and equitable equated to good holistic assessment that ensures an appropriate response to identified, individual need.

"If that wasn't fair and equitably assessed, then she's going to say, well, why does she [neighbour] have a ramp? You know, she goes to bingo every night and walks... You know, so, it's got to be fair and equitable to everybody. And it's about the same information shared. And then it's up to us, as professionals, to work with somebody and help them... You know, look at how they can maximise their independence. Without being too prescriptive straight away."

(Occupational Therapist, Focus Group 4)

However potential housing tenure inequities were also aired.

“Private landlords, as well. They don’t always... They don’t always want their properties adapted, because they are a temporary tenant.”

(Grants Officer, Focus Group 4)

A Local Authority Occupational Therapist suggested that housing associations were increasingly faced with funding issues and hence it seemed that there were delays in getting permissions to follow up an OT assessment of a need for an adaptation:

“I know there’s been a few issues more recently with regard to housing associations. [. . .] That they’re starting to put in a lot more specifications of what they need before they’ll give permission. [. . .] And then that’s a knock-on effect of, well, we need the permission before we can do that.”

(Local authority Occupational Therapist, Focus Group 4)

Local authority practitioners and those supplying major adaptations in particular, also noted a seeming lack of standardised assessment criteria for disability facilities grants.

“People who own their own home don’t realise that there’s disabled facilities grants that are... You know, you can approach the Local Authority to do that. To look at the funding. And from my point of view, this is where it’s very, very difficult - every Local Authority has different rulings on DFGs.”

(Home Adaptations Company, Focus Group 4)

Those from the health and social care sector acknowledged how the Care Act (2014) affords some flexibility but:

“And now we’ve got, sort of, you know, the Care Act and things like that, there’s a little bit more flexibility. But, again, it’s very much up to interpretation. You know, because you’re doing the assessment and you’re identifying, you know, the quality of life that person will or won’t have.”

(NHS Occupational Therapist, Focus Group 4)

Bottlenecks

Bottlenecks from assessment to installation were well recognised and from within local authority home adaptations teams, there was strong agreement that such delays were not due to lack of sufficient disability facilities grants.

"We have more money to spend than we've ever had. That's the thing. We've got more money, we just don't have the resources to spend it at the moment. [. . .] It's just staff. Staff. Lack of staff. We don't have enough staff to... We... We administer as many grants as we can, it's just we need more staff to do it."

(Home Improvement Officer, Focus Group 1)

This focus group discussion extract suggests that lack of contractors may also be a bottleneck issue.

"The irony on the DFG side is we can't get our budgets spent."

(Grants Officer, Focus Group 4)

"Yeah, it's crazy."

(Adaptations Officer, Focus Group 4)

"It's gone from three, four years ago, we were running out of money in October we got the funding from April to April. And now it's the other way round."

(Grants Officer, Focus Group 4)

"So is that a lack of people who qualify?"

(Interviewer, Focus Group 4)

"It's just the time factor. And also the contractors. We haven't got enough... It's more on the sort of... The shower side of things. We haven't got enough builders. It seems crazy because..."

(Grants Officer, Focus Group 4)

Practitioners noted their concerns that installation delays, sometimes of a year or more, not only may leave an already compromised person in a potentially vulnerable and deteriorating state but that some people, might inappropriately 'go it alone'.

"And I have had people where I have, kind of, referred for a bath lift. And because they didn't want to wait, they've gone out the next day and bought it. And, actually, the piece of equipment that they bought, wasn't... Wasn't suitable. I had to go back out and kind of look at it again. But it was that... "Well, I need it and I want it now"."

(Community Occupational Therapist, Focus Group 1)

It was recognised that keeping people informed, giving detail of processes, and particular reasons for a delay in moving from assessment to installation, may ameliorate client frustration.

"I think... I think the key thing is about being as... As upfront with the clients, service users, from the beginning, about what the process is. What happens next in the process, and what they're waiting for. I mean, if we get a complaint, it's usually around communication. [. . .] Just try and keep them updated as regularly as you can, in saying this is the stage it."

(Occupational Therapist, Focus Group 2)

Grant ineligibility can also cause 'going it alone' problems.

"We also find that if people aren't eligible, financially, for a grant, they will buy the cheapest alternative. Which is not necessarily the right alternative. Because you can buy equipment now at [X supermarket]. So you're walking past and you're just, "I'll just have that perching stool." Which really isn't what they need."

(Private Housing Manager, Focus Group 3)

"It's about getting the right contractor there as well. Because people go in the Yellow Pages, find a plumber, and they say you can't put the waste pipe under there, you're going to have to have a step-in shower. And we come and we say, well, you can. He's just lazy. He didn't want to do it."

(Grants Officer, Focus Group 4)

In terms of 'going it alone', practitioners also noted that due to lack of funding, there was no longer an approved, national trades register. From within public and charitable sectors, there was some discussion of the support they could offer.

"In terms of offering a trades register, that's something that we used to be able to do. [. . .]. Unfortunately, the funding for that was cut a couple of years ago now. [. . .]. Which is quite a loss, actually. If it... People often come to us and they say, well, we expect you, as Age UK, to have a... have a list of people. And that's not something we can offer them, unfortunately."

(Age related Charity, Focus Group 1)

Finally, even if people are eligible and assessed as having a need there may be reluctance to accept the adaptation.

"They're not mentally at that point where they realise fully they do need to have them. [. . .]. And if it's not to help them, it's to help their carer. And sometimes that's the avenue to go down. But it... It isn't always... Always accepted instantly or used correctly, [. . .] like, a bath

seat or a shower chair, and they're actually climbing in around it and sitting in front of it – crunched up.”

(NHS Nurse, Focus Group 2)

Negative Associations

Some of the reluctance may be to do with wider cultural associations of adaptations with negative stereotypes of ageing and vulnerability.

“But then you get some people who don't want major adaptations because it makes them disabled, so to speak. Like, you'll not want people with ramps or a key safe because that means 'I'm disabled', and 'other people can see'.”

(Technical Assistant Adaptations, Focus Group 1)

There was also discussion about how such negative associations between adaptations and vulnerability might lead older people to delay acquiring adaptations until a point of crisis.

“And for her [participant's mother] to accept, you know, a step in and out of the shower or a grab rail, [. . .] it's a physical flag in your house. So, anyone that comes round can see that maybe you're not managing as well. So, she's happy with bits of equipment like a walking stick or a helping hand that she can hide away, [. . .]. And it took for my Dad to be very, very seriously ill, and her not cope [to accept adaptations]. And it highlights... And, as you say, a crisis, for it to happen.”

(Home Improvement Officer, Focus Group 3)

Installation

Overall practitioners agreed that once installation was underway, there were few reported problems. From within the two local authorities, it was suggested that an ethos of professionals working together means that proposed installation is doable, ensures both a well-informed client and also an individualised approach to meeting's each service user's needs.

“. . . a technical visit that we do at assessment stage. So, if an OT goes to a property and thinks, "I'm not sure whether that can be done", we can go out and suggest things. We've introduced ourselves to the client and sort of said, "Well, this can be done. That can be done." And then we can give those figures for that, so we know how much it's going to cost when it is ordered.”

(Grants Officer, Focus Group 4)

“And we’re very lucky, I think, anyway, that we’ve got an adaptations team that are fully versed in the therapeutic aspect. [. . .] And how creative, sometimes, as OTs, we need to be. So, yeah...”

(Occupational Therapist, Focus Group 4)

There was also recognition that having established teams, from contractors to fitters and everyone in between, engenders both a culture of trust in each other and affords the client with some confidence, in their ability to complete the installation in a timely and least disruptive way.

“We’ve had that much practice at it. You know, we’ve been a team for years. The turnover of staff is pretty slow, really. So, it’s pretty slick and... Well, I think we maybe get two problems a year.”

(Home Adaptations Officer, Focus Group 2)

“A short period of time that they’re without a toilet. So, a lot of people go and say, “Oh, I’ll be fine. I’ll just knock at my neighbours. You know, if I need... Or I’ll go to my daughter’s for the day or...” Or so... You know, but you always ask that. Or people will mention it to you.”

(Occupational Therapist, Focus Group 2)

“You see, the ones in Local Authority housing – they’ve been using the same squad for about 15 or 16 years now. [. . .] So, it’s as slick as you like. And it’s usually on... The worst-case scenario is that the toilet is taken out at half past seven in the morning, and there isn’t one there at four o’clock at night.”

(Home Adaptations Officer, Focus Group 2)

Aesthetics

Across the focus groups there was agreement that the design of equipment offered can be quite utilitarian, generally white rails, tiles and general fittings.

“You know, the grab rails are probably one of the things that you... That are used significantly throughout. [. . .] Couldn’t they really be designed by some wonderful person at one of our great universities, to make them look more beautiful than they really are now? Because they’re ugly and horrible. And I don’t want to have ugly, horrible things in my house.”

(Age related forum, Focus Group 3)

Focus group participants spoke of clients suggesting that ‘the look of adaptations’ echo”

hospitals and clinics” or “spoil the décor” or “are just awful to grab hold of.” An adaptations manufacturer agreed and suggest a solution at a price.

“The standard grab rails that we produce are the ones you’ve all seen – which are the 300 to 600 white-fluted grab rail. But we do also have grab rails in our range which are stainless steel and polished. And some of them have got a curve in them, so they are aesthetically slightly more pleasing. [. . .] But there’s a cost implication.”

(Adaptations Manufacturer, Focus Group 3)

A Local Authority Home Improvement Officer agreed that choice may come with a cost to the client.

“The DFG will cover... Say, for instance, tiling. £15 a square metre. Plus the labour. We say if you want anything more, that’s between yourself and the contractor. [. . .] But if they wanted anything else, they would have to pay the extra. So, as long as we make them aware of that at the start, they’re normally quite okay with it.”

(Home Improvement Officer, Focus Group 3)

Outcomes

When asked what best captured the success of an adaptation the following extract, is illustrative of the response across the four focus group discussions.

“Something that stops them from accessing hospital. And reduces their amount of falls. So they’re not accessing.”

(Housing Officer, Focus Group 4)

“Promotes independence at...At home.”

(Occupational Therapist, Focus Group 4)

“To reduce the cost of care packages and things as well, yes.”

(Occupational Therapist, Focus Group 4)

“Less reliant on services.”

(Occupational Therapist, Focus Group 4)

"Less reliant on carers, you know. So..."

(Occupational Therapist, Focus Group 4)

There was also recognition that clients' feedback might illuminate broad quality of life improvements.

"And quality of life, as well. I always remember one client saying, "Since my stair lift has gone in... I used to watch the telly, but I couldn't enjoy watching a programme because I was thinking about having to deal with the stairs. And that... It's just... What a difference it's made."

(Grants Officer, Focus Group 4)

The groups were also asked about formal evaluation. Each professional, from Occupational Therapists to Grants Officer, described a range of post-evaluation outcome measures.

"Reviews. Contacting the client and seeing how they're managing. Like, for instance, level access showers. Is the, sort of, grab rails needed or a shower chair needed, in order to make things a lot safer? Like, safer for them using it as well. But... Just to reviewing how they're managing that."

(Occupational Therapist, Focus Group 3)

"Our guys, we do a survey when we complete. And I think the questions are, you know, 'do you feel your health has improved?' 'Do you feel you are socialising more?' [. . .] I suppose the way that you, sort of, really need to measure it is whether there is a reduction in the number of people that are being visited to hospital as a result of it."

(Home Improvement Officer, Focus Group 1)

Post-installation the client might undergo a number of feedback 'checks', including a review of the adaptation itself.

"There's like a survey carried out at the end of every job. [. . .] Like, it asks a whole range of questions. Like, questions... Some of which are regarding the installation itself, but other questions are the process leading up to it. So, we do get feedback and comments about whether, you know, it's met their needs. And, you know, the sort of comments they've been making about how it's changed their life - the quality of life."

(Building Services Manager, Focus Group 4)

"I think anything mechanical - it's on a, like, maintenance [. . .]. Ensuring that it's continuing to work. And if there's any issues, it's brought up. Or if there's any changes, it's kind of..."

Sometimes they've identified that the person is struggling with that, and it comes back in to be reassessed."

(Grants Officer, Focus Group 4)

"Our [Home Adaptations Company] engineers are really good at that. And we have an assessment, and sometimes they see the client getting on to a stair lift or they get to the top of the stairs and they can't actually reach the panel to twist the stair lift."

(Community Occupational Therapist, Focus Group 4)

Improving the Home Adaptations Journey

Finally, when asked about what might be improved, practitioners offered a range of options.

"It's almost like when people ring in, before anything else is done, you need, like, a booklet to go out, don't you? Or some letter or something to say, actually, "this is what it all means. This is what it'll take. You might not get that. You might not be assessed for what you feel you need. " And almost like laying it out honestly."

(NHS Nurse, Focus Group 1)

"If there was, like, a shop, like... I don't know. Like B&Q, but for adaptations, people wouldn't have this expectation that the council would provide everything."

(Occupational Therapist, Focus Group 1)

Some existing examples of good practice, whilst commended, were also discussed in relation to managing expectations.

"We get a lot of praise, our team, because there's always somebody in the office. So the people go, "Oh, there's somebody there." So people... [. .] they like to talk to somebody who can feed them and talk them through what they're going to do."

(Adaptations Officer, Focus Group 1)

"And it's now at the point where we... Sorry, we now get phone calls from people we've done adaptations for who are ringing us for something that's nothing to do with us."

(Technical Assistant, Focus Group 1)

There was also some discussion about future homes in relation to home adaptations. "With new builds that they're building now. Because land is that much at a premium, everything they're building is three, four storeys. In 20, 30 years' time, you're not going to be able to adapt those properties."

(Building Contractor, Focus Group 3)

"So it's actually getting worse because it's cheaper to build upwards, than it is to build out."

(Vision Charity Worker, Focus Group 3)

"Not necessarily. Because some of the townhouses are built designed for ground floor living. So they do have a downstairs toilet facility. They have a room that can be a bedroom. But it means you're not using two floors of your townhouse."

(Housing Manager, Focus Group 3)

"And obviously if you had... If you had the offer of the bungalows out there, that person would sell up, move to the bungalow, and then that townhouse would become a family home. Rather than people... Which is what they're doing now, sitting in really quite inappropriate accommodation."

(Housing Occupational Therapist, Focus Group 3)

There was also talk about thinking through different options, that may not be accessible to everyone.

"There's plenty of information to get, but again – how do you access it? You know, if you... don't have access to the internet, you don't use [on line estate agency]. So, why would you use it? There's a lot... There's shared ownership bungalows out there again. But, again, that's on the internet."

(Housing Manager, Focus Group 3)

Relatedly there was also some reflection on the need for practitioners to keep up with the latest technology, product or development.

"You know, there were various exhibitions [. . .] when they give companies opportunities to show the healthcare professionals, you know, everything. But that's declined somewhat... there's been that many changes since the last time they actually saw the products and what is available. You know, that it may be... It may be specified correctly, but you know, there may be something else available that would have been more suitable."

(Home Adaptations Company, Focus Group 4)

"I absolutely agree. I think there's a continuous professional development – we have to, you know, enhance our learning and things like that. But then there'll be a balance when we say, actually, we need to get the experts in."

(Community Occupational Therapist, Focus Group 4)

Section Summary

Practitioners delivering home adaptations services spoke of an ethos of professionals 'working together' to deliver the best for their clients. They agreed that they tried to execute reasonable and practical action and to be fair and equitable. There was consensus that this is not always easy. Delays and bottlenecks were particularly frustrating. These were not always to do with lack of funding but with lack of resources such as staff or contractors to administer grants and install approved adaptations, in a timely manner. Signposting agencies suggested that even for professionals, navigating a route through to acquiring the right adaptation for the right person, can be challenging. There was understanding and sympathy for perceived tenure 'inequities'. Practitioners valued positive quality of life improvements, reported by clients. There was also some agreement that further guidance from central government on when, how and why to evidence the impact of home adaptation services could be improved upon and that overall, there is a need for a multi-disciplinary, cross-sector, integrated approach to outcome monitoring and reporting.

Findings 2: People with lived experience (case studies)

The images collected by the wearable camera (Autographer, OMG Life) captured a general overview of each user's day and illustrated the everyday use of adaptations and equipment, which is often taken for granted. Home adaptations and equipment, and the individual's interaction with them, were recorded within the images. In addition to being used as a visual dataset on their own, the images were used to stimulate conversation during the interview.

Six participants used the wearable camera over a one-day period (mean 12 hours 52 minutes), gathering a total of 5757 images (mean 960) over the sample. Themes from this dataset illuminating lived experience of using the adaptations and equipment are presented below. These were developed from Content Analysis of the images and themes from the transcribed verbatim interviews for each case study. Two of the case studies are presented individually. These case studies present two distinct cases; the first illustrating an individual which relies on adaptations and equipment to function in any way, and the second illustrating an individual which only relies on adaptations and equipment when she most needs them. Themes from the remaining four case studies are integrated together in one narrative and found in Appendix 6.

Case study one

Participant 02 owned a semi-detached bungalow. She had lived in her home for 40 years and, at the time of data collection, had home assistance. She lived with a long-term mental health condition and Parkinson's. The main adaptation was lowered steps and a grab rail at the entrance of the bungalow, however, the participant also discussed use of various adaptations and equipment; a walker, a trolley, a raised toilet seat, a bath seat, a raised armchair, and self-adapted steps at the rear entrance. A grabber and handrails were captured on the wearable camera but were not discussed as part of the interview. Participant 02 wore the camera for 11 hours 37 minutes. A total of 1033 images were captured throughout the day.

Acquiring and installing adaptations

Participant 02 described the external trigger for home adaptations, equipment and home assistance, including the lowered steps and a grab rail, being through a Social Worker and Occupational Therapist, as well as describing the “smooth”, quick installation process. However, Participant 02 also described her experiences of the system as being a “fight” and she felt that she “had to get annoyed” in order to achieve this desired outcome.

“I’ve never been off the phone. They said they were going to get back to me – they haven’t. At the finish I got annoyed with them. And it did good”

“They just leave you to struggle on your own”

Participant 02 also described barriers to acquiring adaptations, including funding.

“I thought, well, I would get everything free. They said if I needed a ramp for the wheelchair, I would have to pay for it. Because I won my own home”

The participant identified her need for the back entrance of her bungalow to be adapted, in order for her to be able to use her back garden. However, processes meant that this was not possible.

“Oh, yes, [the steps are] pretty high. I haven’t been out there yet, but I am going to... They wouldn’t give me rails for the back. They just gave me them for the front. So I put them out, and I’m hoping to hold on and step down and... So I’m hoping to get out and at least potter, you know”

“You’re just allowed one [...] I would have liked a one on the back. First of all they said they couldn’t attach it to the PVC. I tried to get them myself, you know”

Due to the barrier to acquiring the adaptation, Participant 02 fitted a temporary handrail (Image 1). However, lacked confidence when using the temporary adaptation.



Image 1: Temporary handrail and Zimmer frame.

“Just a rail at the back, I think. Because they are high steps, them. You see, this was a window, originally. A high window. So that’s how it’s so high. So, I would like a rail there. I’m finding it a bit wary about trusting them. And it’s too far to step. I’ve bought these artificial steps myself, but they’re not much good”

Image 1 also shows a Zimmer frame that Participant 02 keeps in the back garden as she cannot transfer her walker, or other walking aids, into the back garden.

Participant 02 evidently modified her own home and used the equipment in ways which were most functional to her in her own daily living due to the barriers of acquiring further home adaptations. Participant 02 described the assessment process as being another barrier to acquiring further adaptations. In discussing her need for further adaptation she described not wanting to “cave in yet” as she was fearful of losing her attendance allowance and was “dreading getting assessed”.

“All that trouble – filling the form in. You’ve got to show your bank statement and... You know? You’re frightened in case you’ve spent too much on something and... You know”

Physical functioning inside and outside of the home

Participant 02 described various ways in which the adaptations and equipment influenced her daily living. Participant 02 viewed the adaptations and equipment as giving her independence, and a secondary perceived outcome was that this independence reduced the need for additional care.

“I’ve still got my independence. I still want to keep it. I don’t want to get care in, if I can help it.”

When describing the adaptations and equipment generally, she articulated that she “couldn’t manage without them”. The participant was completely reliant on the walker to move around the home, and every image in which she was moving around her home presented the walker being used (Image 2).

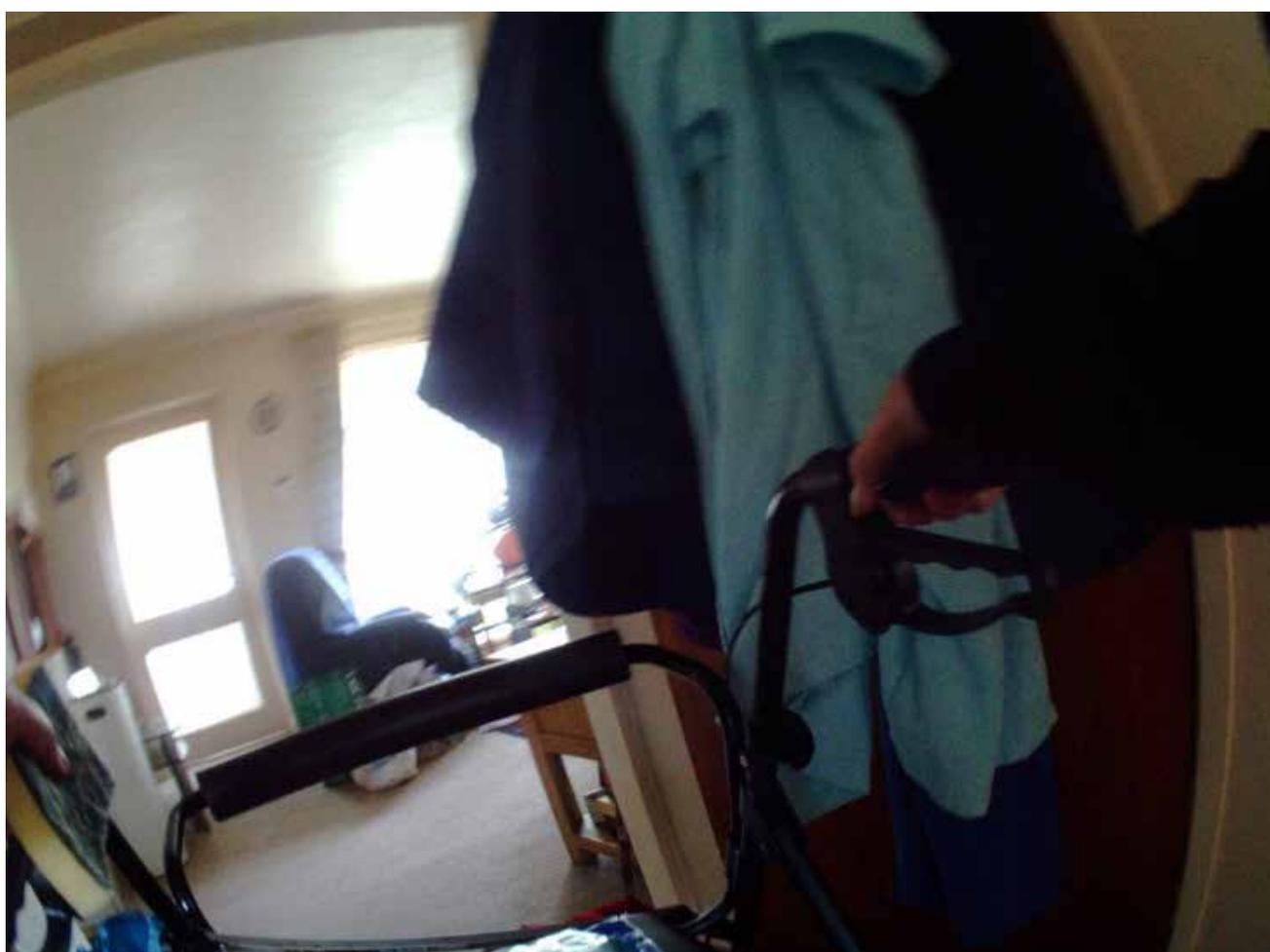


Image 2: Using the walker to move around the home

The compulsory use of the walker was supported within the interview transcripts, as she described the walker as being “her legs”, and stated that she used it “all the time”.

“This is the main thing. The walker. Uh-huh. I wouldn’t be able to manage without that. And, as I say, I used to fall with the three-wheeled one, I bought myself. It used to tip over”

The walker was imperative to her mobility around the home, however this resulted in some areas of her home being out of bounds due to its size. For Participant 02, her home and her possessions meant so much to her, and were more important than her being able to use all of the space. However, the walker did not completely reduce risk when walking around her home, and the participant needed to “sometimes rush back” to her armchair to avoid falling as she could not stand for long periods of time, despite using the walking equipment.

Participant 02 discussed mobility limitations that impacted her sleeping habits. She described sleeping on the sofa, as “it’s not so far to walk to the chair” and the bed is “a bit high”. Image 3 shows the participant’s pillows and duvet on the sofa on which she now sleeps.

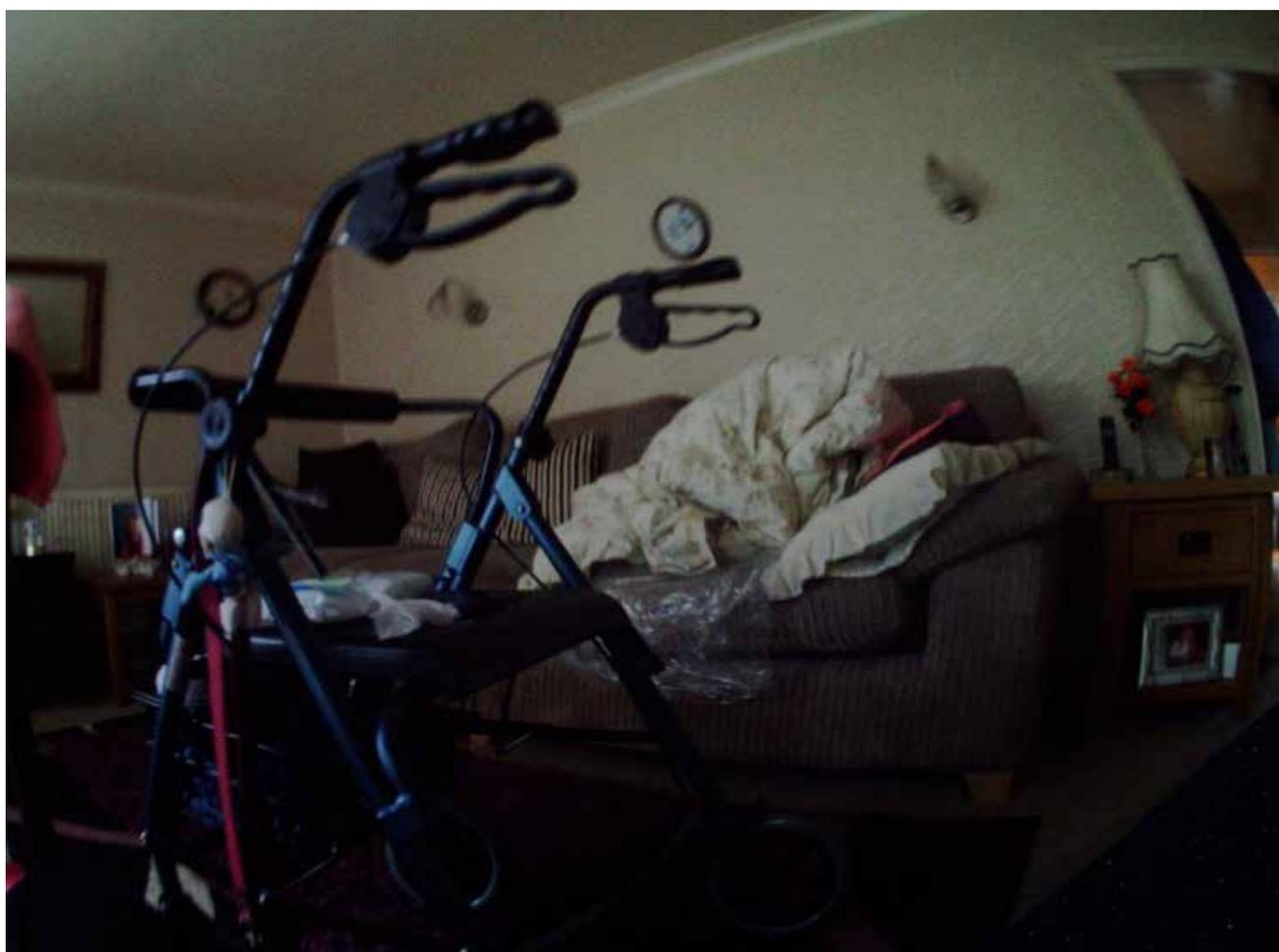


Image 3: Pillow and duvet on the sofa

Once more, Participant 02 acknowledged her own learnt behaviours in knowing the best way for her to use her own home, and to sleep.

