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How do people access and experience home adaptations? Perspectives from people in later life and practitioners

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Summary

This report summarises the findings from recent research conducted on the lived experiences of home adaptations, funded by the Centre for Ageing Better. It draws on the views of both people in later life and practitioners to explore the home adaptations journey, including triggers, access, installation and outcomes.

Given that most older people live in mainstream accommodation and wish to continue living in their current property, the ability to modify one's home environment to meet changing needs is central to facilitating healthy ageing in place. The report highlights the importance of how personal contexts exhibit influence over each stage of the journey and recommends that delivery of home adaptation services and their future evaluations consider important contextual factors.

Background

Housing is widely acknowledged as having the potential to influence health and wellbeing (Gibson *et al.*, 2011; Liddell and Morris, 2010; Marmot, 2010; Thomson and Thomas, 2015; Thomson *et al.*, 2009) and poor housing is estimated to cost the National Health Service between £1.4 and £2.5 billion per annum, with many of the potential savings associated with reducing hazards such as excess cold and those related to falls (Nicol *et al.*, 2015). In the UK, over 80% of homeowners aged 65 and over wish to continue to live at home (Lloyd and Parry 2015). While many of these live independent and fulfilling lives, it can also present many challenges, not least because over 90% of people in the UK over 65 live in mainstream housing (ONS, 2014) which is often unable to support accessible housing features or lacks required adaptations (DCLG, 2016).

Recognition of the duty to ensure the cooperation and integration of services is slowly growing, including housing, where this has the potential to improve health and wellbeing through the prevention, reduction or delay of care needs within local authorities via the Care Act 2014 (LGA 2015). A recently updated Memorandum of Understanding on the health benefits of improving home environments has been agreed by a variety of government departments and agencies and third sector organisations, ranging from the Ministry of Housing, Communities & Local Government and Public Health England to Alzheimer's Society and the Chartered Institute of Housing (<https://www.housinglin.org.uk/Topics/type/Improving-Health-and-Care-through-the-home-A-National-Memorandum-of-Understanding/>). This details progress since 2014 on attempts to widen the debate on health and care needs to include the home, and also sets out the signatories' goals for the future including greater recognition on the preventative potential of housing, greater strategic planning, improved signposting and more shared learning (Alzheimer's Society *et al.* 2018). The House of Commons Communities and Local Government Committee's recent report (2018) into housing for older people has also argued that a national strategy is required.

The ability to modify home environments to better suit one's needs is central in the attempt to facilitate healthy 'ageing in place' (Adams and Hodges, 2018). NHS England statistics demonstrate the influence of home modifications on patient discharge. In 2017, the transfer of care of patients was delayed by 53,198 days for NHS organisations in England due to waits for community equipment and adaptations, up from 51,130 days in 2016 and 43,500 days in 2015 (NHS England, 2018).

Two significant reviews of evidence around home adaptations have been published recently. A review of 77 studies published from 1990 to 2015 from 16 countries conducted by Carnemolla and Bridge (2018) identified 21 different potential outcomes of adaptations spread across seven themes: falls-related evidence; improved function/self-care and independence; physical health and wellbeing; caregiving; economic effectiveness; ageing process; and social participation. The study found that the body of evidence reviewed showed mostly positive relationships across the potential outcomes and that this was strongest for reduction of falls and injuries.

The second review, funded by the Centre for Ageing Better, considered 60 studies published between 2000 and 2016 from a variety of countries. It found strong evidence that minor

modifications can be cost-effective in preventing falls and injuries, improving performance of everyday activities and improving mental health. In addition, they were found to be particularly effective when integrated with other repairs and home improvements and when the decision-making process involves individuals, families and carers (Powell *et al.*, 2017). The evidence also showed that the installation of adaptations can be delayed until a crisis point is reached, potentially reducing their effectiveness. There was more limited evidence on the impact of major adaptations and there is little known about older people's decision-making and overall experiences of acquiring, and living with, home adaptations.

This case study report details the findings of research carried out by Northumbria University, funded by the Centre for Ageing Better and in partnership with Newcastle University, Newcastle City Council, North Tyneside Council and Elders Council of Newcastle. The qualitative project focused on exploring the perspectives of older people who had received home adaptations in the past, to assess their impacts, and service providers who assisted in delivering them. It used in-depth interviews, wearable cameras (capturing taken-for-granted experiences) and practitioner focus groups. Topics for discussion were guided by wearable camera data, and input from lay participant members of the steering group. A total of 30 older people in receipt of home adaptations from a range of backgrounds (e.g. tenure, house type, type of adaptations, etc.) took part, alongside 39 practitioners.