“You work it out, what you can do”

Participant 02 also has a many equipment and adaptations to assist her showering. These included the grab rails above the bath and a seat in the bathroom (Images 4 and 5).



Image 4: Grab rails above the bath

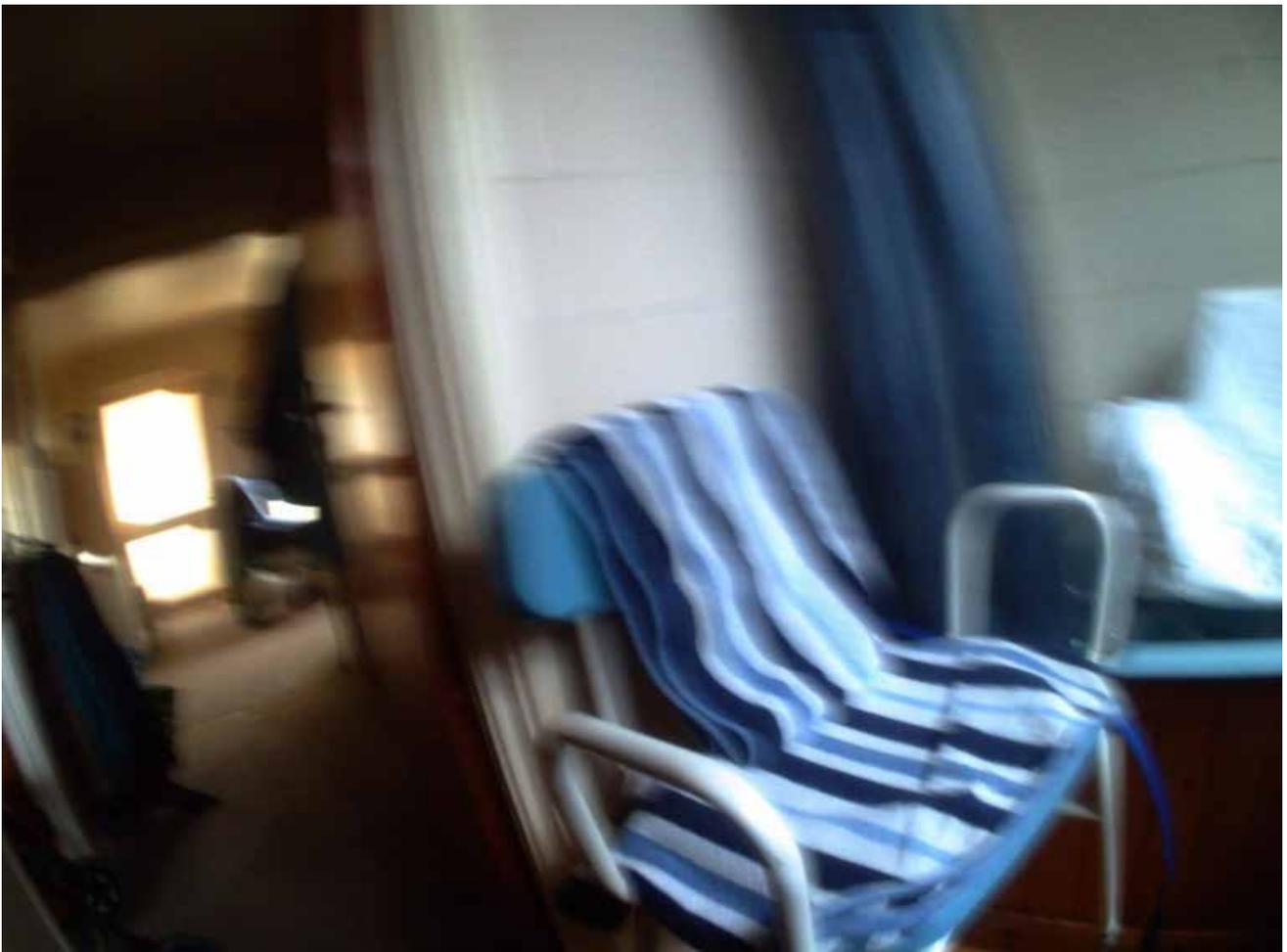


Image 5: A seat used in the bathroom

Once more, despite the use of adaptations to assist showering, there were still occasions in which they were not enough.

“I’ll be honest with you, I don’t get many showers, you know. I use wipes – baby wipes and... On my bad days, you know.”

There was clearly intermittent use of the adaptations and equipment, with Participant 02 using them when she felt physically able to do so, but otherwise needed to adopt other strategies to assist activities of daily living.

Adaptations and equipment not only influenced movement inside of the home, but also outside the home. Participant 02’s most recent adaptation was lowered steps and a grab rail at the entrance of the bungalow, and this had huge physical and psychological impact on the participant.

“A volunteer takes me out on a Tuesday to go shopping, and I can get out. I couldn’t get out before that, I couldn’t get out”

“It’s changed my life”

The participant's confidence negatively influenced her own mobility, which in turn affected her ability to leave the house. Acquiring the adaptation removed this barrier.

"Well, I used to be able to get out and just... I had just, like, these outside. And a grab rail. But... I got where I lost my confidence and couldn't do it, because the steps were high. They even lowered the steps"

Participant 02 also used a trolley and a hired scooter, where available, enabling her to move outside of the home, but she could no longer use a walking stick due to declined mobility. Once more, the participant demonstrated an understanding of her functioning, and her physical changes over time which influenced the way she functioned outside of the home.

Although the adaptations and equipment evidently influence Participant 02's functioning, there are still times when adaptations and equipment are not enough, and it was evident that use of the equipment and adaptations occurred when Participant 02 was functioning at her best.

"I have bad times where I think I can't cope and I'm finished. And then I seem to get strength from somewhere to go on [...] but sometimes you feel like giving up"

Adapting routine and changing behaviour

Participant 02 learnt how best to use her own adaptations, and altered her behaviours and routine to align with the adaptation, ultimately to improve functioning. Participant 02 had a number of other adaptations and equipment around the home that she learned to use.

"I've learned [...] it takes time to get used to them"

Participant 02 described the walker as being imperative to helping movement around the home, but, as well as using the walker in this way, she also used it in a number of unintended ways. The participant described hanging her clothes to dry on the handles of the walker as she was unable to hang them up outside.

"I've got a big clothes horse that I put myself, in the big room. You can have a look. And I'm finding it hard to hang them on. And because I can't hang them out... So I'm just putting them on the radiators, on the walker. And just letting them dry"

Participant 02 also used the seat on the walker to carry her meals into the living room (Image 6), or to carry other items around the home, reducing the frequency of her movement (Image 7).



Image 6: Food and a hot drink being carried into the living room on the seat of the walker

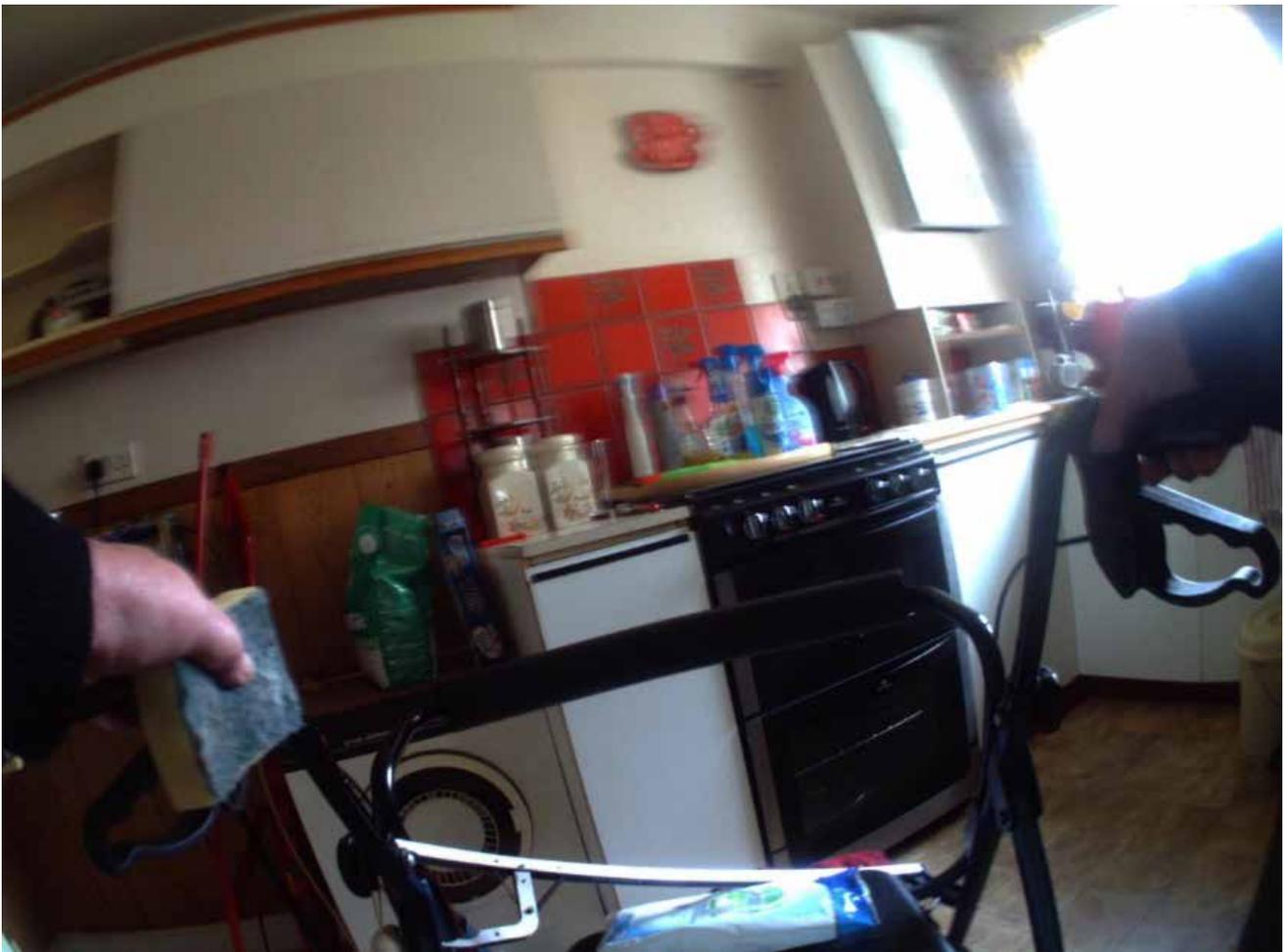


Image 7: Cleaning products, and the grabber, being carried on the seat of the walker

The participant described the way in which she has adapted her behaviours to lessen movement around the home, and the walker helped her to do this.

"I try to do things... You see, I go to the toilet, I try to do a lot of things on my way back. Pick things up and it saves me another journey"

"I've got it if I need it. But I've got to get everything at hand, before I start. You know, towels, dressing gown... That's the only thing – you can't go looking for them afterwards. You've got to have a good memory to get everything"

She described the electric, raised armchair as being "marvellous" but also explained its disadvantages to her particular situation, which influenced its use.

"It can push you up. I don't use it that way because I'm incontinent, and it's very slow. And by the time I get up, I've done it, you know [...] But I might have to, eventually, if I can't get up, you know. I've got to push myself up like that"

Based on experience, Participant 02 acquired an understanding of the adaptation, which led to learnt behaviour of its use, as well as consideration of future physical decline. In this case,

the adjustable chair cannot be used when needing the toilet as it is too slow. Instead, the individual learnt when to use and when not to use the equipment, but justified its benefits as being “better than going to care”.

The participant also used a trolley, which sat in front of her in the living room, and had led to changes in the way she used the space (Image 8).



Image 8: Using the trolley whilst eating

The trolley was the most captured piece of equipment on the wearable camera. The participant kept a plethora of items (as shown above) on the trolley, within reach of her armchair.

“Mainly I eat off it and keep my things handy on it”

Although behaviour changed with the acquirement of adaptations and equipment, there were instances where no equipment or adaptations were available, and the participant had to cope via other strategies.

“I have trouble making a meal [...] I’m just making things that are easy”

“The paving stones aren’t very good outside either. You’ve got to be careful. You know, when you’re walking”

In both cases, Participant 02 adapted her behaviour to manage her functioning, and her environment, in the best way possible without the assistance of equipment, adaptations or other help.

Case study two

Participant 05 was 85 years old and lived alone in a large terraced two-storey house. She had lived in the house since 1956, and had converted it into one home from two separate flats. Her daughter visited daily and acted as an informal carer. Participant 05 also had formal carers and home assistance. Participant 05 had falls in the past, including a fall in the shower. She was diagnosed with osteoporosis and chronic pain due to widespread arthritis, and had undergone a knee replacement.

Participant 05 described having a plethora of adaptations and equipment, all provided by the local authority. She had acquired a: stair lift, walk-in shower, internal and external grab rails, walker, perch stool, bannister, trolley, shower seat, raised bed, bed bars, reclining armchair, raised sofa, bath lift, grabber, equipment to ease putting on socks, walking stick, and a raised toilet seat. The wet room was most recently installed. Participant 05 wore the camera for 10 hours 11 minutes. A total of 1295 images were captured throughout the day.

Acquiring and installing adaptations

Access and installation were described throughout the interview. Triggers to acquiring the home adaptations and equipment were through recommendation from health professionals, or contacting a named person with whom they had previously had contact.

"You've been quite lucky that you've got certain people like... When you came out of hospital after your knee – and you got your walker... My mum was having problems with her hands, and they... Straightaway, the physio said, "Oh, I'll sort out..."

(P005's daughter)

"If my mum needed anything, it would be [Name] would be first port of call"

(P005's daughter)

The importance of people during the installation processes was also discussed, and this was clearly important for both the participant and her daughter.

"They've made a fabulous job. Absolutely. And the workmen were so nice"

(P005)

“And it makes a difference. Yeah, especially to elderly people”

(P005)

“Because I worry when people are coming in to the home for my mum. So, that’s why I always tend to... I like to be there. But once I get to know a workman, if they’ve been before, I think... I know they’ll be fine with my mum”

(P005’s daughter)

However, Participant 05 described one instance in which it was necessary to make her own adaptations. The living room chair was raised before Participant 05 received the reclining armchair. However, appearance became a factor in this process when the local authority only adapted one of the three matching chairs. Therefore, she utilised the skills of her son-in-law to make them “more uniform [...] rather than one being higher than the others”. Not only did this improve the appearance but Participant 05’s daughter also expressed the practical use of this as “it meant my mam can use... like other furniture as well” (Image 9).

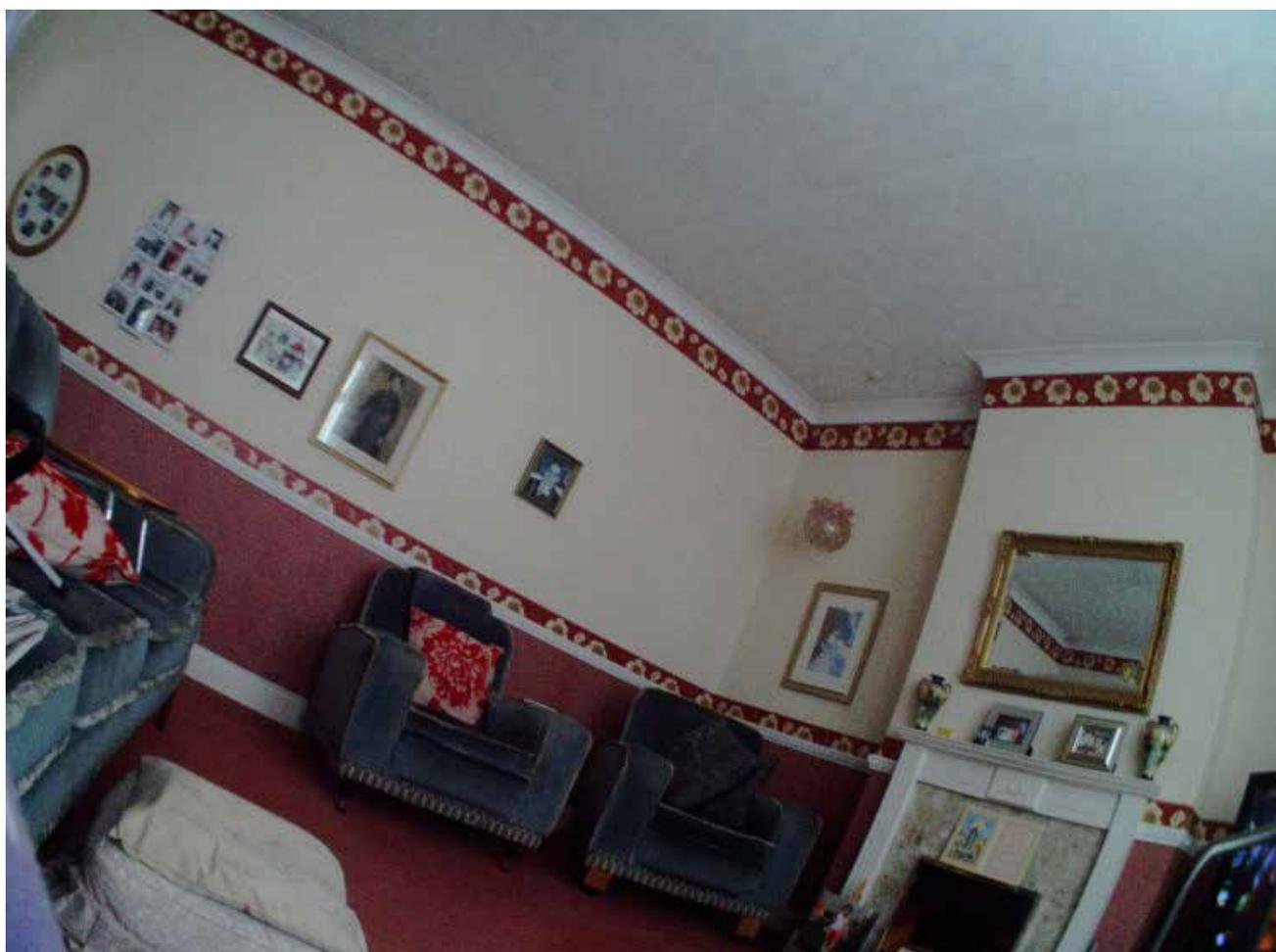


Image 9: Raised armchairs

It is possible to see one chair with black legs (the chair adapted by the local authority) and the chair in the corner has brown legs (the chair adapted by Participant 05’s son-in-law). The sofa in this image also had brown raised legs, and had been adapted by Participant 05’s son-in-law. The participant did not have any input into the adaptation, which meant that she

had to rely on the skills of her family to make the adaptation more appropriate for her own home, and for her use.

Physical functioning in and out of the home

It was evident that the adaptations and equipment had an impact on Participant 05's physical functioning, with the participant and her daughter describing the equipment and adaptations as making her feel "normal".

"You just don't feel as if you're not normal. I keep saying that – not normal"

The adaptations and equipment were viewed as a way of allowing her to function as she used to. A number of adaptations and equipment were used by the participant to assist her in moving around both inside and outside of her home. This included a trolley, as was seen in numerous images throughout the day. In addition to using the trolley as a table to eat from, Participant 05 also used it to carry items through from the kitchen to the living room.

"I can put things on it and take them through to the dining room"

The trolley had changed Participant 05's physical functioning. For example, her daughter described how her mother can now drink a cup of tea in the living room, rather than having to do so in the kitchen as she could not "carry it back through". Image 10 shows Participant 05 walking through her home with a meal on the trolley.



Image 10: Pushing a meal from the kitchen into the living room

Participant 05 also stressed the importance of having a large home as it allowed her to move around with these adaptations.

“Oh, I love my house. Because it doesn’t matter that it’s big, because I have... You know, people come and... And I just... I like my space. The space is good. Because you can get round with no bother”

Participant 05 had a good understanding of her home environment and her functioning in this environment. Participant 05 also had a reclining armchair that she used to enable her to transition from sitting to standing and she used this function every time she got up from the chair (Image 12). Participant 05’s daughter stressed the importance of this especially when Participant 05 was feeling at her “worst”.



Image 11: The reclining chair and surrounding equipment

Image 11 shows the reclining chair in the upright position. It is also possible to see the close proximity of items (including a grabber and tables) to the chair. Despite having all of these equipment to hand, Participant 05 stressed the importance of trying to do things independently in the first instance, and relied on the equipment and adaptations if this was not possible.

“Mind, I always try and do everything myself. [...] If I do drop something, I make sure I can...

You know how people say to you, "Oh, I'll help you." I say, "No, don't. Unless I can't do it." Because I think the longer you do it, you get your muscles going."

It was possible to see Participant 05 using the trolley both to carry things between rooms, and also as a table in front of her armchair (Image 12).



Image 12: Using the trolley as a table to eat breakfast

There were multiple images throughout the day showing the table being used for all meals eaten. Participant 05's functioning had also changed due to a stair lift which had been installed for 12 years. Image 13 shows Participant 05 using the stair lift (first person view of the bannister opposite).



Image 13: Using the stair lift

Before the stair lift was fitted, Participant 05 was “frightened of the stairs” (Participant 05’s daughter), and she was “going out of breath [...] going upstairs” (Participant 05), making the stair lift “a life saver” (Participant 05’s daughter).

“You know, that would stop you from going upstairs, if you didn’t have it. You know, because of the... How it makes you feel so tired trying to get up the stairs and... Yeah, for me it is anyway”

The walk-in shower was the most recently installed adaptation (Image 14).

“Oh, it was marvellous for me. Because I was getting... The step was too high on my own. I had a separate shower, as well as the bath. And this, now, I just... Just walk into it, and it’s absolutely... It’s very easy”

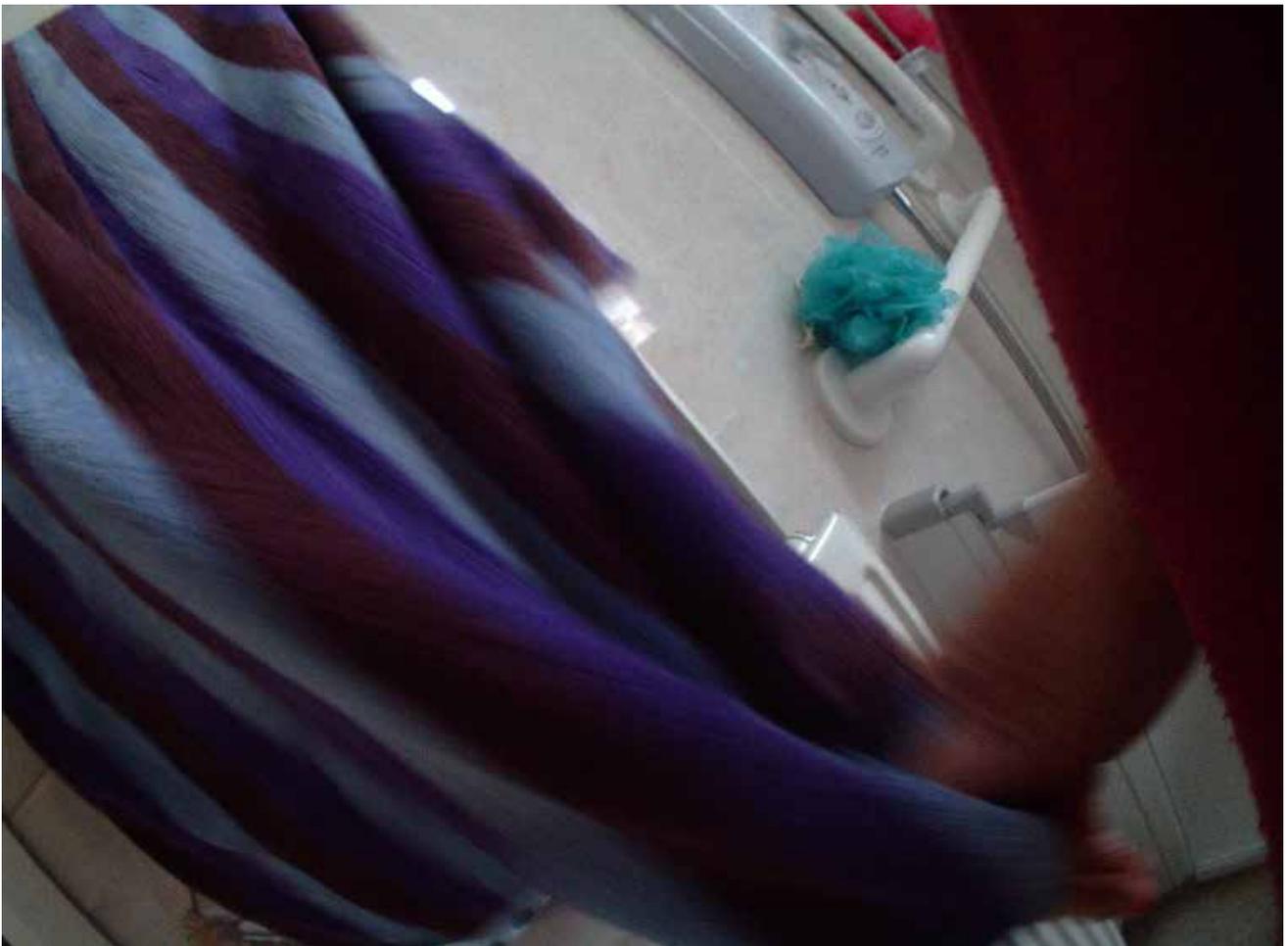


Image 14: Partial view of the walk-in shower with grab rail

Participant 05 described the walk-in shower being beneficial as it did not involve stepping up into the bath, and also had a seat in it, which allowed her to sit down whilst showering. As well as being functional, the appearance of the adaptation was also important.

“I’m quite new-fangled with it. And, you know, keep looking at it”

Benefits were not only evident for Participant 05, but also for Participant 05’s daughter, who stated:

“Because she used to say, “I’m managing.” But I used to worry sick because she did have a fall. Two or three... About three years ago, you had a fall. Luckily she had her alarm on. Well, you didn’t have it on, but you got it pressed”

“It’s given me peace of mind”

Participant 05 also had a raised toilet seat installed in her bathroom (Image 15).

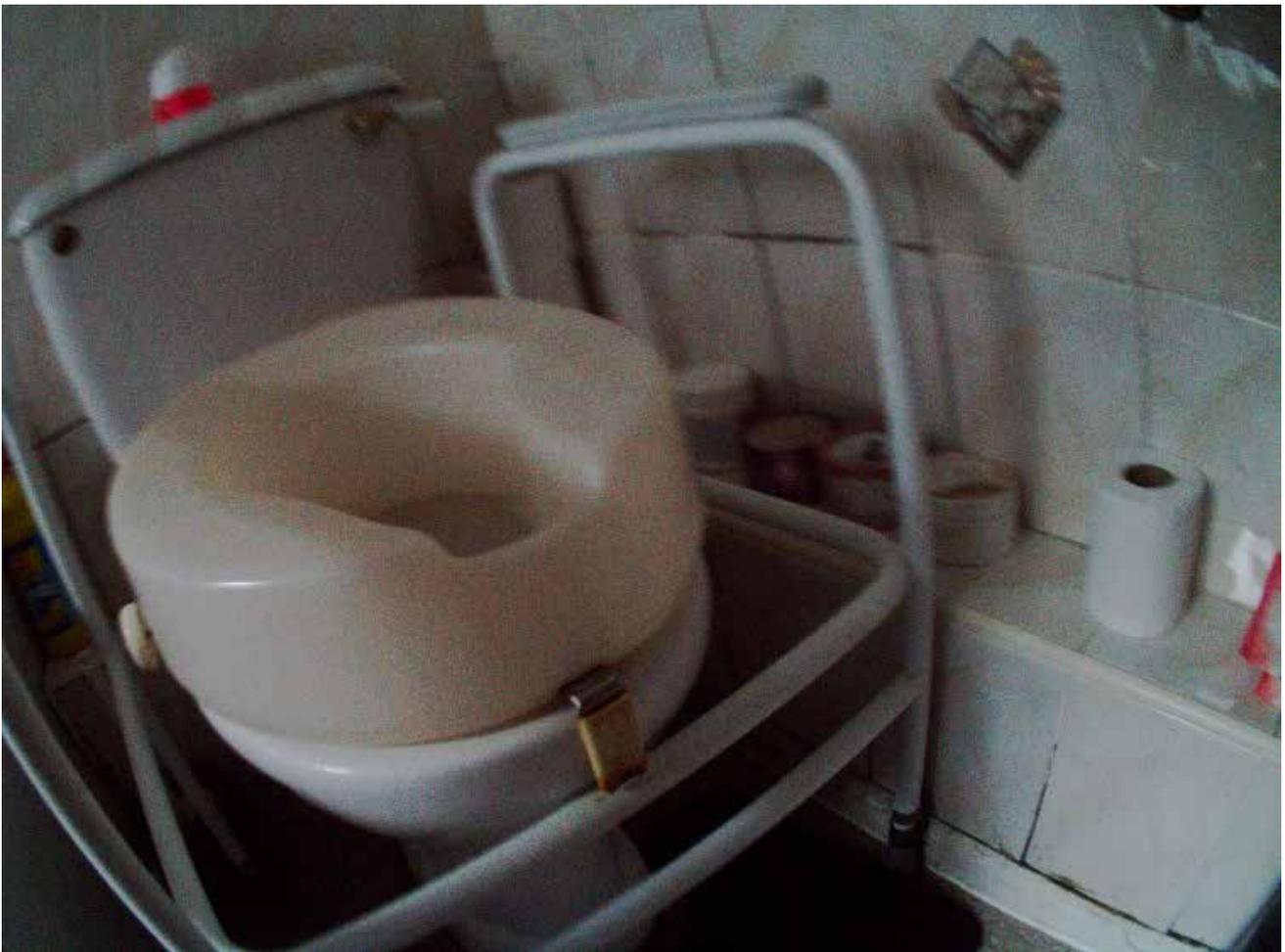


Image 15: Raised toilet seat

The participant discussed the discomfort of sitting on her toilet seat without the raised adaptation as the osteoporosis makes it feel as though “you’re crouched down like that, and all crunched in [...] so, it’s better to have a higher seat on your toilet”.

Participant 05 had both internal and external grab rails on her house.

“The grab rails are good as well. I mean, you’re going out of the property – I mean, you’ve got them there. And at the back as well”

However, Participant 05 found moving around outside her home problematic as she described the need to make multiple trips if sitting out in the yard, as the steps make it impossible for her to use a trolley to transport items, as she did inside of the home.

“But I’ve got to make a few journeys with that. As I go...”

One important aspect of the grab rail installation process, and adaptations more generally, was her own input into their installation.

“I think I’ve got my grab rails in the right place. I think everything has been done right.

Because... I've told them where to put them myself. Well, they ask you, if this alright and that. You know, so that you know what to do"

Being able to have input into her own adaptation meant that Participant 05 felt they were more useful for her own needs.

Adapting routine and changing behaviour

Participant 05 had previously adapted her behaviour before adaptations and equipment were installed. For example, before the shower was installed, and when Participant 05 had initially came home after a long stay from hospital, she used the trolley to wash as she could not manage to shower or bathe.

Alongside this, participant 05 also adapted her behaviour once equipment had been acquired, including sitting on a perch stool to prepare meals or carry out household chores in the kitchen (Image 16).



Image 16: Perch stool

Participant 05 specifically used this perch stool when she felt increasing pain in her back or legs.

"If my legs are... If my back... It's more when my back gets... I'll get the stool and sit on it. It's more uncomfortable, mind, trying to work that way. But it... But, yeah, you've got to put up with it, so... But it takes the pain away"

The importance of adapting behaviour was evident more generally throughout the interview, and Participant 05 discussed her "common sense" in working out strategies to maximise functioning.

"I think I'm good like that – working things out. But... I mean, these days, they don't use their common sense"

Participant 05 also described the way in which she adapted her behaviour to enter and exit the back of her home.

"I've got two steps for you to walk up here. There's two steps to go up into... [...] And I would... I went up the steps and turned round and came down the steps"

Images of the grab rails at the front entrance were not captured on the camera as the participant did not leave her home during use. However, image 17 shows the grab rail at the rear entrance.

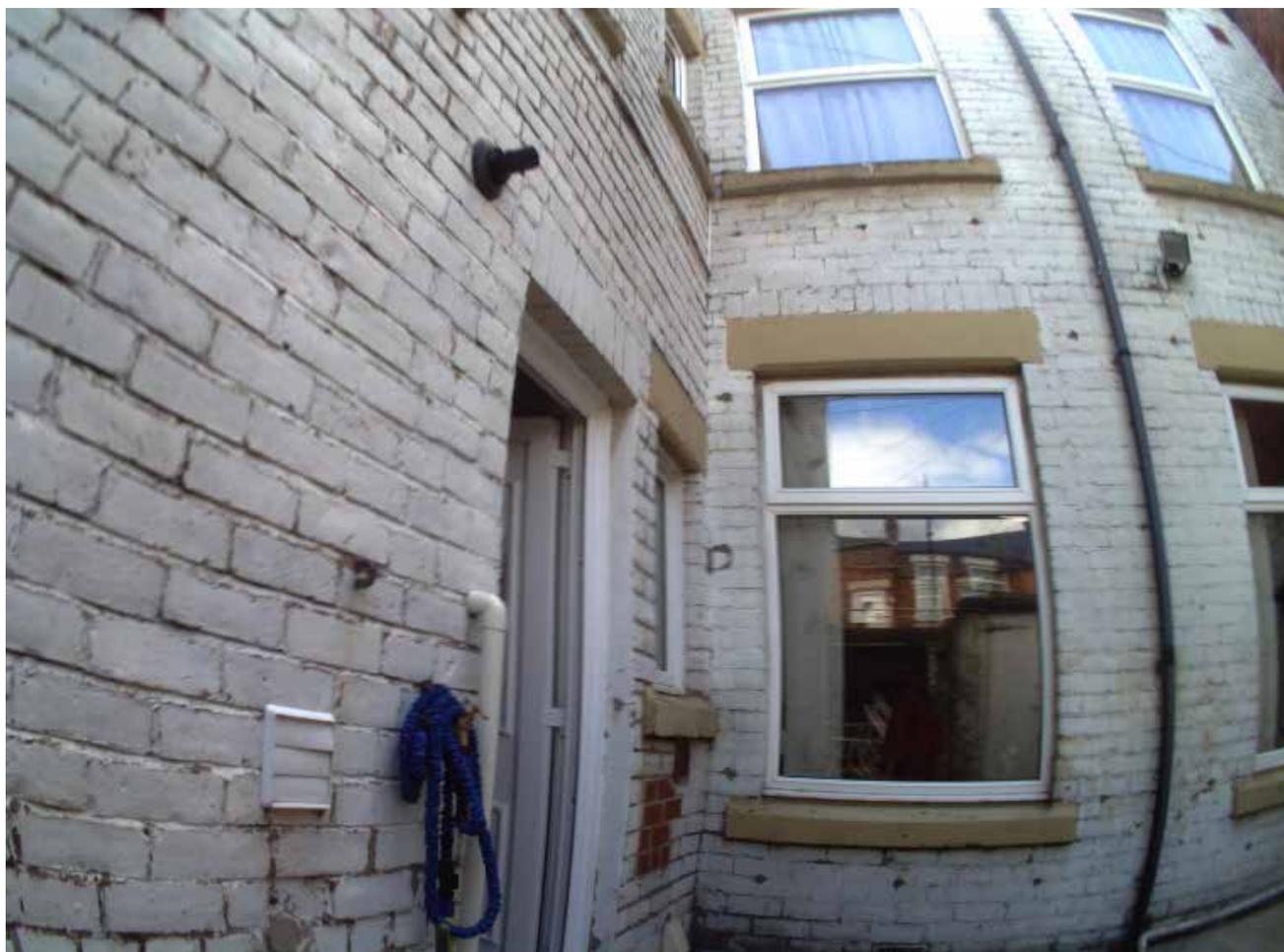


Image 17: Rear entrance grab rail

Participant 05 also described her adapted behaviour when leaving her home, and relied on the taxi driver to assist her when taking her walker with her.

“If I’ve got to go out, I have to use a taxi. So, it’ll cost me a lot more to go out. But I don’t mind, because I think, well, I would rather get out and use that money on that”

The need to take her walker with her meant that she needed to rely on others.

Findings 3: People with lived experiences overview

Contexts and capabilities

This section presents findings relating to the contexts of housing adaptations identified by participants. It is organised into three subsections: personal contexts, resources and service contexts.

As highlighted above, when discussing their lived experiences of home adaptations, participants outlined the importance of a range of factors, which appeared to have no direct connection to the intervention but still helped to define and inform the process and outcomes. These factors, discussed here as contexts and capabilities, were each very specific to the particular characteristics of the participants, but highlighted the importance of the diverse backgrounds and experiences which they brought. They included, but were not limited to, elements of the participants' personalities and aspirations, the knowledge and resources available to them, and how these factors sat within the services and options available, each of which (or in combination) held the power to influence, define and inform the importance of adaptations to the individual. Thus, although it is difficult to summarise the huge range of potentially unrelated and specific contexts and backgrounds of each participant, it is important to acknowledge the important role each can play. As such, although the diversity of issues makes it difficult to imply a generalisability to the contexts outlined, the importance of contexts in general formed a key part of the participant data.

Personal contexts

Individual norms and values

The participants included within the sample offered a diverse range of life experiences and backgrounds within which their need for a housing adaptation sat, only some of which can be summarised here. Although many of these related to the services they would receive, such as a desire for independence, or the difficulty in dealing with a lack of confidence moving around the home, others were expressed as general norms and values about life in general. However, what was important to participants was that the adaptations themselves,

alongside their perceived need and outcomes, and the processes required to access them, underpinned their own desires to continue to live a normal life in their own homes. As such, although participants recounted a wide range of views and backgrounds, from those with experience in architecture or a history of rewiring their own property to those unexpectedly forced to think about adaptations for the first time following a fall, each felt the adaptation should return them to their own individual normal state and allow them to continue to live as they wanted. While this norm obviously varied greatly from person to person, and household to household, these individual personal contexts were the most crucial factors in how the adaptation and the process of accessing it were experienced.

“So, one of the things that Cilla Black said, just to her son, just the day before she died was she’d been to the doctor’s in England and she’d gone home. And she said, “Oh, there’s a bit more of me falling off, and he’s glued it back on, love.” And that’s the way it is, isn’t it?”

(Participant 19a)

“And you’re used to doing things for yourself. You’re not used to getting benefits. You’re not used to getting anything from other... So I never bothered applying. I’m not hard up, and neither am I rich. But I’ve got enough to get by.”

(Participant 24)

As such, each individual brought a great deal of complexity to their journey, including varying levels of confidence, knowledge, resource, desire to be independent, and so on. Yet, these were often recounted by casual and taken-for-granted language by the participants, suggesting how firmly entrenched these views were. The situations they faced, and how they responded to them, were “what they were used to”, “just the way it is” and “normal”. This further suggests their importance to people and the need for services and adaptations that are both tailored to meet these diverse needs and deliver outcomes that address them.

Individual personal contexts were also of great significance in relation to adaptations as they played an important role in how ageing was perceived and prepared for by participants. In keeping with the above, this included a wide range of responses, including those who passively accepted the reactive need for change as part of the ageing process to those who were actively thinking about and preparing for change. There were those who were considered “too proud to ask” for help or afraid to appear old, to those who saw forward planning as a routine and accepted aspect of life. Once again, these diverse and contradictory views were seen as accepted norms by participants, further highlighting the importance of acknowledging the influence of such diversity in the data.

“I wouldn’t have dreamed of having anything like that, you know. What? That’s for old people, that.”

(Participant 04)

“And I just said, well, I’m getting older, I’m not getting younger, it’s time I did something about it. And that’s all.”

(Participant 15)

Changing health status

A possible reason for the importance of individual norms and values in relation to housing adaptations and older people is the role played by changing health status in this population. All participants expressed that they were experiencing health conditions that were having an impact on their daily living in the home, thus creating a perceived tension between their previous experiences and needs and their environment. Not only was this creating difficulties in the immediate future, there was also the perception that problems would continue to deteriorate. However, once again, there was evidence of a diverse range of health problems included in the participant group, and their carers and family members, each of which created their own individual challenges and issues.

“Well, I’ve got severe osteoarthritis, and I didn’t... When I... When I broke my hip, they gave me a bench to put over the bath, and I was fine with that. And then my husband got cancer, and they gave him a bath seat. And they took my bench away, and I couldn’t use the bath seat. And I was struggling to get in to the bath. And then I got sciatica and I could just hardly get in.”

(Participant 13)

“When she first moved in, she used to go upstairs to go to sleep. And have a bath upstairs. And in the last year or so she had another pneumonia attack, and she’s... Her health has deteriorated. So, now she just stays downstairs and uses the downstairs bathroom.”

(Participant 18a)

While these individual changes in health status had an impact on participants in themselves, it was also noticeable that they were often described in terms of how they affected the normal use of the home environment. Functional details, such as the use of certain spaces or facilities in the home, were often described to illustrate the issues such changes in health status created and the individual strategies needed to overcome them.

“And just turning on taps, I couldn’t grip things, you know. So, now I’ve got the easy taps that just turn. And I had a shower over the bath, which was alright when I was fit enough to climb into the bath. But... I just found it was getting more difficult. I was getting unsteady on... I was getting dizzy spells.”

(Participant 10)

"But, as I say, I'm a lot more careful than I used to be. It's... So, I don't go out in the back garden, because I used to fall down. I used to do... I still do my own laundry, sort of style. But... And I used to always like to get it out on the washing line. But I fell down too often, and put too many... Too many holes in different parts of my body."

(Participant 28)

Perceptions and planning

Personal contexts which had an impact on the approach to the housing adaptation also included the participants' perceptions of their home and the importance they placed on forward planning. A number of participants acknowledged that their home itself may not be the most appropriate environment for their current situation, but felt that the importance of remaining in a comfortable, familiar environment which held memories and emotional attachment outweighed this. Relationships with neighbours, local facilities, and proximity of transport links were also key factors to remaining at home. As such, these priorities also impacted on the need for adaptations and the roles they played in people's lives.

"My son agrees. He said, "No, Dad, you've got to feel comfortable. Wherever you go, you have to feel comfortable. If you're not comfortable, it'll come back to haunt you."

(Participant 24)

"I've got good neighbours. And it's handy for the shops."

(Participant 29)

These perceptions of home were also placed into opposition with perceptions of housing alternatives. Although a limited number of participants had recently re-located to improve the accessibility of their homes, the majority were located in family homes in which they had lived for several years. Supported housing, or care homes, were often discussed in negative terms.

"When you see these old people's homes, and their whole... Chairs around a television set. Oh, God spare me that. Really, I think that's... That must be the end, when you're reduced to that kind of thing."

(Participant 23)

However, although participants often discussed a desire to remain at home, there was little evidence of a consistent approach to forward planning to maintain this in the future. As stated above, there were some participants who engaged with planning for the future, with some electing to access housing adaptations as preventative measures before their health status changes. Meanwhile, others were often more passive recipients, and only accessed changes when they were raised and offered by services.

"It hadn't become a problem yet, but I could see in my mind that once the knee operation had been done it would be difficult."

(Participant 08)

"A couple of times this... A fella from the council - I can't remember his name either. He checked it all out, just, and he just said, "Have you got any...? Any problems with it?" And I said no. But he then said, "Do you want a hand rail put in?" Because there wasn't a one where the shower was put in. So they came back and put a hand rail on the wall, yeah."

(Participant 21)

Coping strategies

The tension between the individual desire to stay at home, maintain a norm there, and changing health status, also created a range of coping strategies, such as holding on to doorframes or avoiding using stairs. These approaches, which illustrate both the resourcefulness and knowledge of the environment held by people, also created a number of specific contexts, which influenced the use of adaptations. The majority of strategies described were behavioural, as they allowed individuals to cope with changes in health, and maintain control over their home. However, as these approaches were often seen as temporary, unsafe, and having an impact on quality of life, they could only act to delay the use of housing adaptations or to plan for the future. Thus, the ability to develop behavioural coping strategies, and the perception of their safety and value, acted as another context, which influenced the participants.

"Once a day, yeah. I get up in the morning and I come downstairs - I'm downstairs for the rest of the day and then I go up to bed. And that's it. And it's like I do whatever I need to do upstairs, at the one time, when I'm actually there. So... I limit my... To once a day, and that's it."

(Participant 04)

"Normally speaking, I... When I come in and out of the house, it's... I normally hang on to the window frame. Well, the windowsill and the door handle. Just to help me into the house, you know."

(Participant 28)

Despite this, not all coping strategies involved changes to behaviour in the home. Others involved larger-scale changes, such as increasing the role of the family, use of Power of Attorney and relocation. Once again, however, these were also dependent on the context of the individual and the range of resources available to them.

"I mean, as the lad said, you've got a choice - she either lives upstairs, downstairs or you try and get a bungalow."

(Participant 03a)

"As I say, he had Power of Attorney over me. So I could leave all the financial side of it. I can leave it up to [Family member]. And I trust... I trust all the family. No complaints about that, you know."

(Participant 28)

Resources

Equipment

It was clear from participants that the assistance they had received in supporting the continued use of their home was not limited to structurally-affixed modifications. The receipt of various pieces of equipment was a major component of the background context to the acquisition and use of home adaptations. The equipment discussed included wheelchairs, walking sticks, walking frames, bath boards, shower and bath seats, perching stools, speaking clocks, commodes, toilet seat raisers, toilet frames, item 'grabbers', dining trolleys, remote assistance pendants and mobility scooters, amongst others. When well-suited to both individuals' needs and their home environment, these items increased the participants' ability to maintain their normal status in the home.

And they, for example, have prescribed for me, that trolley. And I push that around because that enables me to get across from, say, the hatch there or the table to the medicine drawer down there. It's not far to go, but in fact actually I find that walking in a void [is] much more difficult.

(Participant 07)

...we were provided with walking frames...and some other hand-held things to get into the downstairs loo. So, we had a whole series of things that were done as part of that. But that weren't to do with the fabric of the house...We had three Zimmer frames on each level in the house.

(Participant 09)

Some participants found that equipment and adaptations could facilitate each other's use, potentially multiplying their impact. The opposite experience was also reported by some participants. For example, one lady was unable to leave her home without assistance because whilst the walker she had received was able to assist her in moving around the home, she was unable to take it down her front steps to use it externally.

Home

Participants discussed various aspects of their homes in relation to ageing and the choices that they had made, or were planning to make, to maintain their quality of life, such as adaptations. This included the size of rooms, potential trip hazards and the overall atmosphere or homeliness.

"And we never thought about how small the room was going to be. So we're looking to get rid of this. And that's...going as well. So, we can have a bit more room. Because it's just a bit crowded in here, I think."

(Participant 21)

"I've looked at other options to move from here. The sort of...not care homes, but sheltered housing systems. But really there's a tremendous loss of quality of life in that respect...the amount of space you've got around you, the things you can take with you. The general atmosphere. So, one is reluctant to give up one's independence and the sort of quality of life that this house represents."

(Participant 07)

Whilst the number of participants privately renting their homes in the sample was small, it was also clear that tenure, and the level of control this affords over one's home, also made an important contribution to individuals' opportunities to age in an appropriate environment. "The landlord is supposed to be doing the outside and everything else, but...over the years, he's been most reluctant to do that."

(Participant 23)

Family

Family members and their involvement and support was a key theme throughout the interviews. While this included the potential for and limitations of caring support, the influence of family was much more complex than this and included factors such as their own worries and experiences caring for other family members in the past.

"[My granddaughter] was worried about the stairs. Apart from that, she knew that she could help me. She will give me all my injections. She told the district nurse not to bother coming in. Just give her the needles – she'll give me them..."

(Participant 26)

"Because I was used to falling over and throwing myself about, you know, I was okay with it. And I just knew how to go down. But... other people would express terrible anxiety for it"

(Participant 19)

Participants also identified family members as a major source of knowledge and advice on how to overcome their housing challenges. This included a son with experience in architecture helping to plan for his relative to live exclusively downstairs, and another son with experience of working with disabled people helping to apply for the installation of a wet room.

"I had to get rid of a lot of furniture, obviously, going in to a one-bedroom place. But fortunately I just rented that for a year. It was up for sale, but my son-in-law advised me not to buy it. Because he's in that trade. And he said once you buy them you have a job getting rid of them. Which I found out afterwards, you know. So I was glad I just rented it for a year, instead of going in for buying it."

(Participant 10)

Knowledge

There was wide variance in the knowledge and understanding of adaptations and services amongst participants (discussed in more detail within the Access section). However, there was also evidence of participants using their own social links and previous experience of housing and architecture to plan for and consider adaptations. One participant in particular possessed considerable knowledge of adaptations from their professional life.

"I was always an architect. I always dealt with housing. So, again, that gives one a background of technical knowledge about how you cope with disability...I've seen situations...30-odd years ago, 40 years ago...You could get sink units that went up and down and these things."

(Participant 07)

This participant discussed how they completed considerable research before completing adaptations to their home and also suggested that their professional experience meant they were, "far more intensely concerned with the visual appearance than the average householder might be" (Participant 07). However, the reverse was true in that there were also a number of participants who had little knowledge of housing and were therefore unprepared when considering housing adaptations.

Finances

Another key resource for people considering adaptations are their finances. Again, these varied among the sample. Some were very conscious of the potential costs of acquiring products and using services, with one commenting, for example, "But you've got to pay for everything, though, haven't you?" (Participant 29). Other participants expressed their ability and willingness to make financial outlays in order to improve their housing environments.

“Don’t get me wrong, I don’t mind paying for things...I never begrudge spending money on the equipment that helped [my wife]. I don’t mind spending it on me myself. I mean, if my eyesight was better...I would get myself one of those little scooters.”

(Participant 28)

Some participants reflected on how not everyone has access to such options, commenting “It depends on how much money people have, whether they can afford to have it done” and “It’s just being able to do things to make one’s life easier. Which I’m aware I’m very fortunate in being able to do that...and having...the resources”

(Participant 12)

Services

Awareness of services

Some participants had greater awareness of the services and contractors available than others, again creating the possibility that this contextual factor could have an influence over their housing adaptations journey.

“I would get in touch with Age UK, just to see about how to go about it. And I would certainly make inquiries first of all to see whether anything could be done to help me, financially.”

(Participant 04)

“I think the recommendation is to try, somehow, to find out who’s a good contractor. And, in the case of the bathroom, we did it by finding out who the local services would have employed. And using my contacts about the garage.”

(Participant 09)

Another participant said that their doctor would be a good contact for accessing community services. Other participants were initially unaware of whom to contact and what services were available, some even after adaptations had been installed. One participant argued that the government should be doing more to raise awareness, “maybe printing some sort of a booklet or something that would give people this help...because there must be an awful lot of people who don’t know about it.”

(Participant 04).

Previous use of services

Some participants had acquired knowledge of the services available through direct and indirect experience. One commented on how they had not used the local authority services previously so decided to purchase the adaptations themselves, while other people were inexperienced because they were reluctant to have to rely on others, even suggesting there was a stigma attached to “phoning the social”.

“I’ve never asked for help...my husband never worked for, God, I don’t know how many years. So I had my two girls and I worked full time. So, I was always independent. I didn’t want to ask for things...If I could manage, I managed. So... it was a big step - phoning the social to say that I needed help. But it’s something that I don’t regret.”

(Participant 10)

Other participants had friends or family members who had received adaptations or other services which provided them with an understanding of what organisations offered.

Section summary

This section has highlighted the broad range of contexts and capabilities that influenced the participants’ housing adaptations journey. Although these contexts varied a great deal, were highly personalised, and reliant on a hugely varied availability of knowledge, information and resources, it is still crucial to note that this complexity in itself was of great significance. This is because these varying factors, ranging from personal beliefs to the provision of local services, were a constant influence on the perceived need for the service in the first instance, the process of accessing and receiving it, and the value placed on its outcomes. Thus, while there is clear importance within each service or adaptation received, how this sits within the context and capabilities of the individual is a crucial factor in the overall journey. As such, the lived experience of each adaptation was crucially particular to the individual participant, their expectations and the home environment within which it would sit.

Triggers and tipping points

This section presents the findings relating to triggers and tipping points, or influencing factors on choosing to obtain a housing adaptation, identified by participants. It is organised into two subsections: personal triggers and external triggers.

Personal triggers

When discussing their decision-making processes and influencing factors which led to them obtaining housing adaptations, participants identified a number of personal or psychological drivers. Rooted in the personal contexts discussed previously, these were often used to highlight a growing tension between changes in, and attitudes towards, health status and the support provided by their housing environment. In some instances, this resulted from a specific event (or trigger) such as a specific health event or fall, while in others it came from a gradual acceptance (or tipping point) that change was likely to be required and current strategies were insufficient.

Declining health status

All participants discussed their understanding that a current or potential decline in their health status was a key driver for the need for a housing adaptation. The changes identified related to a wide range of specific health events or conditions, such as stroke, knee or hip replacements, loss of sight and pneumonia, and were potentially spread across multiple household members. These were often identified as having relevance for housing adaptations as they were described as limiting issues of mobility, which could subsequently be addressed via interventions such as handrails or stair lifts. They also had the impact of both highlighting immediate difficulties in using the home environment or carrying out daily activities and creating an awareness of future decline.

“When I broke my hip, they gave me a bench to put over the bath, and I was fine with that. And then my husband got cancer, and they gave him a bath seat. And they took my bench away, and I couldn’t use the bath seat. And I was struggling to get in to the bath. And then I got sciatica and I could just hardly get in.”