The home adaptations journey

Although the participants in the study accessed a variety of different adaptations in response to a diverse range of health and other concerns, the majority experienced a shared journey. It covered the following phases, each of which will subsequently be discussed in more detail:

- Triggers: the decision that a home 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, it was important not to overlook the wide variation in participants' experiences of this journey, not only in terms of the service received and its resultant benefits, but also in the range of contexts and capabilities (experiences, needs, knowledge, expectations, etc.) they brought with them. This was crucial because it both greatly influenced their individual experience, but also allowed the adaptation, and the process of receiving it, to offer significant subsidiary benefits which may not be captured elsewhere.

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 home 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.

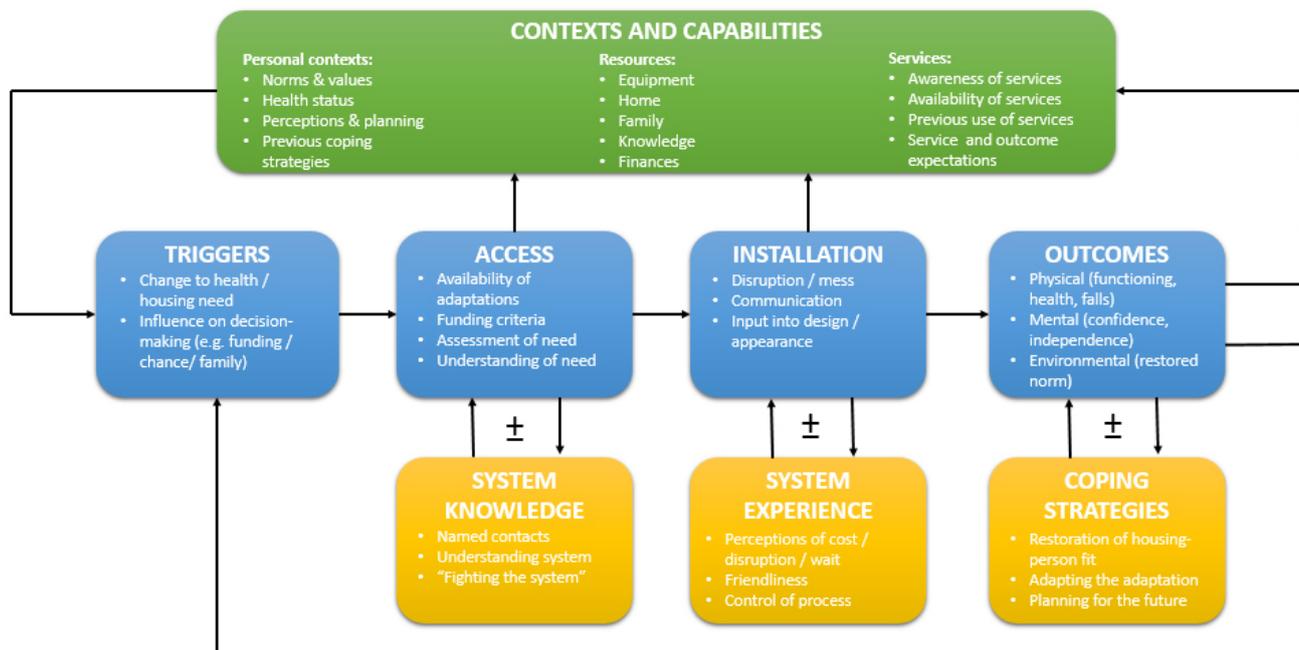


Figure 1: The Home Adaptations Journey

Each stage of the journey will now be discussed in more detail to highlight the range of impacts and benefits experienced, as well as areas of concern and development.

Triggers

Most participants spoke of their decision-making process to install a home adaptation as coming from a mixture of physical and psychological factors. These were often highlighted by 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 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.

A decline in physical health, and an unsupportive environment, was often cited as the main reason for use of an adaptation, and included issues such as a fall, a stroke, knee or hip replacements, loss of sight and pneumonia. Where possible, participants spoke of attempts to develop coping strategies to remain in their own home "as normal" and without change, but more serious or complex concerns, particularly when spread across multiple household members, were commonly seen to trigger the decision for a home adaptation.

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

(Participant 10)

Where physical changes did not dictate an immediate need for an adaptation, psychological factors such as independence, confidence, embarrassment, attachment to the home and future planning all played a significant role in underpinning the decision. 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 for 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). This was often placed in direct opposition to relocation to supported housing or downsizing to a smaller property.

“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)

Aside from the physical and psychological challenges participants were experiencing, several external factors also influenced the decision-making process in relation to home 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.

“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)

“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)

Access

A low level of understanding of what home adaptations were available, and the processes required to access them, was a significant barrier for participants. However, other concerns voiced by participants included potential logistical issues (particularly long time delays and waiting lists), cost (including poor awareness of funding stream available), and tenure (notably for those in the private rented sector). This could result in people attempting to continue in unsuitable environments at home, or even accessing adaptations which were inappropriate for their needs.