(Participant 13)

Although participants highlighted a number of individual health concerns, one recurring theme which acted as a trigger for the use of housing adaptations was experiencing a fall, or considering yourself to be at risk of falling. Participants spoke of coping with or managing health concerns, such as dizziness or limited mobility, but the threat of one or multiple falls in the future was seen as requiring action, as it had a particular negative impact on confidence.

"I fell a few times outside. Just to... Your legs just give way, or you have a dizzy spell and they give way. And that's... That's when I decided I needed more help with things."

(Participant 10)

However, for other participants these triggers were not derived from specific events or conditions, but a general sense that, with age, change was inevitable. Thus, it did not always require a fall or major change in health status to create a trigger for the decision to use a housing adaptation. Instead, the use of evolving coping strategies (such as counting steps) led to a gradual understanding that further and more fixed changes were required in the future. This slow accumulation of evidence and understanding produced a "tipping point" in the decision-making process which was unconnected to an urgent or specific change.

"There was not a, sort of, sudden disaster. But there certainly is a tipping point. One of the first things was in fact the hand rail at the steps at the front door. There are five steps there - with quite a steep rise. And that, again, enabled my wife to identify where she was and give some security, because she couldn't see. But, as time went on, it became important to actually life one up."

(Participant 07)

The impact of declining health status was most often described in terms of providing limitations on the use of the home and its spaces, rather than as a source of pain or discomfort. For example, changes in mobility were seen by participants as a source of anxiety during bathing, limiting the use of spaces by making it difficult to climb the stairs, likely to reduce personal hygiene and creating barriers in terms of being able to leave the house. Thus, the activities of daily living became "an absolute struggle" (Participant 15), which a housing adaptation could potentially overcome.

"I was getting really, really depressed. Especially when I couldn't come downstairs. And then, when I was stuck in that bedroom by myself all the time, because they're at work and that... And my little granddaughter, the nine-year old, said... I mean, I'd been there six weeks, I think. And she said, "Are you still going to be here at Christmas, nanna." She said, "Because we can put the Christmas tree in front of the telly and put my toys under there, you know." And I'm thinking, eh, I don't want to be here that long. But it was... It was driving me crazy."

(Participant 26)

Psychological factors

While health status was seen by participants as a key trigger in terms of restoring functioning, psychological factors such as independence, confidence, embarrassment, attachment to the home and future planning all played a significant role in underpinning the decision. Although participants described clear causal links between changes in their health, limitations of their use of home and the need for adaptations to address this, they also identified mental health benefits as core drivers for their motivation.

Several participants discussed a need to maintain, or regain, independence as critical to their desire to access home adaptations. While independence was identified throughout the data as a key goal to participants in general, it is noticeable that the challenges they were facing were perceived as a direct challenge to this. An adaptation, therefore, had the potential to help participants keep being their "own boss" (Participant 02) and not lose an activity "when you've always done it all your life"

(Participant 10)

"I like to run my own life. And these [adaptations] are things that make it comfortable for me."

(Participant 12)

Adaptations were also seen as having the potential to restore confidence following changes in health and functioning status. Activities which had previously been considered a normal or taken-for-granted part of daily living in the home, such as using the shower or stepping down from the front step, were now felt to be more challenging. Although participants may have been able to cope using temporary strategies, such as holding onto doors to maintain balance or carrying a mobile telephone to call for help if you fall getting out of the bath, these could be challenging. As a result, an adaptation was required to restore the longer-term confidence that could be lost, for example, following a fall or a dizzy spell.

"Because of the step. That's the difficult part. Going down or up. And it's mainly lack of confidence, because of having a fall, you see. And having a dodgy hip."

(Participant 30)

Participants also reported feeling embarrassed when having to rely on family members and carers for help. Being seen as demanding and taking advantage of others was not viewed as a satisfactory solution, while also being unable to maintain individual privacy (for example by being able to access your own post before your partner) was also seen as having a negative impact on life.

"It's a bit embarrassing because you're having to phone my granddaughter to say, "[Granddaughter], I need to go in the shower." You know. Because sometimes the tablets... These tablets that I'm on now, this morphine – I've been on them for a while now – and they're killing me with sweating all the time. [...] But, yeah, she's got two little kiddies herself. She's got one four, and one ten. Little girls. And she works night shift, full-time. And she's still helping look after me, and looking after granddad."

(Participant 26)

However, as discussed previously, despite facing many challenges within their housing environment, the vast majority of participants highlighted their desire to stay in their own homes and rejected opportunities to relocate to supported housing or downsize to a smaller property. They also described their strong emotional attachments to the houses they had lived and raised families in for many years, and the trust they felt for their existing support systems. Thus, while the home environment may act as trigger in one sense, it would have to remain a part of the solution for most participants.

"I've just got memories here, and I don't want to go. I may have to, eventually, because as I say, I'm finding it bad with the stairs and everything. But, up to now, I want to stay."

(Participant 13)

One participant even acknowledged the unsuitability of their own home, but felt the challenges of relocating, such as overseeing a sale and organising personal belongings, would actually be greater than overcoming the daily difficulties they faced. Thus, the necessity of using adaptations to maintain their place in their own home remained the preferred option.

Although the majority of triggers to housing adaptations discussed by participants were reactive, there were limited examples of individuals who made decisions in order to proactively plan for the future. These examples included those who had a good existing understanding of housing and knowledge of potential health challenges they were facing the future.

"And, you know, I quite quickly realised after my husband died that I was going to have to do something about it [the house]. And really, you know, it was a... There was no query about it, and it was an obvious thing to do."

(Participant 12)

However, examples of housing adaptations being considered proactively were limited within

the data. In most cases, psychological drivers for triggers to act were developed as a result of negative experiences or perceptions of temporary support strategies.

External triggers

Aside from the physical and psychological challenges participants were experiencing, several external factors also influenced the decision-making process in relation to housing adaptations. The most significant of these is the importance of family and carers, both as a source of information and advice and in response to the demands of caring. There was also limited evidence of the role played by healthcare and council services in influencing the process, although it was noticeable that this was rarely cited as a source of influence and often required the use of an additional gatekeeper or word of mouth.

Friends and family

Friends and family members were the main source of external information, which influenced participants to access housing adaptations. This was primarily as a source of trusted advice which provided both a valued reflection on functional status and future risk and a route to accessing services, for example by ringing a local council on the participant's behalf. In several cases, as discussed in the context section, this was influenced by the family member's existing knowledge of housing adaptations, such as having previously worked as an Occupational Therapist or architect, or having been employed in disability services and thus having good knowledge of local housing support links. However, even those without prior experience were still a strong influence, as they provided detailed knowledge of both the participant and their home, and were also valued as having the participant's best interests as a key focus.

"Then, I was finding it more difficult because I've got arthritis in the spine. So, I... My daughter and that. You know, they said, "You can't go on like this." And I said, "Well, I'll apply, but if I can't, I'll have to do something."

(Participant 10)

While in the majority of cases participants welcomed the influence of family members, there were also instances where this reflected a greater shift in control. This included situations in which family members made decisions on behalf of the participant, for example one "pushy daughter" (Participant 22) who accessed housing adaptation services for her mother without consulting her in advance. Although these changes were both tolerated and valued by participants due to the close relationships they had with their family, it was noticeable that they were not rooted in the same functional or psychological need that was found elsewhere.

“Well, as I say, my son advised me, and I just went along with it.”

(Participant 13)

However, it was not only as a source of information that family members and carers played a role in influencing the decision to obtain a housing adaptation. The perceived burden that participants felt was being placed on individuals with a caring responsibility also led to a trigger or tipping point in some instances. This often took the form of worrying that adding to existing time pressures, particularly for family members who had competing demands from work and / or children, was creating unnecessary and unfair stresses. Also, those who were reliant on partners, who were often experiencing their own health problems, for the majority of their care were also influenced by their understanding of the potential negative physical impacts of a demanding caring role.

“Because sometimes she looks that tired, you know. So, she’s getting out of bed, earlier. Sleep... Working all night. And then getting up at, like, dinner time to come to see to me. So... And then she had to go back to collect the bairns from school and that. And then come back again. It didn’t seem right. And if I wasn’t well through the night, she wouldn’t care. She texted me... Texted me, “I’ll come along.” But I used to feel embarrassed about getting her up and that, you know. It’s not nice.”

(Participant 26)

Healthcare services, housing services and word of mouth

While information and influence provided by family and friends were referenced frequently in the data as playing a role in triggers and tipping points for obtaining housing adaptations, it was noticeable that external services, including healthcare and housing, played a limited role at this stage. Thus, while decision-making processes were formed in a variety of ways, it was largely at the point of access at which services became involved (as discussed in the following section on access).

Healthcare services did, however, impact decision-making for participants whose health trigger event had involved a hospital stay and a follow-up visit. In these instances, contact with and assessment by healthcare staff, such as Occupational Therapists, was a key determinant of both the types of adaptations used and the value placed on them by participants.

“Yeah, from the hospital. I forgot her name. But she came with... Down, when I came out of the hospital. She said, “I’ll pay you a visit.” She came down with some exercises to do. And she said, “Right, you want...” And she made a list. They made the list - the hospital made the list for things that are needed, you know. And... Then she came and, “Right, you’ll be getting somebody coming to sort them out” you know.”

(Participant 25)

However, although some participants reported Occupational Therapist assessments being carried out by housing services following relocation, the majority of participants remained in their own homes and only accessed housing services after they had decided an adaptation was required. Those who did access council services tended to do so retrospectively.

A final influence was the importance of word of mouth, particularly in relation to having friends or family members who had had previous experience of adaptations. Knowing people who have had an adaptation, or being able to discuss informally the benefits and processes, allowed many people to make their final decisions.

“Well, my friends told me to as well. And also about a wet room as well. A lot of my friends told me to do that as well.”

(Participant 11)

Thus, while there was some evidence of contact with healthcare and housing services at this stage, the main external influences on the decision to access housing adaptations came from family members, both as a source of information and support, and as a driver to reduce dependence and demand on carers.

Section summary

This section has highlighted the influences on participants’ decision-making processes when considering accessing a housing adaptation. It has identified two major pathways, as being via a specific trigger (e.g. a health event such as a fall) or tipping point (e.g. a general understanding that existing strategies are likely to become unmanageable in the future). In each pathway, personal and external factors play a key role in influencing the decision. The former is made up of the participants’ understanding of their changing health status and its influence on the appropriateness on their home environment, particularly in limiting the ability to carry out daily activities, and is underpinned by psychological factors such as the need to maintain independence, use the home with confidence and live well at home both now and in the future. The latter is primarily made up of family influences, as a source of information, acting as an advocate resource and wanting to reduce the burden on carers. It is noticeable that there is limited evidence that information on or awareness of available services as playing a role at this stage (this will be discussed in the following section in more detail). Instead, the physical, psychological and external factors experienced by participants are negotiated by each individual and act as the key triggers and tipping points which influence their decision to obtain housing adaptations.

Access

This section presents the findings relating to the access of housing adaptations identified by participants. It is organised into two subsections: barriers and facilitators.

Participants identified a range of experiences in accessing housing adaptations, both positive and negative. These had a significant impact on the participants, as positive experiences both enabled the ease with which adaptations were accessed, and reinforced the possibility of using similar services in the future. Similarly, negative experiences held the potential to create barriers to accessing effective and appropriate support in the future. Thus, these experiences not only highlight good practice in the area, but also help to identify any potential gaps which represent opportunities in the future to allow people to access housing adaptations in effective, timely and empowering ways.

Barriers to access

As discussed in the previous section, there was limited evidence of knowledge of services or access as having an impact on the decision-making processes of the participants. As such, it was unsurprising that a range of barriers to accessing housing adaptations were identified by participants. These included limited knowledge of services and processes, logistical issues such as time and inconvenience, perceptions of cost, appearance of the adaptation and stigma of ageing, and tenure. Each of these issues held negative impacts for the experience and effectiveness of the adaptation discussed by clients, the likelihood for accessing adaptations in the future and the overall effectiveness and value placed on the adaptation by the clients themselves. Thus, each barrier to access represented a key issue to be addressed by services in the future, both at the stage of accessing services and increasing awareness and knowledge at other stages of the process.

Awareness of local authority services and processes

A number of participants were unaware of what adaptations were available for what purpose, from which service and at what cost, when they decided to access them. The number of participants who reported not being aware of what was available when they began the process of sourcing them from the local authority, and the number who remained unsure about where completed adaptations had been provided, evidenced this. In several instances, this was not only a barrier in the sense of delaying the decision while options were researched, but also created a sense of frustration that information was not readily available in an accessible format. Several participants felt that they had been

expected to negotiate processes by themselves as “nobody tells you anything” (Participant 25). There was also evidence of participants taking inefficient approaches, such as paying for adaptations themselves because they did not know they were available from the local authority.

“I’ll be honest, everything that I’ve got - like, these bits and pieces that I’ve got here - it’s only what I’ve found out myself. But nobody like you came to the door and said, well, you’re entitled to this, and you’re entitled to that.”

(Participant 15)

Several participants even reported that they felt they had only been able to access adaptations through chance encounters with other services, rather than via adaptation services. For example, one participant described that she had only been made aware of the potential uses of adaptations, and her eligibility for them, after a conversation with a professional while attending an appointment with a family member for whom she cared. On reflection, she described this as “rather strange” (Participant 16) as, without it, there was a possibility she would have been continuing to struggle to cope on her own without adaptations. Similarly, other participants reported only being aware of the possibility of accessing such services when meeting with professionals about other health issues, suggesting both low levels of awareness of housing adaptations and the potential for a reactive use, which did not meet their needs in a timely fashion.

“As I say, word of mouth. I mean, it was her.. If she hadn’t have come down to see how I was doing and bring me some exercises down, I wouldn’t have known anything.”

(Participant 25)

There was also evidence of confusion and low levels of awareness when services were being utilised. Some participants discussed a lack of clarity or transparency surrounding eligibility criteria, processes and applications. This was particularly apparent in instances where applications for adaptations were refused, only to be accepted in the future, or where inconsistent messages were received. Again, this lack of awareness held the potential to reinforce barriers in access through not only delaying installation but also making participants unsure of how to access services in the future.

“She [Occupational Therapist] said to him, “You need a rail outside. Why wasn’t it done when you had your first stroke?” I don’t know... You know, she said that should have been done from the beginning. But it wasn’t, and nobody said anything about it. So, she said, “You need a rail either side, for getting you up and down. Somebody will come tomorrow to measure and have a chat.” So this other lady came the next day, and she said, “Oh, you only need the one.” So, we got the one on, didn’t we?”

(Participant 25)

These barriers were also exacerbated in some instances by specific local authority policies, which participants perceived to be inefficient and unsupportive. One example of this was a policy which dictated that hand rails could only be made available on one external access point to the house, either front door or back. In this instance, the provision of one rail only highlighted to participants the dangers of using the other entrance, reinforcing the difficulties they were experiencing without a clear rationale for the denial of a second rail.

"She's [Participant] going to do it when we're not here, and she's going to fall and... You know. So, that was why we basically asked for it to be done. In the first place... But they said that they could only do one - either the front or the back."

(Family member of Participant 22)

This was made even more apparent in one instance where a participant was given a set adaptation to meet the available policies, rather than their desired need. Having requested a rail outside of the property to access the street and reach parked cars so family members could take them shopping, this participant was told that this was unavailable and that a stair lift could be offered as part of a local scheme instead. The participant accepted this, and felt they had benefited from it, but their original need was largely ignored.

"Well, I phoned up to try and get the rail from the front gate down to the house. And then the bloke came and said, "Sorry, but it's too expensive." But, he said, "There's a plan coming off with stair lifts. Are you interested?" I said, "Yes." I said, "If it's going to help." And I just said, "Well, what's it going to cost." He said, "No, we're going to put them in for you." I said, "Right. It'll be brilliant - get on with it."

(Participant 15)

However, it was not only the specific usage of local authority adaptations services that was a potential barrier for participants, as some felt the need to contact the councils in the first instance was a deterrent. Several participants, particularly those who had limited experience of contacting council services, were originally unsure about how to contact them and felt they did not want to be perceived as asking for help unnecessarily. However, once contact was made and a positive experience was completed, they spoke of their willingness to repeat the process in the future.

"No, I dreaded it [contacting the council] in a way, because I've never ever had to get in touch for things like that before. So I was a bit apprehensive about getting in touch with the social about it. But once I did, I couldn't fault them. And, as I say, I would get in touch with them again if I thought things were getting too bad or I needed help with anything."

(Participant 10)

Logistical issues

Negative experiences of logistical issues, such as time delays and the upheaval of having an adaptation installed, also had an impact on participant experiences. Almost all participants experienced delays in terms of access and installation, particularly those who were unable to self-fund, with some experiencing significant delays. Often, in these cases, the time taken to complete application forms, wait for a decision, and then wait for an installation date, was both a source of frustration and unnecessarily elongated the continued use of inappropriate and temporary coping strategies. It also created a negative impression of the use of adaptations services in the future.

"It took a couple of years. A couple of years, for that to be appreciated and eventually the council... The... The council, principally, because they had to do the work, didn't they? Yeah. It had to be a grant from the council to do the work. So, we... Talked and discussed and asked and pressed and nagged. And eventually they said, "You know, you need the wet room."

(Participant 19)

However, despite this, it was also evident that a number of participants were willing to accept significant time delays, as long as they eventually received the adaptation they required. The willingness to wait your turn, acknowledge the pressing needs of others and accept the financial pressures of the current climate meant that participants reported being happy to show patience.

"I was willing to wait, you know. I think some of them will be, like, sort of, hushing them on and... But I think I just have patience."

(Participant 22)

Another logistical issue that had a potential negative impact was the perception of upheaval involved in receiving an adaptation. Like any change to property, the addition of a fixed adaptation was seen as a major occurrence, particularly on larger tasks which would require several days and multiple workmen, while having the potential to create a great deal of mess and disruption. However, in this context, a change to the home, already a key element of individual motivation as discussed earlier, was a particularly significant challenge.

"I'm not used to upheaval like that. It takes a bit of getting used to."

(Participant 04)

Perceptions of cost

As mentioned earlier, cost also played a role in influencing how housing adaptations were accessed by participants. For those who were applying for local authority grants and

services, insecurity relating to eligibility criteria was seen as a potential barrier to access, particularly for those who felt unfairly treated within financial assessments. Meanwhile, others were also unsure about what was available and at what cost.

"I don't really need a stair lift because I've got the two bannisters. I can't really afford one of them, anyway. Because you've got to pay for them – for stair lifts, haven't you?"

(Participant 29)

However, the perception of cost also impacted on access in that it acted as a deterrent for participants attempting to access local authority services, as they feared a rejection on financial grounds would unnecessarily delay or hinder their required adaptation. While this reduced the likelihood of accessing adaptations in some instances, it also helped to create an anxiety that being forced to fund the equipment and installation yourself would either be too costly or result in a poor-quality job.

R1: Now, that's what she said - [Name], the occupation health... She said you're better off letting us put it in because it'll be done properly. You might get somebody that puts it in and might... You know, unless you get a really good workman to do it.

R2: It's going to cost you an awful lot of money.

R1: But she said, "It will be done properly when we do it." You know?

R2: It's not only the council-wise. We would have had financial problems trying to do it that way.

(Participant 21 and partner)

Appearance and perceptions of age and disability

Participants were also concerned about accessing adaptations which they felt would negatively impact the appearance of their house. Although these included a range of both internal and external fittings, a major recurring concern was the need for external handrails around doors and access points. Participants reported feeling reluctant to accept such changes, despite acknowledging their necessity, as they felt a great deal of pride about the appearance of their home and did not want this to be altered by additions which did not fit with the aesthetics of the space.

"I really would have struggled to get in. Because there wasn't a handle. And I don't want a handle at the front door. Because I don't like the look of it. It's like a pipe... A bit like a sewage pipe, you know what I mean?"

(Participant 30)

However, negative attitudes towards adaptations were not limited to their appearance, but also the changes in status and identity that participants felt they represented. Internal and external adaptations were often described as symbols of age and disability, which they did not want to either share with the external world or be reminded of themselves.

“You sort of think of two stair rails as a sign of old age. A sign of incapacity. Which is not something that you want to sort of shout about.”

(Participant 16)

Thus, although participants were aware of needs which could be addressed by adaptations, this was balanced against attitudes towards the issues of appearance and perceptions of age and disability.

Tenure

A final potential barrier to accessing adaptations, particularly for those participants outside of council systems and schemes, was housing tenure. While those who lived in council properties, or were eligible for council funding, had to negotiate complex systems, differing tenures brought differing challenges. One example is those living in the private sector, who were reliant on their relationship with landlords to secure adaptations, and then also on the landlord themselves to provide efficient and timely interventions. Where support was delayed or difficult to secure, participants felt like this placed an extra stress on their relationship with the landlord and, therefore, their future in their homes.

“Well, we haven’t complained to [landlord] [about the need for an adaptation], I mean, because we’ve been... It’s very difficult, you know, when you’ve been here so long. We don’t want to change.”

(Participant 23)

Meanwhile, those who were able to self-fund also faced barriers to access. Although many of these are detailed above, in relation to issues of cost and awareness, the control and autonomy given to those able to source and pay for their own adaptations also brought challenges due to the lack of support and information available. For example, the participant below detailed her experience of sourcing and arranging for an extra step to be supplied without any form of assessment or safety checks. Her ability to ask a contractor who was coincidentally working in the street may have brought about a swift change, but there was little thought given to effectiveness or safety.

“Yeah, I did that myself. I saw a man doing jobs down the road. Cement - he was doing some... So, I said, “Can you get me a paving stone?” And he got one for the front, one for the back. It’s half a paving stone. He had it cut, and it’s about that thick. And he cemented it in.”

(Participant 30)

Facilitators to access

However, participants also offered a number of facilitators to accessing housing adaptations. Many of these were found in the solutions to the problems listed above, but other participants also offered a range of enabling factors which helped them have positive experiences of installation and good outcomes. As such, these facilitators suggest a number of key stages in which services had, and potentially could have, intervened to ensure people are accessing housing adaptations in an effective and enabling manner.

Promotion, awareness and supportive systems

Those participants who either engaged with council services previously, or who had received promotional / awareness-raising information about such services, suggested that this information played a crucial role in them accessing housing adaptations. This was because the information itself had a range of key impacts in being able to bridge the gap in understanding the adaptations are available, how to access them, funding implications and potential benefits.

"[After receiving a letter from the council] We had to start with the shower heightened because you couldn't get underneath it. But we did that, and then when [council contact] came, she organised the grab rails and that, which have been handy."

(Participant 23)

Similarly, once participants accessed the available services, feedback was largely positive. Despite often having been confused about what was available at the outset, remaining committed to the process of sourcing further information brought numerous benefits, including support in applying for funding, assistance in identifying appropriate adaptations and providing efficient and reliable contractors.

"And [assessment officer] came in and she was just, like, no... And she said, "Well, I'm just here to recommend it." And she had to put it all forward. She did all the paperwork they had, and it was approved. Actually, when the... £3,000 off the council, you know."

(Participant 01)

Appearance and utility

While there were several examples of participants who felt the appearance of adaptations was a barrier to access, this was not always the case. Others stated that they were pleased with the appearance, especially if they could maintain control over some elements of the design and additional benefits such as the ease of cleaning were considered. In fact, there were also examples where the adaptation itself was a source of pride in the home overall, both for the utility it offered and the value it represented.

"And you pick what colours you want and things like that, you know. [...] Because they were saying, well, I picked this blue and white colour. He said, "Well, think about it against the white." So I was thinking, oh well, they're going to leave some tiles on, but they took everything off and boarded it all the way round. So, it's sort of dead easy to clean. You've got no grouting to do or anything, you know. It's lovely."

(Participant 10)

This was particularly true when participants balanced their feelings about the appearance of the adaptation with the improved functioning it would give them following installation. In most cases, this outweighed any negative perceptions.

"That was one of the reasons that I didn't want it. Because... Because of the look of it. But then you've got to weigh up the benefits, and the benefits outweighed the... You know, you've got to forget about sort of the look of things and think what benefits it's given you, you know. And now, I never notice... You never notice it."

(Participant 16)

Control

While control was also important within the services offered to participants, it played a particularly significant role in encouraging access among those who were self-funding. As such, the extra resources required to carry this out were often viewed as unimportant in comparison to being able to maintain control of the adaptation. Also, those with enough resources often suggested that it was fair for them to access adaptations themselves, particularly as they did not want to be seen as taking something to which they were not entitled. Thus, they often arranged to pay for adaptations independently without contacting services to see if they were eligible for support.

"And also we do have an above average, sort of, income. You know, to be fair. So, I don't mind paying for the stair lift. It's quite acceptable that we buy it ourselves."

(Participant 07)

Control itself, therefore, was not limited to appearance, but the ability to choose and organise adaptations in an independent manner. As such, having the resources to self-fund often facilitated this.

Having a named contact

While there were a number of factors facilitating access identified by the clients, the most recurrent theme was having a named contact to approach for information and support on housing adaptations. This included council workers, advice services, contractors and others,

and offered participants a range of valuable support and information that was not evident from elsewhere. It was also noticeable that participants often could not recall the role of this contact, or how they accessed them, but stressed that having a person they could ring up for support was a key benefit in accessing adaptations in a positive way.

“And [Council worker] was absolutely brilliant. She just sat there and she said... “I’m coming for...” She said, “You can get them in two days.” And they did. [...] And then when I tried to catch her for something, she’d left. The council had paid her off or something to...”

(Participant 15)

While participants received clear benefits in terms of the increased access and knowledge having a named contact gave, they also valued the interpersonal relationship that developed. Getting to know their contact, and feeling as if they had personally taken an interest in their situation, both helped in making the adaptation journey more efficient and also helped the participants feel the work that was carried out was tailored to their specific needs and situation. As such, the service was then seen as being holistic and centred on them.

“Well, luckily for us, we’ve had people who’ve actually been interested in what you needed. And sorted it out for you.”

(Participant 14)

These perceived benefits also went beyond the process of the adaptation itself. This interpersonal approach was also underpinned by good communication and offered the ability for subsequent follow-up, meaning that the participants felt fully engaged with the process and able to speak up to ensure that it was meeting all their needs.

“She’s been very, very good, [Council worker]. She was phoning up a long time after I finished, where I... Just make sure I was alright and that, you know.”

(Participant 26)

Thus, although described by the participants in simple terms of having somebody “nice” to contact, this personal relationship from having a named contact actually underpinned many of the positive access stories detailed in the data. It ensured that clients were given efficient and effective information, made them feel like they were completely engaged in the process and also offered opportunities for communication and follow up to ensure the adaptation was tailored to the participant’s needs and that future issues could be addressed.

Section summary

This section has outlined the potential barriers and facilitators experienced by participants in accessing housing adaptations. Common barriers arose from the lack of awareness participants had on the availability, uses and processes required to access adaptations. This often resulted in delays in accessing support, assumptions about availability and funding and a lack of engagement with the potential benefits of the process. As such, important facilitators were the provision of information, particularly via a named contact within a local service. This approach was much more significant than simply “being nice”, as it helped provide accurate and timely information, maintained engagement and offered the potential for future support if needs were to change over time. Without this, or similar, support, it is possible that participants would have found it difficult to access housing adaptations appropriately, or may not have accessed them at all.

Installation

This chapter presents the findings relating to the installation of home adaptations. It comprises six sections: logistics of the installation, interaction with traders, tailored to need, disruption, partial or incomplete installation, and family support.

Logistics of the installation

Participants who arranged their work privately engaged in a variety of different processes to organise the installation of their adaptations. Some completed their own independent research on which companies to use, some spent time sourcing multiple quotes, and others used word of mouth to identify traders and adaptations.

“For some time I had had this idea that it would be really convenient to have a toilet in the corner of the bedroom. So, I started looking things up on Google and whatnot. And I found this place which actually does whole pods...I measured up the space, and they had one which would actually fit...When I contacted them for details and so on, they happened to have a shop-soiled one...I just put en-suite pods in [Google]...and came across these people. And I considered various other possibilities. But this was the one that seemed to be the best one.”

(Participant 12)

As discussed previously, those with access to family members with experience, skills and knowledge of installing adaptations, valued the control and ease of access this allowed. The example below came from the partner of one participant who was able, with the help of family members, to install a shower himself.

“Once a decision was made on the shower, we just went out and bought all the stuff... and then once we could organise a time when I could actually whip the bath out and get something in...my middle son, came and helped me put the tray and everything in it.”

(Participant 3a)

There were also however instances where the decision to access a housing adaptation was taken during times of personal stress, for example following the passing of a partner. In these cases, it was possible that inappropriate decisions could be taken and participants regretted changing the home.

"I think they hit me at a bad time and I just agreed to anything and everything. And I should have thought a bit more about it...it was somebody knocking on the door...The firm canvassed and it wasn't a good firm at all...I had to take out a loan, so it's going to be about another five years before it's paid for. Which is annoying as well...It was just sprung on me...I got a fright with not being able to get out of the bath. And I think this was in my mind...the whole time, so...It just hits, I suppose, the right time for them and the wrong time for me..."

(Participant 4)

For most of the participants who received their adaptations via their local authority, traders were organised on their behalf, sometimes with little awareness of who they were, with one participant stating "I don't know what company they use, but they phoned up and suggested...a time and date. That was fine" (Participant 28). One couple, however, explained how they had been included in the process by which the contract was awarded by the local authority.

"There were three lots came to give quotes. And we were very satisfied with the ones that they decided to use...We were happy with all of them, really. They were all very nice. But when they said it was that particular gentleman, we were delighted. Because he was really the person we felt more on the same wavelength with."

(Participant 19)

The value placed on this inclusive approach included the arrangements for the time period in which the work would be completed, particularly when traders took on board the participants' preferences and availability.

"Yeah, yeah - they said...is it convenient to come?...they didn't just say, right, we're coming. They said, "Is it convenient for you to come?" I said, well, at the time...I was going backward and forward to hospital for scans, wasn't I? And...we arranged a time...a date, and they said, "Right, well, we'll be here between ten and eleven o'clock" or whatever..."Is that okay?" Yes, yeah..."

(Participant 25)

Other participants faced delays in having the work completed at the installation stage. In many cases, these were viewed as minor inconveniences and as an expected part of the process. These instances were reported as having little impact on how the overall process of the adaptation was experienced.

"If you have anything done and you have to wait for a plumber to come or the electrician to come or whatever it is...that's life, isn't it?"

(Participant 12)

For other participants, however, the major delays and broken agreements with traders became a serious issue. This not only had an impact on the process of installation, but also led participants to question the overall value of the adaptation itself. For example, one participant who agreed to install a wet room from a door-to-door salesperson recalled:

“They kept promising to turn up, and they didn’t and...the job was only supposed to last...two or three weeks...and it went on to two or three months...They just weren’t turning up. And nobody would take responsibility for the work that was being done or anything...I was not happy with them at all....It was a firm, but they subcontracted the work out for everything, so you can imagine what it was like...one day I would have tilers, joiners, the whole lot. Another day – nobody...it was very hitty-missy.”

(Participant 4)

Two participants reported how the apparent discovery of asbestos had slowed down progress of installing their adaptations, with one being very frustrated by the delays with the inconvenience and impact on his hygiene.

“...It took too long. But initially all the paperwork...the time schedules...I was told it would take five days...Well, it was three weeks by the end. We went up to three weeks... They came on the Monday and then they had a conflag. And it was asbestos in - that was it. They had to take the asbestos...It was only...what I call oil cloth, on the floor to dig it out...With it being the council...nobody just mucks in...and they had to wait for the specialised company. And then it just took time. And then I heard them saying, “Oh, we’re not going to get it done until next week.”...The toilet had been lifted off every day and going on for me...I was stinking, man...”

(Participant 1)

The participant explained how they had subsequently complained to the traders and threatened to report them to politicians at the local authority for their poor service. Thus, this suggests that difficulties in installation held the potential to provide ongoing challenges, which had a significant impact on the participants’ overall experience.

Interaction with traders

When discussing the installation process many of the participants drew attention to their interaction with traders. As evidenced by the extracts above, some participants were disappointed by the lack of clear communication. Others, however, were content with the information they received from the tradespeople and appreciated regular updates:

“They kept in contact. They said what date it would come, and I think maybe it was a week... they were finishing another job. They kept in contact and said it won’t be that date, it’ll be

such-and-such...but they kept you in the loop. You knew what was happening.”

(Participant 14)

Many of the participants focussed on the traders’ interaction with them when completing the work inside their home, valuing people who provided information, were personable and included them in the work. As discussed earlier, the inconvenience and disruption expected by some participants made the need for a supportive and friendly interaction within the home of huge importance.

“He was so friendly and he just got on with things...and he was telling me everything that he was doing and everything. And “come up and have a look” – “what do you think of this?”, type of thing.”

(Participant 13)

Another participant commented that “the workmen were so nice...and it makes a difference...especially to elderly people”, later stating “it makes a big difference, having the right kind of person to do it.” (Participant 5). Some participants discussed how the traders showed them how to use the adaptation after it had been installed, with one recalling that they suggested he should take hold of his new grab rails. As such, these findings show the extent to which older people can value the social and communication skills amongst traders in addition to their technical competence.

Tailored to need

Several participants spoke of how the installation of their adaptation was tailored to their specific requirements, such as traders consulting them on the height and positioning of handrails before installation. One participant who received an adaptation through their local authority explained how they had the opportunity to “choose what type of board I needed for the bathroom and the flooring. And they came out to give me samples” (Participant 13). Meanwhile, another described how they had been provided with drawings of the plans for the new wet room and were given an opportunity to comment on them.

“Well, a guy came out and talked to us...I filled the form in and...[he] talked to us about what they’d do, and how they’d do it...They drew up a plan and got our agreement of the plan. And if we needed to change it, we could do such a thing like that. And then they went away and did it and came back and said, “This is what we propose to do.” And [my wife] said... I said I want to keep the...airing cupboard at the end of the bathroom, because I would have nowhere to air the clothes. And so they changed it and kept the airing cupboard in.”

(Participant 19)

The tailoring of the installation to meet participants' needs was not a universal experience, however. For example, another participant commented on their frustration that other potential minor changes were not considered.

"You see, this is it. When somebody's been to do...her toilet seat [which] has been raised like...a chair. And I don't know why they didn't feel like that she actually needs...a grab rail as well...It depends on the person, whoever is doing the job. But sometimes they just do what they're told to do. Other times they can sort of look around and find out...Oh, yeah, this needs replacing, or this needs replacing. So, it really...it depends on the person."

(Participant 17)

Thus, tailoring the adaptation to an individual's specific needs allowed traders to create effective and efficient changes to the homes, helped the participants feel valued, and created the opportunity for additional needs to be highlighted.

Disruption

Participants who received minor adaptations generally faced little disruption from the work completed. They made reference to a variety of measures that traders took to ensure that disruption was minimised, such as protective films which were laid over floors and the use of small vacuum cleaners to remove dust. Some participants commented on how the disruption they experienced was linked more to the presence of strangers than noise and mess. One family member stated, "I think my mum always feels a bit...when anybody is in the house. Because my mum will say...'You feel as if you can't relax.'" (Participant 5a). Even some participants who received major adaptations experienced relatively little disruption when traders were considerate of their clients. However, others faced more considerable disruption. One participant explained how they needed to take remedial action after installation.

"The trouble is an electrician altered the stair. The electrician was not very good. My son is an electrician...[The electrician] made a bit of a mess of it, but my son...put it all right...and obviously they can't avoid a little bit [of] muck. So it was just a case of painting the walls."

(Participant 3)

Major adaptations, such as the installation of a wet room, clearly caused greater disruption in terms of time, mess, and the need to make alternative arrangements during the process. Although in several cases these problems were overcome by temporary measures such as washing in downstairs sinks or suspending work to use the toilet, other participants felt more significant changes had to be made. These included bathing at nearby family's houses or staying in a hotel for the duration of the work, and were driven by both concerns over disruption and health issues. More significant changes, however, were clearly more likely to result in greater inconvenience and, in some cases, extra cost.

"We went to the [hotel]...and slept there. Because we both have bad chests, and the dust was something we were very fearful of."

(Participant 19)

"The [hotel] went very well. But, what we couldn't get was...respite care...[for] the time that we would be out whilst they did the house...So we would have had to pay for it, and it would have costed us £1,000 for a week."

(Participant 19)

However, as stated above, when the inconvenience was weighed against the benefits the adaptations were offering, they were still valued by participants.

"[Some people] don't want the mess and the upheaval, do they? Some of them...It didn't bother me, that, because I thought, well, I need it done. So..."

(Participant 21)

Partial or incomplete installation

Several participants commented on how the installation of their adaptation was not comprehensive. A frequent example of this was that grab rails were not installed in wet rooms at this time.

"...a fella from the council came and he checked. And I said to him..."I hadn't realised at the time, when the lad had finished." And it was when I went in the shower. I said, "Crikey, there's no grab rail." But I knew the fella was coming from the council, I told him, and then they just came and they...[fitted it]"

(Participant 27)

Such incomplete installation often had negative psychological impacts, with this participant describing themselves as being "on edge" before the grab rail was fitted. The extract also demonstrates the value of post-installation visits, which several participants reported. However, others experiencing the same situation were less unhappy about the installation, and felt further work was an expected part of an already extended process.

"I wasn't really bothered [about grab rails]. It was only a couple of weeks, I think, or something like that."

(Participant 19)

More long-term problems were found in examples where there appeared to have been confusion over the technical feasibility of installing grab rails externally to a property. However, participants again suggested that these issues could be addressed by ongoing dialogue and follow up with suppliers. Once again, the time delays were largely accepted by participants as part of the process.

There were greater concerns, however, when it was felt that there was a limit on the changes local authorities could make. In these instances, it was felt that the job itself was incomplete and did not address the person's need, and participants often felt pressured to find the resources and skills to finalise the installation themselves, or would return to the local authority or the contractor to complain and request further work.

"I was just like, "You're not leaving that like that." There was...a little gap and they put a piece of wood over...There was just a piece of plywood between the door and the ramp, and I went, "Howay, give me a break...even I know that plywood is just going to get wet and rot..." they were like... "Oh, right, we can put some plastic over." And I went, "Ah, you will. That's right. That's what you'll be doing. You'll be putting plastic over and sealing it and making sure that there's no gap." "And, aye, we'll be doing that." And I went, "Yes, you will. Before you go...Get yourselves a piece of plastic." "Aye, right, we'll do that."

(Participant 27)

Family support

As has been identified at other stages of the adaptations journey, a theme running through the installation process was many participants' reliance on family members. Participants referred to how their family supported them when selecting traders, arranging the adaptation, coping with the disruption, and in helping rectify or complete the work. For example, one participant explained how their son made final additions to the wet room they received.

"They didn't make a very good job of painting it...They left a gap [in tiling] there, so that was just paintwork down there. And then, when the lad came to do it, he said, "What they've told me is I've got to leave a gap and do, like, from about there around"...And I told the adaptation person who came to see me, I said, "I'm going to get my son to do that." So I went and bought the tiles and...he did the rest of the tiling for me."

(Participant 27)

However, participants did not always acknowledge the extent to which their family members had facilitated or eased the completion of adaptations and there was generally little reflection upon how participants might have coped without this support. One participant, who had completed adaptations independently, did briefly recognise the advantages of their family situation.

“Well, I suppose it’s...fortunate in a way that we can...still do it. But, also, within the family, we have...a certain amount of know-how as well.”

(Participant 9a)

Section summary

This section has highlighted the positive and negative impact of the installation process on the home adaptations journey. Overall, it has highlighted that, participants’ experiences of installation have been positive. They particularly valued the interaction and support offered by traders, most notably when they have offered a person-centred and considerate service which has helped to limit disruption. Significant issues, such as time delays and significant inconvenience experienced during major adaptations, were also widely accepted as an expected part of the process and worth it when balanced against value received. However, where problems did occur and were acknowledged by participants, their impacts were strong, with the potential to cause long-running disputes, periods of relocation and extra cost. All of which held the potential for a negative impact on how the adaptation was valued. Thus, although a largely successful stage of the journey, including potential examples of good practice, it is still important to recognise the potential difficulties presented by an ineffective installation even with the context of participants’ acceptance of problems and resourcefulness in overcoming them.

Outcomes

This chapter presents the findings relating to outcomes from home adaptations identified by participants. It is organised into five sections: using the adaptation, maintenance of the adaptation, first order impacts, second order impacts, and limited impacts and remaining difficulties.

Using the adaptation

Whilst some participants learned how to use adaptations quickly, several discussed how they took time to familiarise themselves after installation had taken place. One participant spoke of how they were wary about using their new wet room at first because of the 'change' that had occurred. Another participant said that whilst they were not nervous about using their stair lift, they commented on how "you're relying on this machine to bring you all the way down", comparing it to a funfair ride or ascending a mountain (Participant 30). This was particularly the case in relation to participants who had received a stair lift, as they required time to both learn how to use and charge the item.

"...One time I put my hand out halfway down the stairs. Because there was a bit of wallpaper that needed pushing back. And I used my right hand, which was the control hand... and it ground to a halt immediately. And I was stuck halfway up the stairs and...panic...and then I realised what I'd done. I'd taken my hand off the...[joystick]. Because it only works when you're really pressing, and when the light is on. So...I didn't do that again."

(Participant 30)

In many instances the need to learn to use the adaptation was done so experientially, whereas for some it required the support of others, such as professionals, tradesmen during the process of installation or family members.

Some participants spoke of how they had to make changes to the adaptation or their behaviour, to achieve benefits or minimise negative consequences. One participant stated that after the installation of their wet room, "I was swimming when I first used it...But I figured out how to use it" (Participant 01). They recalled how they would sometimes return to the wet room to comb their hair only to get wet socks because of the dampness on the floor. This participant adapted the adaptation, describing how they lowered the curtain further to prevent water splashing across the room. With regard to their stair lift, another participant commented on how they adapted their behaviour in order to operate it.

"It was a bit awkward at first...I was saying, "Is that working or what?"...when you're up the stairs...you've got a wall here...you can't see when that thing is up or down. So you've got to say to the little one, "Can you see if that...?" She stays downstairs. But through the week, I've got to try and get my head under, like this, to see if it's down. It doesn't make a noise..."

(Participant 26)

Another participant commented on how gaining knowledge about products such as adaptations and learning how to use them are simply the reality for many older people, as "if they want to stay in their own homes - which they're having to now, because they can't do anything else...they've got [to] know and they've got to learn. Whether you want to or not." (Participant 04).

Use of the adaptations varied in frequency among participants. One participant commented on how they had used their new downstairs toilet more over time to prevent them needing to ascend the stairs (Participant 04). For some it had become something they used "all the time" (Participant 01) or they "take [the stair lift] for granted now...I've got so used to it" (Participant 30). Others used their adaptation less, depending on how the individual was feeling and the extent to which they required support. For example, when asked about using their bath seat for showering to begin with, one participant stated:

"[It was] very nerve-wracking. In case you fall...I'll be honest with you, I don't get many showers...I use...baby wipes...on my bad days...Mornings and nights are my worst time...I'm on a lot of medication, and they make me sleepy."

(Participant 02)

However, for another participant the (dis)use of their stair lift was influenced by their desire to try to remain healthy.

"I'm trying to keep fit...I never know from one [day] to another what I'm going to be like. So I keep saying to [my husband] I'm going to walk up the stairs to try and keep my fitness... Because I sit around far too much and I try...to do as much as I can."

(Participant 03)

Some participants described how they rarely used their adaptations or equipment, had stopped using them or had never used them. For some participants, minor adaptations and equipment were removed when they became redundant by the installation of major adaptations. Examples included a stair lift replacing a second railing on the stairs, and a wet room replacing a step and bath seat. For others, adaptations did not completely fulfil their needs. One participant spoke of how they had only rarely used their wet room to shower after it was installed, stating "It's quick. And, of course, it's reassuring. I know I'm not going

to get stuck, but I miss my bath.” (Participant 04). Other participants described how they were supplied with inappropriate equipment, which was not subsequently used, such as a shower seat that did not fit in the shower. Thus, although offering many functional benefits (discussed below), it is noticeable that adaptations often took time to be integrated into the normal use of the home, or to be adapted too, particularly when requiring a change in behaviour and norms.

Maintenance and repairs of adaptations

Experiences of maintaining adaptations were mixed. For example, one participant commented, “I have used the shower twice, and I keep meaning to clean it more often than I do. It’s not easy to clean. I don’t think any of these shower units are easy to clean” (Participant 8). Another had the opposite experience, commenting on how the adaptation had reduced maintenance compared to their previous bathroom which was tiled, “they took everything off and boarded it all the way round. So, it’s sort of dead easy to clean. You’ve got no grouting to do or anything...it’s lovely”

(Participant 10)

Functional issues were also of great importance, and consequences were often negative where adaptations were relied upon, and then failed or experienced problems. This highlights the need for a quick repairs service from companies providing such adaptations and the need for individuals to consider contingency plans if an adaptation should malfunction.

“It went wrong once, but they came very quickly and put it right, because I was marooned upstairs...I was absolutely stuck upstairs...But I’ve got four telephones in the house...I must have phoned for some sort of help. Anyway, the man came and mended it, and there was no charge. But it shouldn’t have gone wrong...Another time...my cleaner left the Zimmer at the end of the travel of the stair lift...You ride backwards. So, I didn’t see this Zimmer...The chair crashed into it and stuck. And the man had to come then...But we got that sorted out.”

(Participant 30)

First order impacts

The impact of the home adaptations received by the participants were wide-ranging. Many saw the changes as positive, with them variously described as “a boon” (Participant 06), “a life-saver” (Participant 5) and that they “changed my life” (Participant 02). Discussions with some participants raised the concept of normality and how adaptations had allowed them to return to a more positive former state and restore aspects of their life which had been degraded by a combination of health issues and their home environment. For others, the

changes were not found to achieve their aim or led to negative consequences. This section explores the direct or 'first order' impacts of the adaptations for the participants.

Mobility around the home

Many participants commented on how the adaptations installed had impacted on their mobility around the home.

"Without the hand rails and without the stair lift and the trolley around, I would find it much more difficult getting about. Really, because it's now at a stage where one's muscles aren't strong enough. So they tire, so they ache and this sort of thing. So, you benefit in that sense."

(Participant 07)

This increased mobility offered a number of benefits, particularly increased ability to use the home environment without limitations (by going upstairs more) and avoiding risky behaviours like negotiating stairs on your hands and knees. It also gave participants more energy and allowed use them to use the toilet more often and as they wished. Without adaptations to aid mobility, participants also worried about being forced to live on one floor and having to use aids, such as a commode. In one instance, the installation of handrails even had benefits for a participant's partner who was blind and used them as a guide to move around the house.

"Part of the reason why we have hand rails was that they can provide some sort of system for guiding you around the house. It's not perfect, but...it's there in addition to the pure function of supporting you physically. It helps cognitively, so that [my partner] can identify where she is."

(Participant 07)

The restorative potential of adaptations through increased mobility was captured by one participant who commented, "You...feel normal because...you get the stair lift and you're just moving around as if you're just alright" (Participant 05). However, some participants did remark on the slow speed of their stair lifts being an annoyance.

Use of the home and completion of daily tasks

Many participants discussed the relationship between the adaptations installed and how they used their home, and completed tasks as part of their normal routine. Here, the problems discussed as triggers and tipping points were largely described as having been solved via the adaptation and changes in behaviour. This was common among participants whose adaptations related to their bathroom.

It would have been murder...I don't know how I would have managed to get in and out of the shower. Using the toilet, I mean, I can always hang on to the radiator. But it's easier having a grab rail. And it's definitely a lot...easier having the grab rail in the shower.

(Participant 28)

The impact of such adaptations on the frequency of showering and bathing varied among participants. For some it was mostly the ease of the task which had improved, "I still only shower the same amount...I shower every day, once a day... But...it's a lot easier. It's a lot easier to just go in and sit down and turn the shower on..." (Participant 19). Others reported increased frequency, with one commenting "I'm always showering now" (Participant 23) after alterations to their showerhead. This issue was also influenced by adaptations, such as stair lifts.

"I can go upstairs and get a shower a lot more often than I did...I can go up and get changed a lot more. You know, when I used to say, "Oh, I'll just stay like this." Instead of trying to go up the stairs. Or "I'll get a shower later" instead of just going up."

(Participant 11)

Impacts on the use of the home were not limited to use of bathrooms and wet rooms, and some participants raised facilitation of cooking. One said that lighting improvements meant that they found it easier to cook in the kitchen, whilst another commented, "I don't think I would have been going out into the garage go much [without grab rails]. Because I do my own cooking...I keep my potatoes in the garage, so you see I use the grab rail to go and get the potatoes" (Participant 30). Another participant with vision problems described how stickers placed on buttons had made it easier for them to use the microwave and set the correct temperature on the oven.

There was a large variety of other daily tasks that adaptations and equipment allowed participants to complete. These included a perching stool which facilitated ironing, a stair-lift used to transport laundry and other items and using a grab rail to assist in exiting the property to dispose of recycling. Adaptations were also used in unconventional manners in order to aid functional tasks.

"When I had the washing and ironing, carrying the clothes up, I can't carry on this arm, because of the arthritis in that elbow. So, it was a chore, carrying things up and trying to hang on to a bannister...So, now it's just absolutely great. I have no problem. I can put the things on my knee and go upstairs and...it's such a difference."

(Participant 10)

Other unconventional uses of aids and adaptations included using a wet room as a space to dry clothes and using a walker to transport meals, eat from or as a surface upon which a bowl of water could be placed to facilitate washing.

Adaptations did not have universally positive impacts on the use of the home for participants. Two participants identified the installation of seats as making it more difficult to use their bath or shower. One described it as “a little more cramped than it used to be, but it’s alright” (Participant 09) and another stating that they “struggled to get in. I would never do without a shower. But I was finding it hard to get in” (Participant 13). One participant regretted their decision to acquire adaptations as they missed their bath and as a result used their new wet room very infrequently. Others commented on how the speed of their stair lift had the potential to slow down their access to their toilet or how the conversion of their bedroom into a shower room had initially created some difficulties.

“It’s in the back bedroom. I can’t use it as a bedroom anymore...because I used to sleep in the back for the quiet...I mean, not that it’s noisy outside, but...the central heating boiler and everything is in the front room. And it comes on through the night, just to keep it going... and it aggravates me...it doesn’t bother me now I’ve got used to it. But when I first went in I couldn’t sleep properly for it.”

(Participant 06)

Travel outside the home

In addition to increased and / or easier mobility within the home, several participants reported impacts on their travel outside their property. However, for many these benefits were associated with equipment, such as walkers and mobility scooters.

“[I] had sciatica, and... I’ve just been stuck in the house. But, now I’ve got one of those walker things. The shoppers. And I just go out now like that. So, that’s how I was able to go away for a few days last week. I took that with me.”

(Participant 13)

Some participants described how adaptations, often used with equipment, had impacted on travel outside the home, particularly as they often helped to encourage them to leave their home. Many others reported no change in the frequency with which they went outside but said that the ease by which they could enter and exit their property had been improved. This included one participant who used a ramp at the back of their property to facilitate their journey to the hairdressers using their walker and another who was able to park their mobility scooter at the front of their house, rather than inside their garage, because of the grab rails which helped them down the steps to it. One participant provided an interesting example of how two adaptations and one piece of equipment worked in unison to facilitate the ease of travelling outside their home.

"And when I go to the shops, I have a three-wheeler. I wouldn't dare go without that...But I have a step - as you saw at the front door. Now, I have an automatic opening of the garage, and there's no step there. So, I go in and out. So, the grab rails [between the garage and house] lead me to the exit that's easiest for me. The garage one. Because there's no step there. And because the door just goes up so easily...with my three-wheeler...Bob's your uncle."

(Participant 30)

Falls

Several participants reported that they had experienced fewer falls after adaptations had been installed. In relation to their new wet room, one participant stated:

"...in terms of their being a problem and in terms of me falling as much, I don't fall so much now. It just gives away now and then, but...because I've got all sorts of grab rails and things like that...I'm able to cope a lot better."

(Participant 19)

There were limited instances where participants reported that falls actually resulted from the supply of inappropriate equipment or adaptations. One said that they would fall when the first walker they received would tip over, before it was replaced by a more suitable model. Another commented, "I've got a walking stick in the car, but I keep tripping over the end of it, to be honest...it's lethal." (Participant 04). One couple described a dangerous situation which led to a fall because of the way a stair lift had been installed.

"Initially, they made a mistake. They had it parked right on the last stair at the top. And on the bend at the bottom...It was dangerous... In fact, I slipped down...I didn't hurt myself, fortunately. And they came back and social has had a look and they made them alter it. Because we don't understand how it ended up there in the first place. Because even the electrician came and put the point in for it to go right across the landing. But anyway, they sorted it."

(Participant 03a)

Confidence, safety and security

Several participants discussed how adaptations had impacted on their sense of confidence, safety and security. This was often discussed in relation to the potential for an accident to occur and the reduced risk that adaptations could achieve. One participant said, "Well, it was stepping in and out of the bath. And I just couldn't trust myself. If I slipped, that was me snookered. So...I got the shower put in and I've never...regretted it." (Participant 15). Participants also reported that just the presence of adaptations could have an impact,

stating “knowing the grab rails are there, certainly gives [me] the confidence...A lot of it is in the mind” (Participant 28). One commented, “[the wet room’s] quick. And, of course, it’s reassuring. I know I’m not going to get stuck” (Participant 04). Several participants, particularly those who lived alone, also commented on how adaptations provided security given that they had the potential to be used if they were needed.

“I think it’s good knowing that [the grab rail’s] there. If you need to get a hold. Sometimes, when I’m washing my hair, I get a bit dizzy and I shut my eyes. So, I know that that’s there. I can grab that.”

(Participant 21)

Where adaptations and aids were deemed inappropriate or incomplete, participants reported negative impacts on their safety.

“So, he could really hurt himself on a board. So, we then explained that to them that that wasn’t working. And we got a swivel chair. And so he sat on a chair and we had to lift his legs up and get him over the side of the bath...And we just carried on with that until we got the... the wet room.”

(Participant 19a)

Another participant explained how some tap turners that were installed were “the most stupidest things I’ve ever seen” (Participant 27), explaining how they created greater risk.

“I couldn’t manage the taps with the way my hands are...they came with these things and they’ve got...like a half tennis ball with plastic handles, and you had to push them back and forwards. Well, they broke and I couldn’t manage them. And when you were actually standing in the bath, you were catching the handles. So the hot water was [flowing]...if you caught the hot water one... and then when the adaptation team came, I told him and I said, “They’re useless.” I said, “They’re no good whatsoever.” I said, “They’re actually more dangerous.” So they did the whole lot.”

(Participant 27)

Mental health

Several participants discussed how adaptations had reduced feelings of depression, anxiety and frustration, which they had previously experienced and/or increased self-esteem and happiness. One participant reported that as a result of their adaptations and equipment they felt “more content” and “happier” (Participant 04). Another participant who had received a wet room connected their improved mood to their hygiene, commenting, “it makes you a lot happier because you’re clean” (Participant 10). When asked about any mental health impacts of their adaptations, another participant commented:

"It's stopped me from crying...I was getting really, really depressed. Especially when I couldn't come downstairs. And then, when I was stuck in that bedroom by myself all the time, because [my family are] at work...I'd been there six weeks, I think. And [my granddaughter] said, "Are you still going to be here at Christmas, nanna." She said, "Because we can put the Christmas tree in front of the telly and put my toys under there, you know." And I'm thinking, eh, I don't want to be here that long...It was driving me crazy."