“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)

Practitioners also voiced the concern that these barriers could be exacerbated by inefficient processes of referral, assessment (including financial) and installation, which could result in low awareness of processes and significant delays. Although important, financial resources alone were not seen as a solution to this issue, as problems were more often underpinned by staffing and system issues.

“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.”

(Grants Officer)

One additional barrier which also held potential negative impacts was the appearance of adaptations and perceptions of age and disability. Design aspects of certain adaptations, particularly those which were clearly visible on the outside of the property (such as handrails) or due to their size (such as stair lifts), meant they were considered undesirable by participants. This could be because they were seen to spoil the aesthetic of the home environment, but most often it was because their visual presence was a reminder of the stigma of ageing or a sign of vulnerability.

“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)

This perception of age and disability was balanced in many cases by expectations of utility, which acted as a key enabler for access elsewhere.

“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)

Although other key facilitators included the use of promotion and awareness-raising of home adaptations and their systems, there was limited evidence of this occurring. Instead, participants expressed the benefits of having a named contact to approach and navigate them through the system. Few accessed information about home adaptations and assessment processes online, but there were positive experiences reported when participants had a contact (including local authority staff, but also having trusted building contractors) they could approach for advice and guidance.

“And [Council worker] was absolutely brilliant. She just sat there and she said... “You can get them in two days.” And they did.”

(Participant 15)



Figure 2

Unable to access an adaptation at the rear of her property, Participant 02 fitted a temporary handrail which she lacked confidence in using. A Zimmer frame can also be seen 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. She described the assessment process as being another barrier to acquiring further adaptations which she needed, stating she did not want to “*cave in yet*” as she was fearful of losing her attendance allowance and was “*dreading getting assessed*”.

Installation

Installation processes were often positively described by participants, particularly where there was clear communication and timelines in place. Where this was disrupted, negative impacts on wellbeing could result:

"...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 01)

Participants particularly welcomed the ability to form positive relationships with traders who were respectful and tailored the process to meet their need.

"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)

When design and installation did not meet this need, or installation was left incomplete or took longer than expected without clear communication, this had a clearly negative impact on the participant.

The most significant element of the installation process, however, was the perception of disruption. In some cases, this was seen as a potential barrier to accessing home adaptations and, like aesthetics, had to be weighed against potential utility. In most cases traders were described as being aware of this, and very sensitive to issues of noise and cleanliness, often ensuring that temporary toilet facilities remained available throughout. Yet, in other cases the mess was seen to have a negative impact on health concerns, and one household even completed the expensive step of staying in a hotel throughout the process.

"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)



Figure 3

A living room chair was raised for Participant 05, but 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*” (Participant 05). 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. 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... other furniture as well*”.

Outcomes

Once the journey was complete, participants highlighted almost universally positive outcomes following installation of the home adaptation. A number of these were seen to directly address the physical decline issues discussed as a trigger. These included better mobility around the home, more efficient use of the home and completion of daily tasks, greater ease in being able to travel outside the home and reduced falls. This suggests the potential for significant health impacts and the delay of requirements for services being involved in the future.

"...in terms of there 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)

Meanwhile, these outcomes were also underpinned by significant positive changes to mental health. The ability to live as they wanted in their own home, and carry out daily tasks as part of their normal routine was described by one participant to have *"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). Crucially, this is because adaptations were seen to address many of the psychological needs participants identified as triggers in the first instance, most notably confidence, security, control and independence.

"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)

"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)

However, positive outcomes were not limited to issues which were directly personal, as a number of more general benefits were also identified. These included prevention of the need to relocate from the home against the participant's wishes, increased social interaction through being more able to get in and out of the home, reduced need for additional support from services and family carers and increased value to the property.

Meanwhile, there were some limitations to impacts and remaining difficulties. These were primarily found in instances when health needs created problems which could not be overcome by adaptations (such as small bathrooms requiring wheelchair access or where adaptations themselves required a change in behaviour from a preferred option, such as no longer being able to use a bath). There was also a feeling from some participants that future decline and issues were inevitable, and that adaptations were merely temporarily delaying problems.

"So you have to live within your limitations. They... Modify the limitations, but they don't remove them."

(Participant 07)

The problem for practitioners, therefore, remained the difficulty to capture such wide-ranging benefits. Although existing processes captured some feedback information, much of this was functional and related to maintenance and ongoing need. Little was in place to capture any impact on psychological or wider benefits.