(Participant 26)

This participant went on to say that the adaptations, including a stair lift, had "made a new person of me, because I'm not upset. I'm not angry...being able to come up and down as I want" (Participant 26). Another participant, who described bathing as previously "terrifying" (Participant 27), explained the difference their wet room had made.

"It's had a big impact. I haven't got the worry when I go in. I can just stand and have a nice shower...I mean, there are times when my ankle is swollen up - I just stand there and I hold the rail of my shower...I would say from the way I was to what it is now...it's made a 75% improvement to me...from having the bath, I haven't got the worry...because even if I did get down in the bath, it was getting out. Because...you were down and putting the pressure on this foot and trying to get a hold...to push myself up. It was frightening...but now I'm over the moon with it...I haven't got the worry...that's the main thing."

(Participant 27)

Some participants connected their reduced anxiety and frustration to the greater independence they felt because they no longer had to rely on other people. One individual, discussing their railing on their outside steps, said, "I don't rely on [my family] now, which I didn't want to at one time...I had to, but I didn't want to...and that's why I used to get frustrated" (Participant 25). Another participant commented similarly about their lighting improvements, "Well, it gives you a little bit more self-confidence and self-worth. You know, you're able to do things and without asking people. I intend to do as much as I can for as long as I can"

(Participant 16)

Independence

Crucially, as this had already been identified as a trigger and tipping point in the participant journey, many of the participants discussed how they had an increased sense of independence as a result of the changes to their home, providing them with a sense of fulfilment.

"I used to enjoy the bath. But I enjoy the shower better now. And I think it's knowing that I'm going in there and I've got my own independence...That's the big thing...I push myself to do what I can...To me my own independence is one of the main things. And I've always been that way. I want to do what I can do..."

(Participant 27)

"It means independence. I don't have to ask for help. I find it very hard to ask for help. I mean, everybody has got busy lives. They haven't got time to be bothering on with you...If you can manage yourself, then it's half the battle."

(Participant 04)

Several participants described how adaptations had dramatically reduced the extent to which they required support and care from other members of their family.

"That means I've got independence in...my shower. I can go in myself, and I can come out myself. I don't have to wait until somebody comes and gets a hold of my hands and takes me..."

(Participant 26)

This participant was previously "embarrassed" at having to rely on family members when they were "free to do it for me" (Participant 26). Another participant similarly explained how they were now able to ascend the stairs during the daytime when previously they had needed to wait until their adult son returned home from work. Thus, the ability for adaptations to remove the need for participants to rely on family members, acted as another potential solution to a problem identified as a trigger or tipping point.

Other participants, whilst not previously needing the support of others, reported that the adaptations were preventing their potential loss of independence rather than necessarily restoring it.

"You don't have to rely anybody to come in and help you. You can keep your modesty and everything...your independence. Which is a big thing. I would hate to have to wait for somebody to come in and help me into the shower or things like that."

(Participant 10)

Physical health

Physical health was another concern identified as acting as a trigger or tipping point, which was identified as a potential outcome of adaptations. For example, one participant recovering from a stroke explained how a second rail on his stairs had benefited him:

"First of all, it gave me confidence to walk up. But mostly coming downstairs. I didn't have to come down like...trying to walk properly...Very, very good confidence-wise...it learned me to walk...One time I was just a one step at a time...when you're coming down one stair and bringing your foot down...but this time I was walking properly. Yeah, it was great."

(Participant 25)

Second order impacts

This section comprises impacts that participants discussed which were thought to be secondary, generally relying on one or more of the first order impacts for them to be realised.

Prevention of relocation

Two participants discussed how the home adaptations they had received were a positive alternative to relocating to a different property. One had rejected the local authority's original suggestion of moving to nearby age-specific accommodation because of the size of the dwellings and the participant's existing social connections to nearby family and neighbours.

"I think it's two bedrooms, but you've got one big sitting room, you've got no kitchenette... You've got nowhere for a washing machine or anything. You've got to go into the community. It's like going to the wash house when we were younger...I said, "I'm not doing that. No way am I doing that." So, I was very, very strict about it. I don't want to leave here. I've got lovely neighbours...When I was poorly they would say, "Don't forget, if you need anything..." They used to knock and ask if I was alright...And I'm so pleased that they've put these things in so I can stop here...I couldn't have coped on those stairs if [the stair lift] hadn't have been there."

(Participant 26)

Social interaction

Some participants identified a link between adaptations and social interaction. For most, this was connected in relation to the ease or frequency with which they could now exit their property. One participant found it easier to exit her property via a ramp and "go to the hairdressers every Wednesday", commenting that she "really appreciate[s] that because they're...lovely girls" (Participant 22). Another discussed how the installation of a grab rail and the reduction in the height of steps outside their property allowed them to go out shopping with a volunteer once a week and have a cup of coffee at a local park. One couple commented on how they had previously felt "socially unacceptable" (Participant 21), because they were unable to shower as frequently as they would have liked.

"You used to go to the community centre to meet your friends over there. Well, before it was all the deodorant for in case there was any lingering [smell]"

(Participant 21a)

This individual's partner said that they were now "getting involved with all sorts of stuff. They're doing pantomimes...all sorts...I've got a lot more confidence", commenting that their new wet room definitely has "something to do with it"

(Participant 21)

One participant identified a different link between an adaptation and social interaction. She explained how she had asked a local trader to use a concrete slab to create an extra step at the front of her property to aid accessibility not for herself, but visitors.

"I always go in and out [through the garage]. But when friends call, they find it a great help. Because a lot of my friends are my age...and... Modern doors, with that sealing bit - I think they're tricky. You've got to step over it, you know."

(Participant 30)

These comments demonstrate the potential for adaptations to facilitate social interaction by easing the ability of friends to enter one's home as well as the resident's ability to leave.

Impact on services

Two participants discussed how adaptations to their home had reduced their reliance on social care services.

"...It was the gradual progress from, as you broke your hip, we moved your bed downstairs and he began sleeping downstairs. We had carers coming in every morning to wash you and get you out of bed and get dressed. All in that room. So, we were carrying water in, etc. And it took two - two of them - to come together to do that. But then, as you, sort of, progressed beyond that - the fact that those adaptations have been done to the shower meant that once you could get upstairs to the bathroom, you could wash yourself...because the adaptations that we had done were to put the... shower head on a sliding thing...It was possible to sit on a seat and soap yourself, and then rinse it off. So that you then only needed one carer to just supervise what you were doing and then help you out of the shower and dry your back. And then help you to get... dressed. So that was a further stage where those adaptations helped."

(Participant 9a)

"...that very day, the helpers didn't come...because I could get upstairs. The help stopped immediately. They must have reported that I now had a stair lift. But that was fine, because I could get upstairs then. Much to everybody's relief."

(Participant 30)

Family members and friends

The impacts of home adaptations were not confined to the intended recipient, with interviews revealing how the changes affected family members and friends. For some this related to how other people had benefited from the adaptations.

"I have got a couple of friends that are disabled. So, when they come round they can use the stair lift to get upstairs, if they...want to use the upstairs toilet. Because with this seat being higher in the bathroom, they prefer using that toilet."

(Participant 11)

One participant explained how her new wet room had also been beneficial for her husband given that he had received two knee replacements. Other participants discussed how adaptations originally installed for partners who had passed away had become useful for them. One participant said, "In the beginning, they were all for my husband...the bath seat was put in for my husband. But I asked could I keep the seat, and they said yes. So they're in my name"

(Participant 29)

Some participants also commented on how grandchildren enjoyed riding on their stair lift.

Other family members' interaction with the adaptations was not always positive, however. One participant commented, "I've got a toilet up-raiser – I've got to take it off, because [my partner] doesn't like it. You've got to take it off and put it back on again. Take it off, and put it back on"

(Participant 26).

The husband of one participant how their stair lift made it more difficult to complete daily tasks.

"R1: Well, it's difficult...for [my husband] carrying stuff up...

R2: So, I usually send it to the top. I park at the top or park halfway.

R1: Halfway up the stairs...and when it's parked in the middle, it's hopeless, really. But it's the only place it could be...So, we've just got to put up with it, because that's the way it is."

(Participant 03/03a)

For some family members who acted as carers the impact of the adaptations was indirect, resulting from a positive outcome for the intended recipient. Some no longer needed to provide some forms of assistance, which changed their routine and meant they had more choice over how they spent their time. For example, one participant explained how before her stair lift was installed, her son's time in the evening was partially restricted as "my son used to take my hand... He used to take me up the stairs to bed. But it wasn't fair, because he mightn't want to go to bed then. Or I mightn't have wanted to go to bed then" (Participant 20). Similarly, the daughter of a lady who had a ramp installed at the entrance to her property explained, "I used to have to...take [my mother] to the hairdressers and wait for her to come back. Now...we can go home...I can...know that she's going to walk back" (Participant 22a). One couple interviewed explained how the installation of an electric garage door was vital in facilitating driving again, with the wife explaining that she was no longer solely relied upon for some tasks: "[my husband] being able to use the car again means that I can have help with the heavy shopping now" (Participant 09). For some family members the adaptations reduced the previous concern they had felt for the recipient of the adaptation, "Because she used to say, "I'm managing." But I used to worry sick because she did have a fall...about three years ago, you had a fall"

(Participant 05a)

The wife of one participant had suffered considerable health issues as a result of her caring responsibilities. Before the adaptation was made she explained how her physical health had worsened as result of caring for her husband after his stroke, which also had an impact on the wider family. When asked what they would have done if a wet room had not been installed, the wife stated she would have to persevere until:

"...whichever one of us died from the consequence of falling or lifting...I can't do the lifting... I developed a heart problem from it all...if I was really poorly and [my husband] had fallen...I would have to be phoning round the family and seeing if someone would come and help."

(Participant 19)

This heart condition had led the couple to re-landscape their back garden, removing the lawn as the wife now felt unable to cut the grass. The installation of a wet room in their home positively impacted on both her mental and physical health. She said that her health condition had stabilised as a result of the new wet room, commenting, "I'm very, very pleased, because I'm not pulling muscles and all sorts of things trying to keep you from falling on the ground" (Participant 19a).

She also said that the adaptation was “absolutely wonderful. It’s made a real...difference to the stress and strain of coping with [my husband’s] disability at the moment. Absolutely wonderful”

(Participant 19a)

Saleability or value of property

One participant, when discussing their new wet room, referred to the hypothetical sale of their home and the future occupants of the property.

“It’s also...[an] additive. If I was selling the house, it would be wonderful for someone who was really keen on gardening to be able to walk out of that garden into here, and go and have a shower. Instead of walking through the house to do so. It’s a bonus.”

(Participant 8)

Limited impacts and remaining difficulties

For some participants the impact of the adaptations they had received was limited. One participant was provided with grab rails, a bath board, and a swivel bath chair which all had limited success before the wet room they sought was finally installed.

“Well, it made things different. I’m not sure it made it easier, but it made it different. You still had the problem of getting the...wheelchair in[to the bathroom]. Particularly if I wanted to use the toilet...but getting into the shower was a little bit easier.”

(Participant 19)

In this case, the grab rails that were originally installed could not have weight placed on them due to the nature of the walls, rendering them unusable.

For some participants the changes made were not always consistent with their norms and how they wanted to use their home

“to be perfectly honest, the seat was never much of a success...because I like to lie in the bath”

(Participant 04)

Another participant explained how her son had installed a bathroom grab rail on the outside of her property instead of one intended for external use, which subsequently needed to be replaced. Others commented on the fundamental limitations of some adaptations, with one

participant explaining how, even though they had received a second rail on their stairs, “I still can’t carry stuff up and down the stairs. Because I’ve got to hold onto them” (Participant 29). Indeed, one participant succinctly explained how adaptations and equipment are unable to solve every aspect of the challenges older people can face.

“Well, obviously they don’t overcome the problem - so you’re left with the problem, really... I’ve got a trolley to get around, but in fact my mobility is restricted. And...you want to get something...[but] you don’t want to have to reach over and get the trolley, you really want to...reach over and get something straightaway...So you have to live within your limitations. They...modify the limitations, but they don’t remove them.”

(Participant 07)

Section summary

This section has highlighted the varied outcomes expressed by participants following the installation of housing adaptations. The majority of outcomes expressed were positive, both in terms of functional and physical benefits such as increased mobility and use of space, and psychological benefits such as increased confidence and feelings of independence. However, this process was not always straightforward, as participants often had to learn to use, or adapt to, their new adaptations. Despite this, it is noticeable the extent to which the solutions and outcomes identified were directly related to the problems that featured as triggers and tipping points in the first instance. For some participants, however, problems remained, both in the view that adaptations were ineffective in meeting their needs and the perspective that future changes and decline was inevitable. Those instances aside, however, participants still identified a range of positive outcomes that can be seen as contributing to their quality of life and their resources and capabilities in the future.

Discussion

Introduction

There is good evidence that home adaptations, particularly minor ones, such as hand rails, achieve their aims. They can support people to adapt to mobility challenges, disease and injurious accidents that are more common in later life. Our research focused on the opinions of individuals aged 65 and older, their experiences, and perceived overall outcomes, for themselves, family, friends and wider networks. Within this qualitative study, the majority of participants have reported positive outcomes, from less falls, to regaining lost physical spaces in their home, such as the first floor, the garage, and the garden. Participants also loudly proclaimed getting back to normal, regaining control over everyday activity and, critically, choosing when they need to use the adaptation. As one participant said “that’s what independence is to me!”. There was also agreement that getting back to normal includes regaining confidence, and an identity that is not just premised on being ‘a faller’, or ‘being old’. Exit and entry adaptations such as ramps and rails, enabled physical access to the outside world, to social networks and local facilities. Regaining confidence enabled the participant to step over their inside / outside threshold to reclaim their wider, perhaps more fulfilling life.

For a small minority of our participants, home adaptations did not work. For example, whilst a walk in shower was functional, they missed the comfort of bathing. For a few, and post-installation, -the adaptation was too much of a marker of disability and decline; the outside ramp felt ‘like a hospital’, the hand rails, white and ‘clinical’, could not be disguised, their home no longer reflecting who they wanted to be. Furthermore, the thirty participants who volunteered to take part in our study, had all taken on the home adaptations journey. We do not know about those who do not wish to consider this option and that is beyond the scope of this study.

Delivering home adaptations

In this study, practitioners included a range of professionals, contractors, suppliers and those from signposting agencies and charities seeking best outcomes for home adaptations’ users. Through our wearable camera and interview data, we mapped a common home adaptations journey, and this guided our discussions with practitioners. For the 38 practitioners (information givers, supporters, sign posters, deliverers, ‘fixers’, evaluators and others), there was a real momentum of wanting to work together and work with the participant, to get the best outcome for them. Across our four mixed focus groups, all agreed that common referral

routes were via GPs, Adult Social Care, Community and Voluntary Sector, Care Agencies, and family / self. There was also some recognition that even for professionals, navigating a route through to acquiring the right adaptation for the right person, can be challenging. There was the business of accessing the home adaptation services, getting reliable information, finding a 'gateway person' who can guide the enquirer through referral and assessment, or point to reputable alternatives. There was understanding and sympathy for the low income, home owner who may not be eligible or be means tested, for an adaptation that a registered social landlord tenant, may automatically acquire.

Practitioners also spoke of reasonable and practical action, this equating with holistic assessment of individual need and appropriate response. This is not always easy. Our homes have emotional roots. Being fair and equitable, might mean a discussion with an older person living alone in a large property, about moving to a smaller property and freeing up their existing home for a family. Practitioners know how hard these decisions are for everyone, particularly those who may be long lived in their home. Equally though, some decisions, such as grab rails offered for only one point of entry / exit to the home, are frustrating. This meets a functional need but neglects the emotional attachment to a back garden and indeed benefits of access to green space.

Recent increases to central government funding, such as Disabled Facility Grants are welcome. However, for local authorities, even with the Care Act (2014) affording some flexibility, there is still some confusion about assessment and eligibility criteria. There is also common agreement that the successful and timely distribution of this funding is dependent upon other resources. It was suggested that bottlenecks, from assessment to installation, were due to lack of staff to administer the grants and also in some cases lack of contractors to carry out the major adaptations. Increases to the Disabled Facility Grant budget without simultaneous increases in funding to aspects of the adaptations process, may hamper attempts to improve outputs.

Despite these challenges, and against a background of seven years of significant local government austerity cuts, our two participating local authorities drew on an ethos of professionals 'working together' to deliver the best adaptations services, for their clients. For example, an Occupational Therapist, Building Contractor and Grants Officer working with an older person to ensure the proposed adaptations installation is practical, appropriately meeting needs and that the recipient is well informed throughout the process. There was also common talk of well-established adaptations teams, from contractors to fitters and everyone in between, engendering a culture of trust in each other and this in turn affording a positive experience for the client. A 'job well done' was clearly rewarding and practitioners valued positive outcomes reported by clients, particularly those that improved quality of life. However, it was also acknowledged that whilst there are sector specific review and outcome processes, further guidance from central government on when, how and why to evidence the impact of home adaptation services could be improved upon. There was also recognition that there is a need for a multi-disciplinary, cross sector, integrated approach to outcome monitoring and reporting.

Policy and practice implications

We are delighted with the publication of the Communities and Local Government (CLG) Committee's report on Housing for Older People (CLG, 2018). This is good news and speaks to our recommendations. During this the 70th year of the NHS, Jeremy Hunt became the Secretary for a Department of Health and Social Care. The CLG Housing for Older People report reminds us that policy and service integration, should also include housing. The report calls for a national housing strategy for older people. It asserts that: "an appropriate, comfortable and well-located home can improve a person's physical and mental health, wellbeing, social life and independence, while the converse can have a detrimental effect." It also recognizes diversity in our older population with a range of issues and needs: "from home maintenance, adaptations and repairs, to access to financial advice, and to housing supply" (CLG, 2018, page 3).

We agree and would add that as well as 'age proofing' new homes, we need to 'age proof' ourselves and society. The HAPPI reports from 2009 onwards endorsed aspirational planning for future living and our findings suggest that there is still much to do, to get us all planning for later life across the life course and to change ageist attitudes. Reinvigorating the 'First Stop Advice' service and implementing strategies to support moving home in later life, are welcome but there needs to be realistic choice and provision. There also needs to be equal weight placed on advice which can assist people to age in place, including guidance on home adaptations. As we have found through our exploration of two local authorities' experiences of providing home adaptations, as well as adequate central government funding, there is a need for a multi-disciplinary service infrastructure, across housing, health and social care sectors, which is flexible enough to meet a diversity of need and provide personalised support. Such diversity of needs was pleasingly acknowledged in the Housing for Older People report (2018).

As we, with other colleagues noted within our published submission to the Housing for Older People report's (CLG, 2018) call for evidence (Hodgson et al. 2017 [HOP 038]), we know that we also need to understand housing needs from the point of view of older people themselves. Within this study, we were privileged to not only capture what older people said about living with adaptations but through some participants' willingness to use a wearable camera, we were also able to capture their daily interaction with these adaptations. What we found is that the impacts of health or mobility changes are not just to do with how accessible and safe their home felt, but also to do with their wider social, physical and emotional environment (links to family, friends and neighbours, a sense of community, the proximity to and availability of services, access to green spaces). Home adaptations can and do have the potential to reinstate a good quality of life. The CLG's committee's call for a Home Improvement Agency to be in every community, with available funding to be used innovatively and flexibly by people to make changes to their homes is thus welcome.

However, we suggest that there is also an urgent need for positive messaging about the benefits of home adaptations. We need more opportunities for conversations similar to the death café movement (<http://deathcafe.com/>) where people can come together to explore options and visualise what might work for them. More broadly we need a national conversation and consult with people of all ages to consider a range of housing, health and social care integrated 'living' models, such as co-housing, mutual, community-led approaches, collaborative care and 'living labs' (see, Five Year Forward View, NHS 2014a; Lifestyle/HAPPI pre-retirement model, Best and Porteus, 2016). It is clear that future living planning should not address housing in isolation and we very much hope that the forthcoming social care green paper reflects this.

Strengths of the study

As far as we are aware, this is the first UK study that has actively sought the lived experiences of home adaptations for people aged 65 and over. Our participants, older people and practitioners, and strong cross sector partnership, has ensured, timely and meaningful findings that are embedded in people's lives. Our local authority collaborators have a wealth of home adaptations experiences and each are innovators in different ways, with North Tyneside's Select and Direct and Newcastle's My Equipment Newcastle; they were also significant in recruitment processes. The Elders Council of Newcastle, as the voice of people aged 50 and over has significant local, regional and national reach, respected across the later life policy and practice arena and active in research and lobbying alike. Through steering group activity, Elders Council has given significant advice, as well as managing recruitment activity outside of our local authorities and has also played a significant role in data analysis. This was to ensure that our presentation of older people's stories is credible, accessible and impartial. Newcastle University has provided a strong academic, strategic and applied steer as has our Steering Group Chair and its members. Our funder, Centre for Ageing Better has been supportive throughout

Limitations of the study

Our locality has a smaller Black, Asian or Minority Ethnic origin population, than other regions in the UK, particularly London and Yorkshire and the Humber (ONS, 2012). Population ageing, although still at about 18% of the UK population being 65 and over and with a large cohort now aged 69, is slowing to some degree, but the North East is the second highest projected rise by 2024 (the South west being the highest) (ONS, 2017). These facts are limitations to our study findings. However, whilst our study is small and located within just two contiguous local authority regions in the North east of England, our sampling profile and subsequent recruited participants, captures a diversity of income, tenure and health and wellbeing, that is present within the UK older population. As our recommendations endorse, this study's findings are of national significance and need to be noted.

Conclusion

Below we conclude the report with our recommendations.

Recommendations

In light of the data collected, findings and discussion, the following recommendations can be made:

1. More needs to be known about why people delay installing home adaptations (please see recommendation 2) to support independent living and there needs to be practical, accessible and affordable support and advice that encourages proactive planning for future needs.
2. There is an urgent need for positive messaging about the benefits of home adaptations. We need more opportunities for conversations similar to the death café movement (<http://deathcafe.com/>) where people can come together to explore options and visualise what might work for them. Perhaps too the Government needs to offer a 'Facilitating Independence Grant' rather than a 'Disabled Facility Grant' [DFG].
3. Formal services need to work with signposting agencies to proactively raise awareness of the benefits of securing timely and individually assessed, home adaptations. They also need to provide up to date information of locally available, home adaptations services, including anticipated benefits. For those individuals growing older without family support (e.g. people ageing without children) this recommendation is an urgent priority.
4. There needs to be investment in a 'front of house', home adaptations service delivery model. Trained local authority workforce should proactively work with received referrals and enquiries and a multi-disciplinary, cross sector home adaptations team, to ensure the service recipient is fully informed of processes and the detail pertinent to their case. Older people should feel central to the process and be provided with a good understanding of what adaptations are available and the eligibility criteria.
5. A planned review of the DFG may address some of these barriers. There also needs to be recognition that home ownership is spread across all income deciles including the lowest. Related to recommendation 2), there also needs to be more imaginative ways of sharing information about the DFG and individual eligibility.

6. Recent increases to the DFG by central government are welcome. However, central government should recognise that the successful and timely distribution of this funding is dependent upon other resources. Increases to the DFG budget without simultaneous increases in funding to aspects of the adaptations process, may hamper attempts to improve outputs.
7. Post-installation visits to properties provide the opportunity for recipients to raise issues and request alterations. Adaptation teams should consider how they can facilitate and fund the temporary relocation of clients experiencing considerable disruption, including respite care where necessary.
8. Home adaptations may not only restore functional ability but have very positive outcomes for restoring a sense of normality and having command over every day routine and activity. Small but significant quality of life benefits need to be emphasised to remove negative and ageist associations with home adaptations and focus on their life affirming potential
9.
 - a. **Short term** - As well as cost benefit analyses, home adaptation services need to evidence the short, medium and longer term, quality of life impacts of their provision on service-users. Validated and evidence based outcome measures need to be identified and agreed as well as the frequency of data collection and methods of analysis, synthesis and sharing of outcomes. A holistic approach to data collection should be taken.
 - b. **Long term** - Central Government needs to provide guidance for key measurement outcomes for home adaptations, progress against which could be linked to funding increases in the DFG budget. The forthcoming review of the DFG needs to agree key outcome requirements with the Department of Health and Social Care. Such metrics need to be devised based on robust evidence of what services can achieve as well as policy goals. Local services should have the flexibility to achieve such outcomes according to local need and local context.

Bibliography

Age UK (2017). 'Briefing: Health and Care of Older People in England 2017'. London: Age UK.

Best, and Porteus, J (2016) 'Housing our Ageing Population: Positive Ideas (HAPPI 3) All Parliamentary Group on Housing and care for Older People'. Retrieved from: <http://www.insidehousing.co.uk/journals/2016/06/07/o/x/p/HAPPI3.pdf>

Care Act (2014). 'Care Act 2014'. Retrieved from: <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>

Cornwell, E.Y., & Waite, L.J. (2009). 'Social disconnectedness, perceived isolation, and health among older adults'. *Journal of Health and Social Behaviour*, 50(1), 31-48.

Department for Communities and Local Government (2018). 'Housing for Older People. Second Report of Session 2017-19'. House of Commons. Retrieved from: <https://publications.parliament.uk/pa/cm201719/cmselect/cmcomloc/370/370.pdf>

Department for Communities and Local Government (2016). 'English housing survey 2014 to 2015: adaptations and accessibility of homes report'. London: Department of Communities and Local Government.

Department of Communities and Local Government (2015). 'English Indices of Deprivation 2015 File 10 Local Authority District Summaries'. London: Department of Communities and Local Government.

Department for Work and Pensions (2014). 'Disability facts and figures'. London: Department for Work and Pensions.

Department for Communities and Local Government (2012). '2012-based household projections'. London: Department of Communities and Local Government

National Health Services (2014a) 'Five Year Forward'. Retrieved from: <https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>

Hodgson, P., Bailey, C., Forster, N., Aitken, D., van der Graaf, P., Lhussier, M. (2017). *Housing and Older People: Written Evidence submitted by Northumbria University [HOP 038]*.

Retrieved from:

<http://data.parliament.uk/WrittenEvidence/CommitteeEvidence.svc/EvidenceDocument/Communities%20and%20Local%20Government/Housing%20for%20older%20people/written/49283.html>

Hrobonova, E., Breeze, E., Fletcher, A.E. (2011). 'Higher levels and intensity of physical activity are associated with reduced mortality among community dwelling older people'. *Journal of Aging Research*. DOI: 10.4061/2011/651931

Kelly, P., Marshall, S. J., Badland, H., Kerr, J., Oliver, M., Doherty, A. R., & Foster, C. (2013). 'An ethical framework for automated, wearable cameras in health behavior research'. *American journal of preventive medicine*, 44(3), 314-319.

Manen Mv. (1997) 'From meaning to method'. *Qualitative Health Research* 7: 345-369.

Office for National Statistics (2017). 'Overview of the UK population: July 2017'. Retrieved from:

<https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/articles/overviewoftheukpopulation/july2017>.

Office for National Statistics (2016). 'Population estimates – local authority based by five year age band. Annual mid-year estimates 2015'.

Office for National Statistics (2012). 'Census 2011' Table KS201EW Ethnic group.

Office for National Statistics (2011) '2011 Census: Key Statistics for England and Wales, March 2011. Statistical Bulletin'. Retrieved from:

<https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/bulletins/2011censuskeystatisticsforenglandandwales/2012-12-11>.

Powell, J., McIntosh, S., Bird, E. Ige, J., Garrett, H., Roys, M. (2017). 'The role of home adaptations in improving later life'. University West of England, Building Research Establishment, Centre for Ageing Better. Retrieved from:

<https://www.ageing-better.org.uk/sites/default/files/2017-12/The%20role%20of%20home%20adaptations%20in%20improving%20later%20life.pdf>.

Public Health England (2017). 'Public Health Outcomes Framework'. Retrieved from:

<http://www.phoutcomes.info/public-health-outcomes-framework#page/0/gid/1000042/pat/6/par/E12000001/ati/102/are/E08000022/iid/338/age/1/sex/4>.

Salisbury, C., Johnson L., Purdy, S., Valderas, J., Montgomery, A. (2011). 'Epidemiology and impact of multimorbidity in primary care: a retrospective cohort study'. *British Journal of General Practice*, 61, e12-e21.

Sen, A. (1985). 'Commodities and Capabilities'. North-Holland.

Sen, A. (1999). 'Development as Freedom'. Oxford University Press.

Sen, A. (2004). 'Capabilities, Lists, and Public Reason: Continuing the Conversation'. *Feminist Economics*, 10, 77-80.

Shared Lives Plus (2018). Retrieved from: <https://sharedlivesplus.org.uk/about-shared-lives-plus>

Swanson-Kauffman, K., & Schonwald, E. (1988). Phenomenology. *NLN publications*, (15-2233), 97-105.

UK Cohousing (2018). Retrieved from: <https://cohousing.org.uk/>

Wilson, G., Jones, D., Schofield, P., & Martin, D. J. (2016). 'Experiences of using a wearable camera to record activity, participation and health-related behaviours: Qualitative reflections of using the Sensecam'. *Digital Health*, 2, DOI: 2055207616682628.

Woodcock, J., Franco, O.H., Orsini, N., Roberts, I. (2011). 'Non-vigorous physical activity and all-cause mortality: systematic review and meta-analysis of cohort studies'. *International Journal of Epidemiology*, 40 (1), 121-138.

Appendices

Appendix one: Participant information sheet (camera user)

CAMERA USERS

Lived experiences of home adaptations for older people – Participant Information Sheet [Participant Phase One – Camera-users]

As an older resident of Newcastle or North Tyneside who has recently received a home adaptation, you are invited to take part in this research project investigating people's experiences of home adaptations. Before you decide to take part, it is important for you to have the information about why the research is taking place and what it will involve. Please take time to read the following carefully and discuss it with others if you wish. You will have an opportunity to ask questions if there is anything that is not clear or if you would like more information, as someone connected with the research team will telephone you within a few days of receiving this information. Take time to decide whether or not you wish to take part.

What is the research about?

A consortium led by Northumbria University has won a contract from the charitable foundation Centre for Ageing Better to complete research into understanding the role of home adaptations in improving later life. The consortium also comprises representatives from Newcastle University, Newcastle City Council, North Tyneside Council and Elders Council. This means that they would like to hear from you about your experiences of home adaptations and the challenges and benefits associated with them.

What is the purpose of the research?

The purpose of the project is to find out people's experiences of the processes required for adapting their home and how adaptations may have made a difference. The Centre for Ageing Better would also like to know how adaptations might improve later life. The research also involves talking to practitioners about their view of adaptations.

Why have I been chosen?

You have been asked to take part in the research because you are an older resident of

Newcastle or North Tyneside and have relatively recent experience of home adaptations. A mixture of people are being recruited from these two local authority areas.

Do I have to take part?

It is up to you whether you take part. If you decide to take part you will be asked to sign a consent form. You can stop at any time and you do not have to give any reason for changing your mind. It is possible to withdraw your information if you choose to leave the project. However following your participation information collected is anonymised and at this stage, it will not be possible to withdraw your information. The decision you make about participation will not affect your housing or access to any local authority service.

What should I expect if I take part?

You will be invited to wear a camera known as an Autographer. This camera is worn around the neck on a lanyard or clipped to your clothing. The camera automatically takes a still photograph every 30 seconds. It does not record moving images or sound. You are invited to wear the Autographer for one day, during which time the camera will automatically take still photographs of your home from your perspective. You will be shown how to use the camera by a member of the research team. The camera has a function which allows you to pause the taking of photographs if you would like to prevent it from doing so during the day. You will be asked to remove the Autographer if you decide to leave your home at any time. You will be provided with contact details for a member of the research team who will be available throughout the day should you have queries regarding the camera.

Once complete, the researcher will plan a suitable time to help you to upload these images on password-protected software. The researcher will then allow you to view each image alone, and you will be able to delete any image you do not wish to share, before the research team see them.

You will then be invited to take part in a face-to-face interview whilst watching back the photos as a 'slideshow'. The interview will take place in your own home or if you would prefer an alternative venue, we will do our best to find a suitable and convenient place with a quiet room. The interview will be carried out by one of the research team. The interview will take about an hour and we will ask to audio record the conversation. This is to help us write up the interview. Everything you tell us will be held in the strictest confidence and all written and audio material will be securely stored and not shared with others. We will not name you.

Discussion will centre around the home adaptations seen in the images. The interview will ask you questions about why you decided to have adaptations made, what adaptations you have had completed, your experiences of the processes involved in completing adaptations and how the adaptations have made a difference to your life.

Who will be carrying out the Evaluation?

The research will be carried out by Cathy Bailey, Gemma Wilson and Phil Hodgson from Northumbria University and Dominic Aitken from Newcastle University. All are research and academic staff with years of experience of working with older people.

Will my taking part in the project be confidential?

As we have mentioned above, all information collected from you during the research, including photographic images, will be kept strictly confidential unless you tell the researcher about, or they observe, harm to yourself or someone else, in which case she may need to share that information. The information you provide will be made anonymous by removing any personal details so that you cannot be recognised from it. All data storage and use will comply with the Data Protection Act 1998 and other data will be kept for five years after the end of this study.

Are there any disadvantages of taking part?

You are being asked to give up some of your time to take part in the study. During the interview, you may decide that you don't want to answer some of the questions or feel that you would like to close the discussion. This is fine and you can withdraw from the discussion at any time. Also talking about personal issues, for example around illness, can sometimes be upsetting. If you feel upset and would like to stop the interview, the researcher will do so and you can complete it at a later date if you wish to. The researcher will also be able to give you information about local support for the issues you are upset about.

What are the possible benefits of taking part?

You may not benefit directly from the research. However, based on your views and opinions, we hope that the findings from the research will help the Centre for Ageing Better understand how adaptations, and the processes by which older people access them, can be improved.

Who will review the way you plan to carry out the discussions?

The study has been reviewed by Northumbria University's, Faculty of Health and Life Sciences, Ethics subcommittee.

What will happen to the results of the discussions?

The information from the interviews will be written up in a report for the Centre for Ageing Better. Academic paper(s) may also be written to share findings more widely. The

researchers may use what you say during the discussion in these reports, but will make sure that you cannot be identified.

Thank you for your interest in taking part in this research project. Someone connected to the research team will telephone shortly and if you are still interested we will be in touch to make the necessary arrangements. Meanwhile if you would like further information please contact Cathy Bailey or Gemma Wilson as below.

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Thank you for helping us with our research

Appendix two: Participant information sheet (interview only)

INTERVIEW ONLY

Lived experiences of home adaptations for older people – Participant Information Sheet [Participant Phase Two – Interview]

As an older resident of Newcastle or North Tyneside who has recently received a home adaptation, you are invited to take part in this research project investigating people's experiences of home adaptations. Before you decide to take part, it is important for you to have the information about why the research is taking place and what it will involve. Please take time to read the following carefully and discuss it with others if you wish. You will have an opportunity to ask questions if there is anything that is not clear or if you would like more information, as someone connected with the research team will telephone you within a few days of receiving this information. Take time to decide whether or not you wish to take part.

What is the research about?

A consortium led by Northumbria University has won a contract from the charitable foundation Centre for Ageing Better to complete research into understanding the role of home adaptations in improving later life. The consortium also comprises representatives from Newcastle University, Newcastle City Council, North Tyneside Council and Elders Council. This means that they would like to hear from you about your experiences of home adaptations and the challenges and benefits associated with them.

What is the purpose of the research?

The purpose of the project is to find out people's experiences of the processes required for adapting their home and how adaptations may have made a difference. The Centre for Ageing Better would also like to know how adaptations might improve later life. The research also involves talking to practitioners about their view of adaptations.

Why have I been chosen?

You have been asked to take part in the research because you are an older resident of Newcastle or North Tyneside and have relatively recent experience of home adaptations. A mixture of people are being recruited from these two local authority areas.

Do I have to take part?

It is up to you whether you take part. If you decide to take part you will be asked to sign

a consent form. You can stop at any time and you do not have to give any reason for changing your mind. It is possible to withdraw your information if you choose to leave the project. However following your participation information collected is anonymised and at this stage, it will not be possible to withdraw your information. The decision you make about participation will not affect your housing or access to any local authority service.

What should I expect if I take part?

You will be invited to take part in a face-to-face interview. The interview will take place in your own home or if you would prefer an alternative venue, we will do our best to find a suitable and convenient place with a quiet room. The interview will be carried out by one of the research team. The interview will take about an hour and we will ask to audio record the conversation. This is to help us write up the interview. Everything you tell us will be held in the strictest confidence and all written and audio material will be securely stored and not shared with others. We will not name you.

Discussion will centre around the home adaptations you have received. The interview will ask you questions about why you decided to have adaptations made, what adaptations you have had completed, your experiences of the processes involved in completing adaptations and how the adaptations have made a difference to your life.

Who will be carrying out the Evaluation?

The research will be carried out by Cathy Bailey, Gemma Wilson and Phil Hodgson from Northumbria University and Dominic Aitken from Newcastle University. All are research and academic staff with years of experience of working with older people.

Will my taking part in the project be confidential?

As we have mentioned above, all information collected from you during the research, will be kept strictly confidential unless you tell the researcher about, or they observe, harm to yourself or someone else, in which case she may need to share that information. The information you provide will be made anonymous by removing any personal details so that you cannot be recognised from it. All data storage and use will comply with the Data Protection Act 1998 and other data will be kept for five years after the end of this study.

Are there any disadvantages of taking part?

You are being asked to give up some of your time to take part in the study. During the interview, you may decide that you don't want to answer some of the questions or feel that you would like to close the discussion. This is fine and you can withdraw from the discussion at any time. Also talking about personal issues, for example around illness, can sometimes be upsetting. If you feel upset and would like to stop the interview, the

researcher will do so and you can complete it at a later date if you wish to. The researcher will also be able to give you information about local support for the issues you are upset about.

What are the possible benefits of taking part?

You may not benefit directly from the research. However, based on your views and opinions, we hope that the findings from the research will help the Centre for Ageing Better understand how adaptations, and the processes by which older people access them, can be improved.

Who will review the way you plan to carry out the discussions?

The study has been reviewed by Northumbria University's, Faculty of Health and Life Sciences, Ethics subcommittee.

What will happen to the results of the discussions?

The information from the interviews will be written up in a report for the Centre for Ageing Better. Academic paper(s) may also be written to share findings more widely. The researchers may use what you say during the discussion in these reports, but will make sure that you cannot be identified.

Thank you for your interest in taking part in this research project. Someone connected to the research team will telephone shortly and if you are still interested we will be in touch to make the necessary arrangements. Meanwhile if you would like further information please contact Cathy Bailey, Phil Hodgson or Dominic Aitken as below.

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Thank you for helping us with our research

Appendix three: Participant information sheet (practitioner)

Lived experiences of home adaptations for older people – Participant Information Sheet [Practitioner]

As a practitioner involved in facilitating adaptations for residents in Newcastle or North Tyneside, you are invited to take part in a research project on home adaptations for older people. Before you decide to take part, it is important for you to have the information about why the research is taking place and what it will involve. Please take time to read the following carefully and discuss it with others if you wish. You will have an opportunity to ask questions if there is anything that is not clear or if you would like more information.

What is the Research about?

A consortium led by Northumbria University has won a contract from the charitable foundation Centre for Ageing Better to complete research into understanding the role of home adaptations in improving later life. The consortium also comprises representatives from Newcastle University, Newcastle City Council, North Tyneside Council and Elders Council. This means that they would like to hear from you about your professional experiences relating to home adaptations.

What is the purpose of the Research?

The purpose of the project is to find how adaptations might improve later life. The Centre for Ageing Better is interested in practitioners' views on how adaptations make or do not make a difference to the lives of older people, what information they draw on to determine whether adaptations have been successful and how practitioners encourage and support older people to adapt their homes and overcome barriers. The research also involves talking to older people about their experiences of adaptations.

Why have I been chosen?

You have been asked to take part in the research because you are a practitioner involved in facilitating adaptations in Newcastle or North Tyneside.

Do I have to take part?

It is up to you whether you take part. If you decide to take part you will be asked to sign a consent form. You can stop at any time and you do not have to give any reason for changing your mind. It is possible to withdraw your information if you choose to leave the

project. However, once the, information collected is anonymised it will not be possible to withdraw your information.

What should I expect if I take part?

You will be invited to take part in a focus group. The focus group will be carried out in at a mutually convenient venue confirmed in advance with participants. The purpose of these focus groups is to explore practitioners' views on home adaptations for older people and their impact. The focus groups will be multi-disciplinary and feature a range of professionals / suppliers and informal key contacts relating to home adaptations. With permission, the focus group will be audio recorded and should last no more than an hour.

Who will be carrying out the Research?

The research will be carried out by Cathy Bailey, Gemma Wilson and Phil Hodgson from Northumbria University and Dominic Aitken from Newcastle University. All are research and academic staff with years of experience of working with older people.

Will my taking part in the project be confidential?

As we have mentioned above, all information collected from you during the research, will be kept strictly confidential unless you tell the researcher about, or they observe, harm to yourself or someone else, in which case she may need to share that information. The information you provide will be made anonymous by removing any personal details so that you cannot be recognised from it. All data storage and use will comply with the Data Protection Act 1998 and other data will be kept for five years after the end of this study.

Are there any disadvantages of taking part?

During the interview, you may decide that you don't want to answer some of the questions or feel that you would like to close the discussion. This is fine and you can withdraw from the discussion at any time.

What are the possible benefits of taking part?

You may not benefit directly from the research. However, based on your views and opinions, we hope that the findings from the research will help the Centre for Ageing Better understand how adaptations, and the processes by which older people access them, can be improved.

Who will review the way you plan to carry out the discussions?

The study has been reviewed by Northumbria University's, Faculty of Health and Life Sciences, Ethics subcommittee.

What will happen to the results of the discussions?

The information from the interviews will be written up in a report for the Centre for Ageing Better. Academic paper(s) may also be written to share findings more widely. The researchers may use what you say during the discussion in these reports, but will make sure that you cannot be identified.

Thank you for your interest in taking part in this research project. Someone connected to the research team will telephone shortly and if you are still interested we will be in touch to make the necessary arrangements. Meanwhile if you would like further information please contact Cathy Bailey, Phil Hodgson or Dominic Aitken as below.

Contact for further information:

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Thank you for helping us with our research

Appendix four: Interview topic guide (participant lived experiences)

Introduction

Information sheet review opportunity

Consent form

1. Maybe you could tell me a little bit about yourself to begin with?
 - a. How long have you lived here?
 - b. Who else lives with you?
 - c. How you like the property and the area generally?

2. Let me take you back to before you received your adaptation(s). Would you be able to tell me a little about your health and how easily you found it to move around your home at that time?
 - a. Explore behavioural changes
 - b. Explore DIY adaptations/using features in different ways
 - c. Explore avoiding certain spaces/using spaces differently

3. What made you think about adaptation(s) at the particular time you did?
 - a. Explore potential tipping/crisis point
 - b. Explore family/friend guidance/pressure

4. Did you know that it was that particular adaptation that you needed?
 - a. How?

5. Did you get any advice or guidance about adaptations?
 - a. Who from?
 - b. When?
 - c. Why from that party?
 - d. How useful was it?

6. Why did/didn't you go to the local authority for the adaptation(s)?

7. Process:

- a. [If local authority]: Can you try to take me through the process you went through to get the adaptation before it was installed?
 - i. Explore Occupational Therapist assessment
 - ii. Explore technical officer visit
 - iii. Explore funding assessment, having to provide financial details
 - iv. Explore getting quotations from tradespeople
 - v. Explore completion of application forms
 - vi. Explore use of quick telephone/internet service if used
 - vii. Explore length of time taken for process
 - viii. Explore satisfaction with the process/how it could be improved
- b. [If self-funding]: Can you try to take me through the process you went through to get the adaptation before it was installed?
 - i. Explore getting quotations from tradespeople or use of family/friend DIY help
 - ii. Explore specification of work
 - iii. Explore negotiating price
 - iv. Explore length of time taken
 - v. Explore satisfaction with the process/how could it be improved?

8. Can you take me through the installation of the adaptation(s)?

- a. Arranging day/time for works
- b. Disruption, mess, noise, being w/o rooms/WC
- c. Interaction with tradespeople
- d. Satisfaction with installation/how can it be improved?

9. What is your view of the adaptation(s)?

- a. Does it fulfil its intended purpose?
- b. What do you think to its appearance?
- c. Could it be improved in any way?

10. What difference has the adaptation made to your daily life? Potential probes:

- a. Using it as intended?
- b. Behaviour changes?
- c. Change/increase in use of certain spaces?
- d. Changes to social interaction?
- e. Preventing accidents?
- f. Confidence/mental health benefits?
- g. Use of carers/other services?

11. How have you found the entire process from start to end?

a. How could it be improved?

12. Anything else you would like to add?

Thanks

Debrief sheet

Appendix five: Interview topic guide (practitioner lived experience)

Lived experiences of home adaptations for older people - Indicative Questions [Focus Group]

1. Referral and first point of contact

- a. What problems do people usually have if you identify they would benefit from an adaptation?
- b. What are the common motivations for and barriers against adaptations?
- c. What would be their process in relation to your role (i.e. who would you refer to)?
- d. What sorts of adaptations does your service provide?
- e. How are people usually aware that adaptations are available (i.e. through a practitioner, general enquiry, promotion, family member)?
- f. Are there any common problems in identifying the need for an adaptation / starting the process of getting one?

2. Assessment and organisation

- a. How are people assessed for what adaptation is required / available to them?
- b. Who carries out this assessment?
- c. What are the common sources of funding available?
- d. How aware are people of these options?
- e. Are there any common problems in relation to assessment for or organisation of adaptations?

3. Delivery and installation

- a. What are the actual processes of installing the adaptation (i.e. which organisations are involved, how is this organised)?
- b. What processes are in place to ensure the appropriateness of the following:
 - i. Function of the adaptation
 - ii. Appearance of the adaptation
 - iii. Disruption and mess with installation
 - iv. Communication with the resident
- c. Are there any common problems in relation to delivery and installation of adaptations?

4. Outcomes and evaluation

- a. What are the benefits you feel people have from receiving adaptations?

- b. Are there any adaptations which don't have an impact?
- c. What are the factors that determine whether an adaptation is successful?
- d. Do you assess whether the adaptations have been successful? If so, what information do you use?
- e. Does your service have ongoing contact with people beyond the installation? If so, what are the benefits of this?

5. Key recommendations

- a. What do you feel are the key facilitators for housing adaptations having a positive impact on people's lives?
- b. What do you feel are the key barriers for housing adaptations having a positive impact on people's lives? What resources would help you overcome this?

Appendix six: Case study analysis

Physical functioning in and out of the home

Participant 01 continuously described his difficulty in accepting himself as “disabled”. He described his embarrassment of being “centre of attention” during the process of acquiring the adaptations, and also of using the equipment outside of his home.

“I don’t know how many walking sticks I’ve got, but I won’t use them[...]I might be wrong, but I think people tend to look at you, you know, and I don’t want to be disabled”

(Participant 01)

“I don’t want to be disabled, you know what I mean?”

(Participant 01)

The image of disability was evidently difficult for Participant 01, and this sense of disability was heightened by the need for adaptations, especially those seen outside of the house. This ultimately impacted his functioning outside of the home. When discussing the two grab rails placed at the rear entrance of his bungalow (Image 19), Participant 01 describes them as “spot on” but justifies his use of them as “a number of people use them”, highlighting the importance of perception.

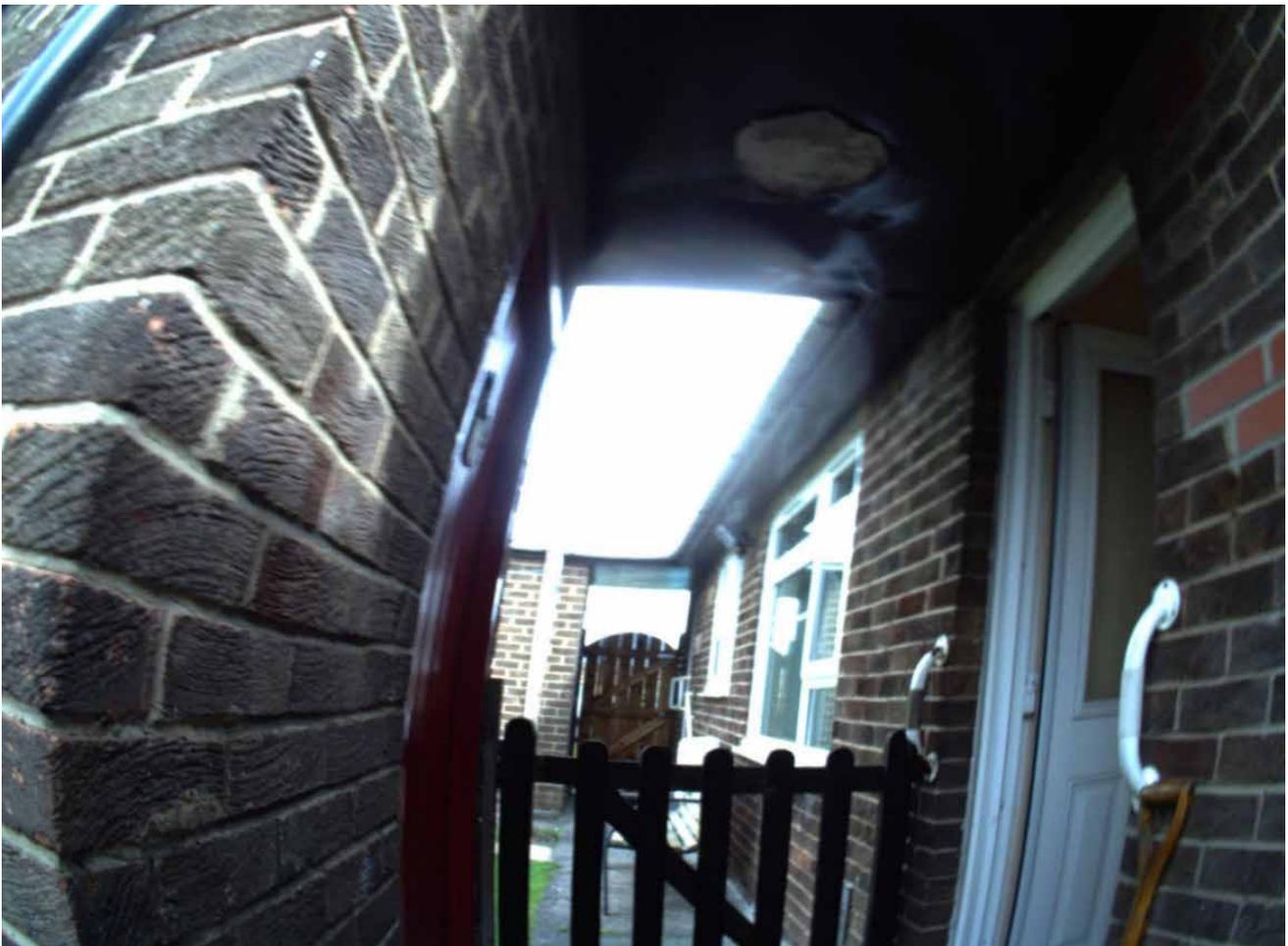


Image 19: Grab rails at rear entrance (Participant 01)

Interestingly, individuals did not always utilise the adaptations and equipment, despite them being in their home, and their use was dependent upon several factors, including physical health and psychological reassurance.

Participant 03's intermittent use of adaptations including the shower seat and stair lift depended upon her physical health.

"I never know from one to another what I'm going to be like"

(Participant 03)

"I'm going to walk up the stairs to try and keep my fitness-do you know what I mean? Just to try and...Because I sit around far too much and I try...I try to do as much as I can"

(Participant 03)

"If she's not really up [for it], she can go in and just sit down and have a shower"

(Participant 03)

Participant 03's intermittent use of the walk-in shower was typically using the shower seat at times if she was not physically able to shower without it.

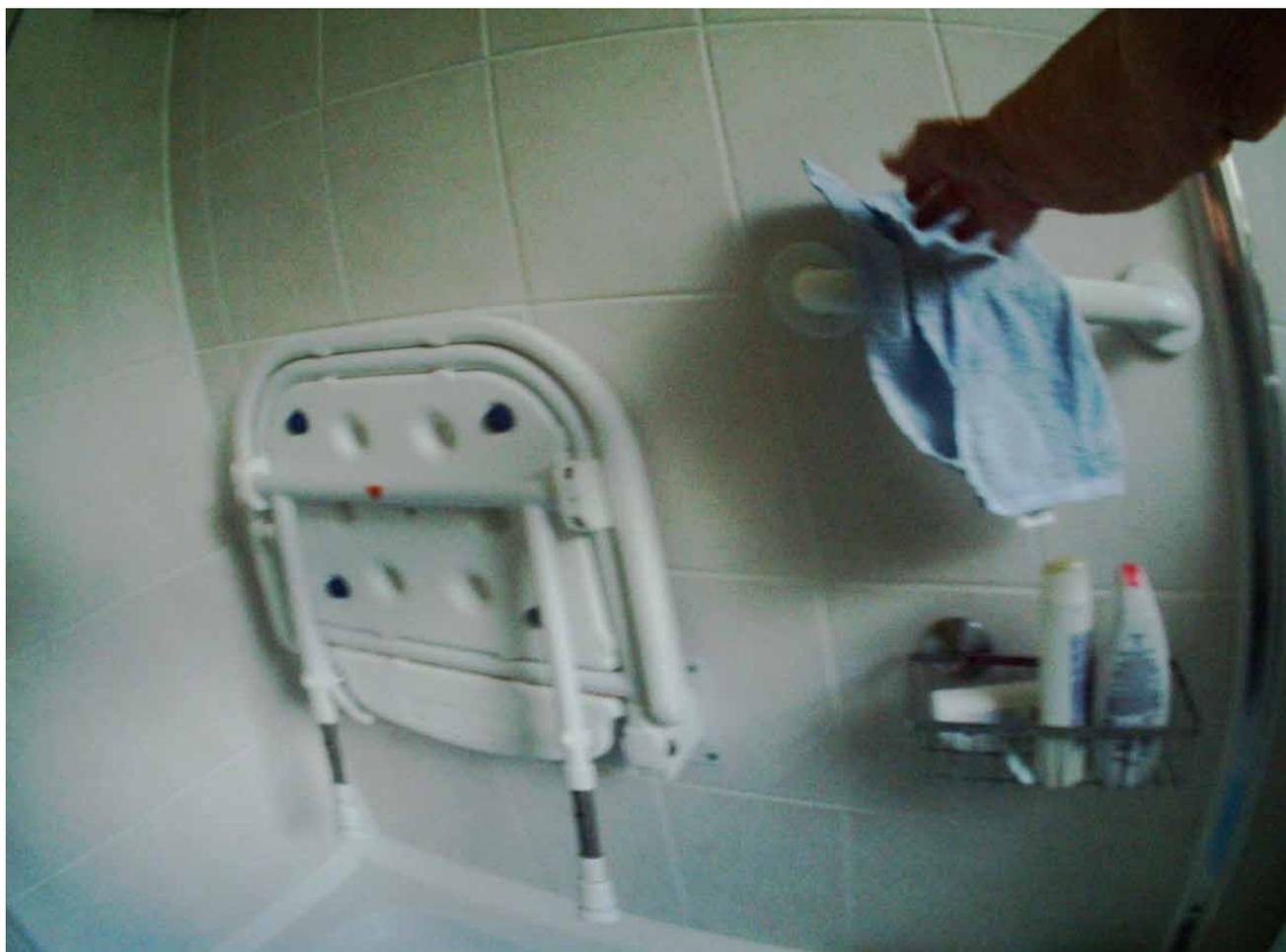


Image 20: Walk-in shower with self-placed grab rail (Participant 03)

As well as providing Participant 03 with the physical ability to shower, the shower seat and grab rails also gave her confidence.