“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)

Contexts

Although there was a shared journey for older people in receipt of a home adaptation, how this was experienced often varied greatly due to individual contexts of the person and their environment. In fact, in many cases it was clear that this context was often the most significant factor in determining how the adaptation was accessed and experienced. For example, one participant with a professional background in architecture, or a family member working in local authority disability services, may have greater access to information and understanding on home adaptations than a participant who had never accessed services before or had little interest in housing. As such, individual contextual factors which were found to have an impact included, but were not limited to: attitudes to ageing; health concerns; attitude to future planning; existing coping strategies; access to equipment such as trolleys and perching stools; the design of the home; family and social networks; knowledge; finances; and understanding and availability of services. These issues all contained a spectrum of positions occupied by each individual which underpinned their perceived need for an adaptation, their expectations for the process and the values placed on outcomes, as illustrated by the two quotes below.

“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)

The significance of context was not only important in guiding the participant’s journey, but also therefore offered the possibility of the journey itself to influence the individual’s context in relation to future service use and need. A positive experience in this instance, the identification of a future contract or raised awareness about services, could help to influence timely and effective use of home adaptations in the future. As such, impacts were not just limited to the immediate use of one home adaptation, but held the possibility to guide awareness and service use beyond the individual cycle of one journey.

Discussion and Conclusion:

There has been considerable discussion about the need to consider development of housing to meet the needs of an ageing population and how these homes should be designed (Barac and Park, 2009; Best and Porteus, 2012; Best and Porteus, 2016; Wood, 2013; Wood and Vibert, 2017; Park and Porteus, 2018). The present study instead draws attention to ageing in place. Providing the opportunity for people in later life to remain living where they wish should arguably be of equal, if not greater, concern to policymakers and practitioners. By visiting people and using wearable cameras and a qualitative approach, the research was able to explore not only the processes of how home adaptations were accessed, but what expectations people held for them, how their impacts were experienced and used, and how this entire journey was underpinned by the wealth of diverse factors people, particularly in their own homes, bring.

The provision of home adaptations holds the potential to make a critical contribution to healthy ageing in place. This study has demonstrated the multiple potential benefits of home adaptations to people in later life. Several of these have not been identified or have been underexplored in previous research, such as impacts on travel outside the home, the prevention of relocation and the facilitation of ongoing support (Canemolla and Bridge, 2018). Several outcomes identified in the present study could conceivably have positive outcomes for public services through lower use from improved physical and mental health and greater levels of independence. Yet, even within such a diverse sample including a range of backgrounds, expectations and health conditions, home adaptations were almost always found to have a positive impact on people's lives and helped them to live as they wished in their own homes.

However, the research found that local authorities may not necessarily be capturing the wide range of outcomes which could potentially be achieved. There is no government guidance provided on the measurement of outcomes and no requirement to record them on the annual grant return completed for the government in relation to the DFG funding (called the 'LOGASnet'), which may represent a missed opportunity. Whilst the DFG has been considerably increased in recent years, at a time when public money is especially tight within local authorities the need to evidence whether and how different adaptations benefit recipients remains very pertinent. Some work is already underway in this regard. Following discussion at the 2018 British Society of Gerontology (BSG) conference in Manchester, Dr Rachel Russell of the University of Salford is now exploring the development of a BSG Special Interest Group which will consider how a consistent approach to measuring outcomes from home adaptations can be achieved and has also set up a discussion group which people can join.¹ It is hoped a more unified approach can be developed, the results from which can inform policy and practice.

The present study highlights the importance of context in this regard, demonstrating how triggers, access, installation and outcomes are all potentially influenced by factors specific to the individual. This creates a tension between the need for services to assess and capture "objective" outcomes and the fact that people experience and hope to use their home environments in entirely personal

1 <https://www.jiscmail.ac.uk/cgi-bin/webadmin?SUBED1=GENHOME2&A=1>

ways. Adequate understanding of adaptation recipients' 'baseline', such as their original physical and social environment, attitudes, health and service use will be central to understanding the impact of changes to the home and the processes required to support them. Key to this is timely, accessible and useful information, and the local understanding required to develop and deliver it, that enables informed decision making about the likely benefits of home adaptations. This in turn should better inform individuals of the 'home adaptation journey', such as the processes involved in accessing home adaptations via financial and health eligibility assessments. As such, home adaptation services and evaluations of processes and outcomes should take account of contextual factors as much as possible.

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Note

The views expressed in this paper are those of the authors and not necessarily those of the Housing Learning and Improvement Network.

About the Housing LIN

The Housing LIN is a sophisticated network bringing together over 40,000 housing, health and social care professionals in England and Wales to exemplify innovative housing solutions for an ageing population.

Recognised by government and industry as a leading 'knowledge hub' on specialist housing, our online and regional networked activities:

- connect people, ideas and resources to inform and improve the range of housing choices that enable older and disabled people to live independently
- provide intelligence on latest funding, research, policy and practice developments, and
- raise the profile of specialist housing with developers, commissioners and providers to plan, design and deliver aspirational housing for an ageing population.

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