"I think it's knowing [the shower seat is] there. It gives her confidence. Because we've got grab rails"

(Participant 03a)

Similarly, Participant 03 discussed only using the stair lift when she is "ill", otherwise trying to "keep fit" by using the stairs (Images 26-27). Images captured whilst Participant 03 was using the camera show her using the stair lift, and she specifically states within the interview that she would only generally use the stair lift if she is "feeling like today-like I've been the last few days".

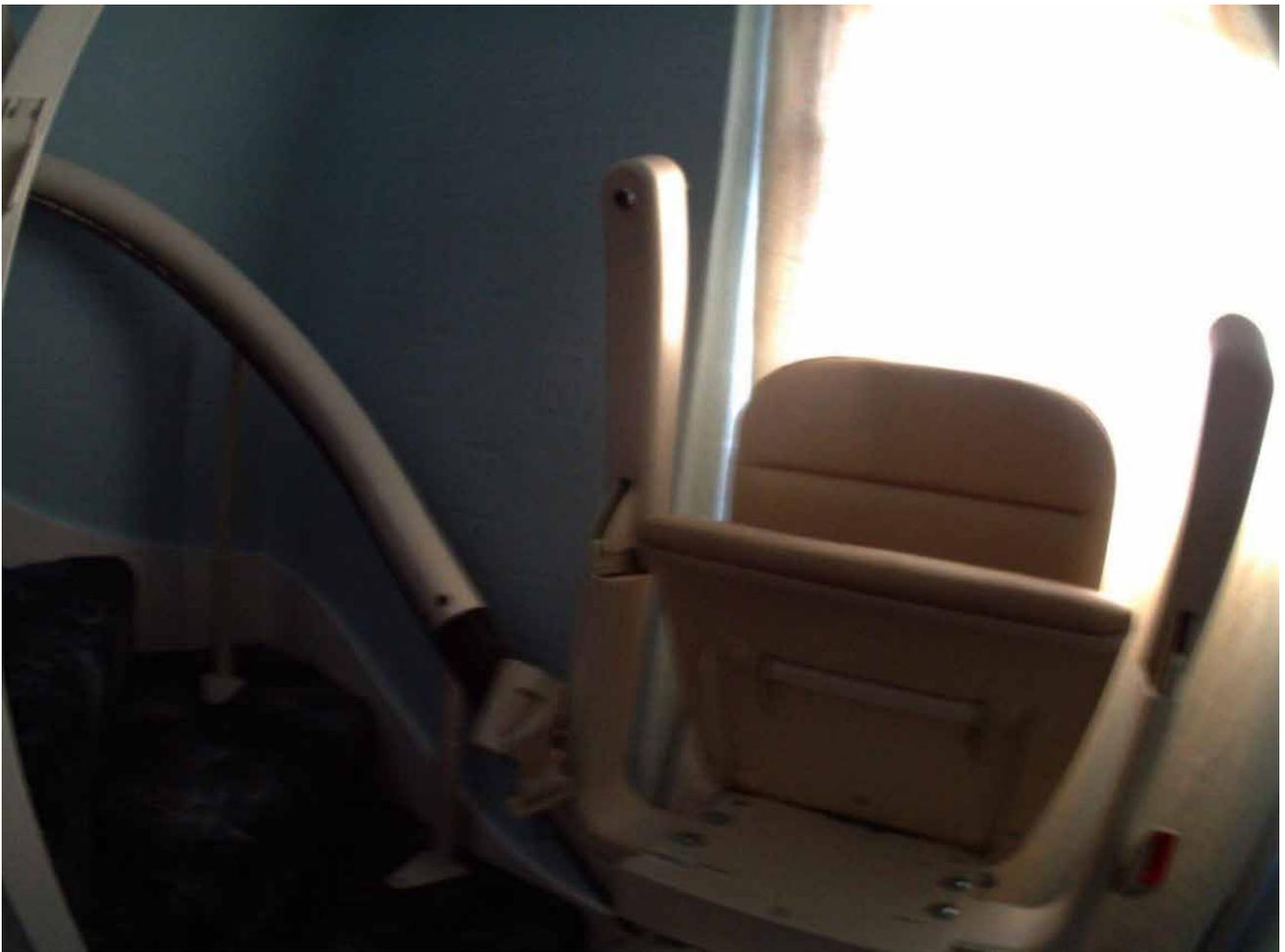


Image 26: The stair (Participant 03)



Image 27: The stair lift in use (Participant 03)

The camera images show the stair lift as the participant faces it, as well as showing Participant 03 using the stair lift (the first-person camera view faces the bannister, and descends throughout the sequence of images). The stair lift influenced the participant's, and her husband's, daily living in a number of ways.

"[My husband] had to push me up the stairs[...]you know to get to the bedroom and whatnot"

(Participant 03)

"You don't have to think six times about can I be bothered to go upstairs or not"

(Participant 03)

On the images recorded by the camera, and at a time in which Participant 03 was using the stair lift daily because of her physical health, the camera recorded Participant 03 using the stair lift 12 times to ascend and descend the stairs, mainly to use the toilet. This demonstrates the difference in daily functioning, and the reduction of anxiety and "having to think" (Participant 03) about going upstairs.

The impact of the stair lift for Participant 03 is apparent, and Participant 03 even stated that she was “jumping for joy” when she was told she could have a stair lift, however, at the same time, she did not want it.

“I don’t like it, really. If I’m truthful, I could do without it. If I could, I would not have it, you know”

(Participant 03)

There were some downfalls to its use, and P003 highlighted issues with the stair lift being “so slow” which was especially problematic when she needed to go the toilet, which was seen to be the main reason for its use, and the stair lift took up a lot of space, getting in the way for her husband when carrying things upstairs.

In considering the perceptions of their own physical functioning and disability, some participants considered their own physical decline, and therefore the possible heightened need for adaptations in the future.

“I mean, as the lad said, you’ve got a choice-she either lives upstairs, downstairs or you try and get a bungalow”

(Participant 03a)

“We know eventually what’s going to happen[...]I’m going to be hopeless, you know when I’m on oxygen and goodness knows what”

(Participant 03)

“Thinking of a time when, if I can’t manage the stairs, I can live downstairs permanently, you know”

(Participant 04)

“Now I’m gearing everything to it getting worse”

(Participant 04)

Participant 04 is describing a downstairs toilet which she has had modernised to make sure she can remain living at home in the future, whereas for Participant 03 and her husband, the provision of the stair lift reduced worry and anxiety, as well as long-term health concerns and the decision to stay living at home.

Participant 04 described having a wet room installed, to replace her bath, and the reasons for having the adaptation fitted initially.

"I just didn't have the power in my legs to pull myself out of the bath"

(Participant 04)

"First of all, I got the...a rail fitted. And then I had a step and seat, yeah. Mind to be perfectly honest, the seat was never much of a success[...]it's because like to lie in the bath, so it was probably me"

(Participant 04)

However, despite its benefits, Participant 04 immediately regretted having the wet room installed.

"Of course, it's reassuring. I know I'm not going to get stuck, but I miss my bath"

(Participant 04)

Participant 04 had a very different experience, and self-funded all of her adaptations, but the wet room from a firm canvassing door-to-door.

"It was somebody knocking on the door [...] the firm canvassed and it wasn't a good firm at all"

(Participant 04)

"I had to take out a loan, so it's going to be another five years before it's paid off"

(Participant 04)

"I think they hit me at a bad time, and I just agreed to anything and everything. And I should have thought a bit more about it"

(Participant 04)

Her experiences meant that she had felt pressured and duped into buying the adaptation. Participant 04 had installed and retained adaptations and equipment for the future, and was "hanging on" to the walker to use outside "when [her] legs are bad" (Image 25).

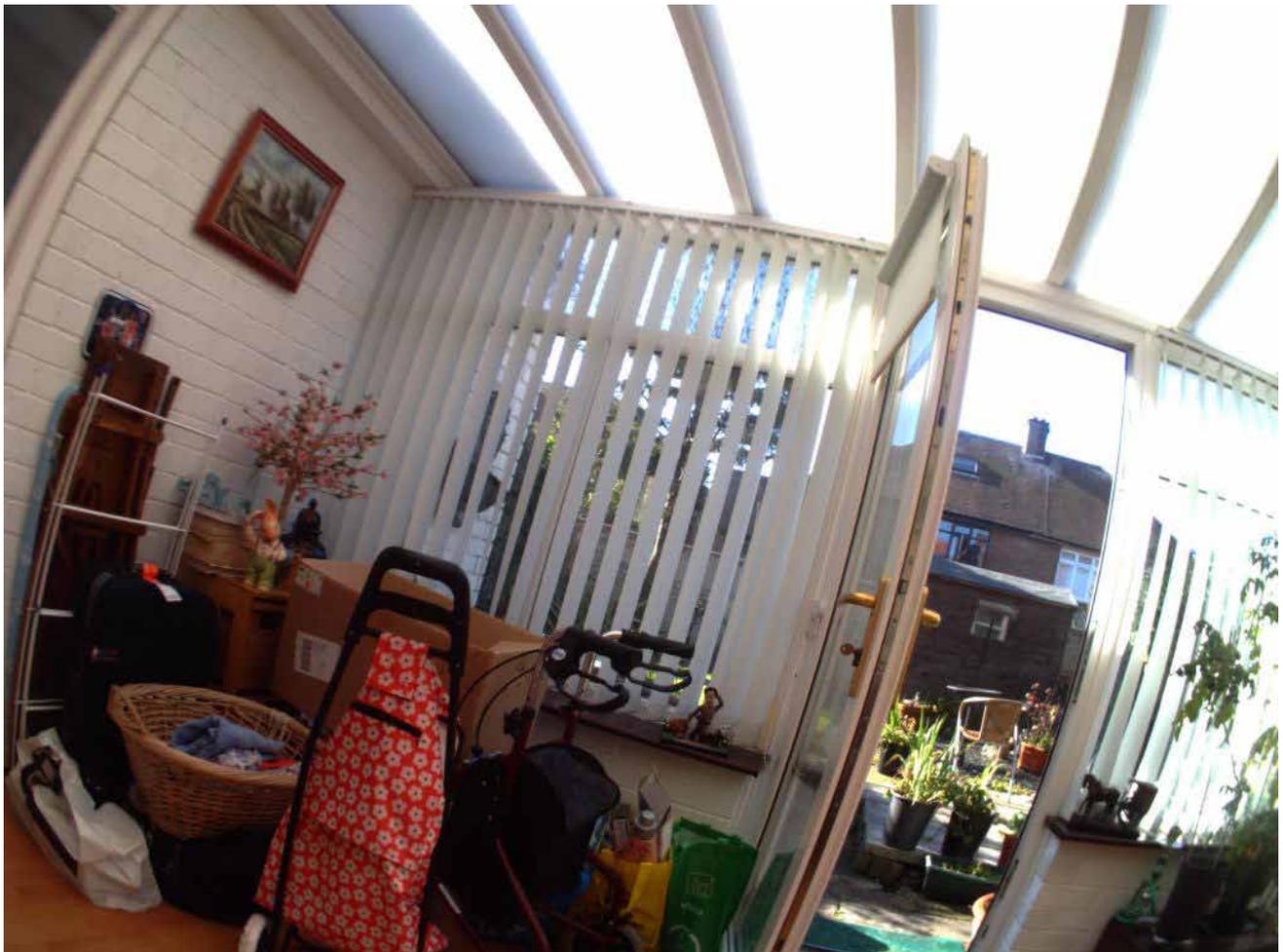


Image 25: Shopping trolley and walker (Participant 04)

The image shows the walker, as well as a shopping trolley of which Participant 04 explained the intermittent use.

“It depends on how confident I’m feeling on the day”

(Participant 04)

“I’ve got these things...not much for now, but...for time to come”

(Participant 04)

Adapting routine and changing behaviour

Some participants directly adapted their behaviour based on the acquirement for adaptations and equipment. Some placed equipment strategically around their home whereas others carried aids around with them. In Participant 01’s image set, it was possible to see a grabber hanging up in his kitchen which he describes using “all the time” and confirmed that this equipment remains in the kitchen, as well as a walking stick stood by the back door. This demonstrates the way in which individuals learn to adapt, and come to

understand their own needs. Other participants (including Participant 02 and Participant 05) have kept their grabber, and/or walking stick, near their armchair, and in Participant 05's case, carried it around the home. However, Participant 01 strategically places the equipment around his home (Image 21), dependent on how he uses the equipment. In considering taken for granted changes to one's routine, the equipment were not discussed by the participant, and when discussing the equipment in his own home, neither of these equipment were mentioned until prompted.



Image 21: Grabber and walking stick placed around the home (Participant 01)

Prompted discussion based on the camera images also opened up conversation in which Participant 01 discusses the use of a stool in the kitchen which he uses 'all the time'. Image 22 below clearly illustrates Participant 01 sitting whilst washing the dishes.



Image 22: Sitting on the perch stool to carry out household tasks (Participant 01)

Participant 01 also describes using the stool whilst carrying out other household chores.

“When I do my ironing, I use that plug there and I stand up here and sit with the ironing board here”

(Participant 01)

The stool allows Participant 01 to maintain participation in household chores, that he could otherwise not do due to standing for too long. However, it is also evident from the image below that Participant 01 has adapted this adaptation for his own use, and has the unintended use of a space to temporally hold his ironing once done (Image 23).



Image 23: Unintended use of stool (Participant 01)

The wearable camera also showed P006 sitting down whilst completing household chores that would typically be carried out whilst standing up, due to long-term pain caused by arthritis (Image 24).

"If I stand too long, I can't walk properly, you know. So I just [food to prepare into the living room] and sit there to do it"

(Participant 06)

"I've tried standing at the sink. I can stand long enough to wash dishes and empty a washing machine, you know. But when I'm standing a long time my hip hurts"

(Participant 06)



Image 24: Adapting behaviour to maintain functioning (Participant 06)

Although some food preparation was seen being completed standing at the kitchen bench, some was carried out whilst sat in the living room.

Behavioural adaptations did not only occur when the adaptation was installed, but also before and during the process of installation. Participant 06 described the negative adjustments experienced whilst she waited for the shower to be installed.

"I was sneaking showers as well"

(Participant 06)

"Honestly, I hated getting a wash down. It's not...that's not clean enough to me"

(Participant 06)

"My granddaughter used to come down and sit in the bathroom, just in case I feel or I needed help"

(Participant 06)

Participant 04 also acknowledges her change in behaviour due to increasing struggle to climb the stairs.

“I’m having to more or less pull myself up the stairs. And I’m going up sideways, you know. Two hands clinging on to the bannister, more or less”

(Participant 04)

As a result of this, she has adapted her own behaviour to limit her own use of the stairs. “[I go upstairs] once a day, yeah. I get up in the morning and I come downstairs-I’m downstairs for the rest of the day and then I go up to bed”

(Participant 04)

It is financial reasons, and appearance, as to why P004 has not yet gotten a stair lift. Furthermore, Participant 04 still views herself as being able to “manage the stairs” and will leave it as long as she can to have this installed.

Appendix seven: Elder's Council analysis

Elders Council (EC) lay expert data analysis workshop – 10th November 2017, 10-12noon

Attendees: Four members of Elders Council and the research team

Purpose of Workshop–

- To share with Elders Council members', project analysis activity (older people data), including interview and camera data and developing, ordering and modelling of key aspects/context related to common issues/themes that research team suggest are present across the data;
- Sharing this activity to have lay expert input and feedback about 'real world relevance' of what we think we are finding and how we are proposing to present and discuss such findings

Content

Cathy introduced the project, Phil presented the developing ordering/organising contextual model, Dom illustrated common themes/issues with verbatim extracts from interview data and Gemma presented camera data, case study

Elders Council Feedback Key points

1. The Model

The model is good as it gives a visual overview of a complex web of relationships between older person, home adaptation service/provider, the older person's resources and the services and funding sources. The more abstract content (the green boxes!) are less easy to understand than the relationship between the older person and the eservices (the blue and yellow boxes)

Need to revisit language e.g. capabilities, resources, capital – these seem quite organisational rather than personal. People might assume that we are discussing these at the level of systems rather than considering participants' resources such as assets and knowledge of systems. Also 'capabilities' might suggest a deficit!

Do not interpret others language or replace theirs with your own language. We understand that sometimes you use this language to relate findings to other evidence but you can challenge the language that is being used from within this evidence.

Need to mention home owners more explicitly.

How do we capture differences about what are optimal resources?

Research team response – Can we use the language of: information, choice and resources? We will consider this and also how to unpack the more abstract concepts (capabilities, capital). We can also engage with other academics using and developing this sort of model to suggest the need for 'inclusive' real world language.

2. Interview Common issues

- i) **Triggers** – self, family initiation e.g. meeting care needs
Downsizing – residential satisfaction,
- ii) **Access** – knowing where to ask, word of mouth, peer sharing re. 'know how', influences, lack of knowledge of systems
 - o Some discussion about access points through GP social prescribing route – is there a chance that such schemes are now focusing too narrowly on 'activities', people's social networks etc., rather than including wider issues, such as housing and home adaptations, that can have significant impact on quality of life and well being?
 - o Also if the route to home adaptation services might be through a third party such as a GP, is the older person's perspective, their goals, considered from within the consultation – who is making the decisions?
 - o There are different agendas and different dynamics in families, so family may take over older person's decision about home adaptations.
 - o There are people who don't ask for help just as there are those who don't know where to go for help.
- iii) **Installation** - Some participants experience delays but what troubled them most was not being informed, rather than the delay itself. Whilst for some there were some problems and disruption, in general, participants reported very positive outcomes including: improved movement, preventing relocation, improved independence with personal care, mental health impacts, greater control over life in general and positive impacts on family members
 - o A lot family members don't consider themselves as carers. Good to explore more the extent to which other family members, particularly adult children who are themselves ageing, gain positive benefits from older relative having home adaptations installed and how this may relieve some of the, 'having to manage someone who doesn't want to make changes and is not getting this help'.
 - o Also it is now common for families not to live physically close by, so home adaptations might ease their worry.
 - o EC's 'Information NOW', there is a spike in usage over Christmas and New Year period and perhaps this might be when family are visiting and notice that their older relative isn't coping that well. So visiting

intermittently, family members may notice change over time.

Research team response – in terms of recommendations for future research, useful to explore further, relationship between social prescribing and home adaptations. Also the need to explore family carers, particularly those in their 50s/60s, in relation to their role in older person's home adaptations, decision making and the impact of this on their quality of life and well being. Particularly those in their 50s/60s and

3. Camera data case study

A **case study** using camera images to describe use of fixed home adaptations and portable equipment, as well as self instigated home adaptations and equipment (e.g. installing non-fixed rails alongside outside steep steps leading down to the garden and leaving a zimmer frame at the bottom, for use in the garden. Participant using walking equipment in their bungalow, a mobile trolley to transport items they needed throughout the day and chose to sleep on their sofa in the living room. Of two bedroom, one was full of participant's furniture and memorabilia that they were attached to,

Discussion particular to this participant: did the person feel adaptation might help them to use a bed (e.g. automatic raising and lowering of the bed)? With some help perhaps the home could be decluttered?

General discussion:

- o How do we adapt ourselves to ageing and life stages in general? It is distressing that we have these sorts of examples such as people insisting on staying in a house even if it no longer functions for them at any level.
- o We need to go back a little further in people's lives. Your house is yours, your roots and giving this up, for some people that is very, very difficult.
- o I know resources are tight but level access from one point seems unfair. What if you need access to a garden? (Some local authorities will install hand rails etc. at one point of access to the outside, usually at the front of the house). It's (the rails) not expensive. Yes and if [participant] fell in the back that would be hugely expensive.
- o We had the same issue back in 1999 (recalling a local project)!
- o EC also raised question about whether research team had data on the private rented sector. It was explained that we had a small cohort because in general it had been very difficult to identify and recruit from this segment of the housing market. It seems that from within this sector, some local authorities don't routinely record data on major housing adaptations.
- o EC suggested they understand how hard it is to access private renters but that local authorities should keep such records.
- o Research team also noted similar issues with housing associations who because of changes to their home adaptations funding, now work with local

- o councils and this extends the assessment period.
- o EC also suggest that there is a lack of 'joined upness' in relation to home adaptations, for example people are likely to be in touch with social services and yet we probably aren't aware of what is taking place from within social services. We need joined up thinking and joined up intelligence
- o There are also enormous problems with sharing data online and across different organisations
- o How to apply new innovation to address health inequalities?
- o What do we know of people's lived experiences? Voice north is online, what of others? Are we reaching the people who are just getting by 'just managing'?
- o What of intergenerational homelessness?
- o Infrastructure is critical in terms of how do people get that bit of helping hand in terms of how they navigate the system and find the information they need? We do have 'Info Now', we have the information hub (Age UK?) but we don't have the next step in place. There used to be a housing navigation service. Care & Repair England might have aspirations but within public sector, there need to be social enterprise, for example links to hospital discharge plans.

Research team response Need to raise the need to focus on the private rental sector particularly as increasing number of older people, are becoming homeless. There are also issues of rising rents and having to chase some reluctant landlords to initiate and install home adaptations, as needed.

Also considering recommendations coming out of this project:

- o There are also issues with Housing Associations
- o Reaching the just managing is also a critical area
- o Intergenerational homelessness needs further exploration
- o Infrastructure in terms of facilitation people to navigate the system and find the right information at the right time

Appendix eight: Lived Experiences Housing Adaptations – Stakeholder event 25th May 2018

Feedback

Following project completion, a closed stakeholder feedback event was held at Northumbria University, convened by project partners Newcastle City Council, North Tyneside Council and Elders Council and supported by our funder Centre for Ageing Better. The purpose of the event was to confidentially share key findings and to give relevant stakeholders an opportunity to respond to our recommendations. This was to help us to ensure that our recommendations have real world relevance.

HousingLIN offered to host this event as part of their North east regional programme of events. 53 stakeholders attended the event, including those from local authority housing, adult social care, housing associations, architects, charities and voluntary organisations working with older people, health care trusts, companies involved with home adaptations and technology providers, as well as some independents.

Presentation and discussion of project findings and its recommendations, were embargoed until our official launch at the British Society of Gerontology annual conference (<https://www.britishgerontology.org/events-and-courses/bsg-annual-conference>) on the 6th July 2018. Following this presentation and also that of our funder Centre for Ageing Better, the project's research team convened small group discussion. This was guided by eight questions that encompass our proposed recommendations. These and the feedback we received at the event are presented below.

1. People wait too long (e.g. until a point of crisis) before they consider accessing home adaptations

- o Need to promote a team + integrated approach / be proactive not reactive (normalise/prevention)
- o Remove stigma + clinical connotations (aesthetics?)
- o National Advice Centre
- o Drip feed information and advice/engage early (help may not be available until a crisis e.g. medical referrals; priority basis, not known to services)
- o MOU carried through to policy

2. The processes (e.g. application, assessment and installation) of getting home adaptations take too long and may exacerbate problematic circumstances

- o Sure Start for older populations
- o Need to assess and evaluate 'wants' and 'needs' (proportionate perhaps – smaller adaptations – self certified?)

- Use regulatory reform orders (RRO) to simply process locally
- Standardise policy nationally
- Need realistic investment
- Simplify online assessment for minor adaptations
- Less variation in policy across the country
- Need decent homes standards future proofing our homes

3. In general, people don't know what's available, or what they're entitled to, in terms of home adaptations

- Raising the profile of DFG & social care
- Need national standards on what should be provided
- Need new models of living rather than care
- Need accessible and understandable information
- Need to be aware of language around home and product design
- Support people to move at a point of optimal life choices and wellbeing (? Use Older People/s assemblies to promote this)
- Promote the value of prevention (e.g. making good lifestyle choices)

4. As systems providing home adaptations are messy, and can involve multiple services, it's hard for people to find their way through the whole process

- Single point of access
- Navigator to start people on the journey
- Joined up working across the different teams
- Need housing MOTs to check safety

5. To deliver home adaptations requires a large amount of resources for services which may be (in the current economic climate) under-funded and/or overwhelmed, leading to unacceptable waiting times

- Invest in a handyperson scheme
- Government to set targets for DFG processing with penalty system if not met
- Redirect resources from health + future proof what might be needed (e.g. increase in Type 2 diabetes might lead to more amputations and greater need for wheelchairs)
- Transfer funding from acute to community services for speedier processing
- Post installation, need one year follow up and review
- Fee income from DFG needs ring fencing to resource administrative staff
- Policy responses and resources – are there alternative ways of dealing with home adaptations
- North East has specific needs (linked to deprivation)
- Bench marking – NE share NE Adaptations Reports within + between local authority, senior management

6. Many people use coping strategies, or self-fund adaptations, which may be unsuitable in meeting their needs

- o Combat stigma asking for help / people don't want to be financially assessed
- o Change from cure to prevention
- o Offer assessment for home owners at reduced cost
- o Make better use of new technology (e.g. smart exit/entry system makes key safe redundant) that gives more choice (e.g. reducing stigma)
- o Housing needs to work better within health and social care
- o There needs to be a single point of contact
- o Media awareness + offer videos of successful case studies (make it 'personal')
- o Need regulation to deal with 'scams'

7. Even if appropriate, home adaptations will not be valued and used efficiently if they are not "trusted" or integrated into the person's daily life

- o Imposed solutions – crisis / health and safety concerns vs. what person wants
- o Need a full assessment not just 'functional'/'utility'
- o "Try before you buy" – let people experience items first
- o Pro-active approaches for timely decisions
- o Trader (contractor) needs to have good rapport with service user as well as 'produce' quality work (wear identifiable uniform and follow code of conduct)

8. There is superficial and inconsistent monitoring and evaluation of home adaptations and their outcomes

- o Difficulty agreeing what is important to measure
- o Local transformational partnerships (LTPs) need to integrate into national frameworks
- o Need to capture: return on social investment, impact on individual Housing Associations and retaining customers
- o Differing priorities for different working
- o Structured feedback should be mandated Need anonymised data sharing nationwide
- o Demonstrate cost benefit of early, appropriate interventions informed by evidence from monitoring and evaluation
- o Increase joint working partnerships

This report is available at www.ageing-better.org.uk | For more info email info@ageing-better.org.uk



The Centre for Ageing Better received £50 million from the Big Lottery Fund in January 2015 in the form of an endowment to enable it to identify what works in the ageing sector by bridging the gap between research, evidence and practice.