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Versus Arthritis  
Copeman House  
St Mary's Gate  
Chesterfield  
S41 7TD

A report about aids and adaptations 2019

# ADAPTED HOMES, EMPOWERED LIVES

Adapted homes, empowered lives - A report about aids and adaptations 2019



## VERSUS ARTHRITIS

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## AUTHORSHIP AND CONTRIBUTION

This report was produced by Versus Arthritis' Policy and Public Affairs team. The lead author was Katherine Stevenson and the supporting author was Laura Boothman. Ollie Phelan led the final development of the recommendations, production and dissemination of the report. Additional support was provided by Sophia Steinberger, Tracey Loftis, Morgan Vine, Shona Cleland and James O'Malley.

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## FOREWORD FROM LIAM O'TOOLE, CEO VERSUS ARTHRITIS

Arthritis and related conditions of muscles, bones and joints affect 17.8 million people across the UK. People with these conditions lose their ability to move freely and often experience ongoing pain and fatigue. This can make ordinary, everyday activities a struggle or an impossibility. For some people with arthritis getting up from a chair, going up or down stairs or bathing is a major challenge. For people with arthritis in their hands doing up buttons, writing, cooking or using a phone can be difficult, time consuming and painful. These conditions steal quality of life from millions of people every day and can lead to a loss of their independence.

Versus Arthritis works alongside volunteers, healthcare professionals, researchers, friends and families to do everything we can to push back against arthritis. Together, we develop breakthrough treatments, campaign for arthritis to be a priority and provide support. Our remit covers all types of musculoskeletal conditions, including rheumatoid arthritis, osteoarthritis, back pain and osteoporosis. Through our policy work we identify opportunities to improve the services, support and information available to people with arthritis and musculoskeletal conditions to drive improvement.

In this report, we explore the difference aids and adaptations in the home can make to people with arthritis. Through interviews and a research survey we listened to people's experiences of using aids and adaptations – from bottle openers, chair raisers and grab rails, to ramps, stair lifts and wet rooms. We reached three key conclusions:

Firstly, aids and adaptations in the home have a positive impact on the quality of life for many people with arthritis. For some people, having an aid or adaptation can make the difference between being able to do certain everyday activities independently, rather than being reliant on someone else.

Secondly, although many people with arthritis are eligible to have aids and adaptations provided free of charge by their local authorities, few people access this support. In our study, 16% of people with eligible care needs had aids and adaptations provided by their local authority.

Lastly, people are too often unaware of the support which should be available to them or how to access it. Only 16% of people with eligible care needs know of their local authority's duty to provide aids and adaptations.

Our report includes the direct experiences of people with arthritis, in their own words. It also includes a series of recommendations for change. We have identified actions for both local and national Government to improve the ways that aids and adaptations are provided and to tackle potential unwarranted variation across the country. Versus Arthritis is keen to work with decision makers, local authorities, directors of adult social services and others with an interest in this important area of social care so that, together, we can push back against arthritis.

**Liam O'Toole, CEO, Versus Arthritis**



Liam O'Toole



## FOREWORD FROM DR ANNA DIXON, CHIEF EXECUTIVE, CENTRE FOR AGEING BETTER

The homes we live in are a crucial determinant for our wellbeing, health and happiness. As we age, our needs change and so must our homes. People are living longer, but many are doing so with reduced mobility and multiple long-term conditions. Yet, the vast majority of the homes we have built are not suitable for the later stages of our lives. Fitting aids and adaptations into homes is a cost-effective way to meet the needs of an ageing and changing population.

Our own research shows that major home adaptations, such as wet-rooms or stair-lifts, can help people with long-term conditions to live safely and comfortably in their homes, and can help people to maintain their quality of life and independence. Equally, the provision of smaller aids and adaptations can help people to keep on doing the things they want to do for longer. Activities such as cooking and washing, which they previously struggled with, become manageable again.

Investment in adaptations is highly cost-effective, helping to improve well-being, keep people out of hospital, prevent or delay moves into residential care and reduce the need for carers. This is particularly true when they are installed early on and in combination with repairs and improvements.

This report from Versus Arthritis is a welcome addition to the evidence base and highlights the positive impact aids and adaptations can have for people with arthritis and related musculoskeletal conditions. It also echoes our own findings on how the current system is letting people down.

All too often, people struggle to access the aids and adaptations that could transform their lives for the better. Local authorities are legally obliged to fund aids and adaptations costing up to £1,000 for people with eligible care needs, but too many people miss out because they don't know about the support available. Information and advice about these services is often difficult to find, despite this also being a legal duty. For the Disabled Facilities Grant, which provides crucial funding for major home adaptations, the application process can be slow, difficult and inconsistent.

With 80% of the homes that we will live in by 2050 already built, we urgently need to adapt our current housing stock. This report and its recommendations should serve as a catalyst for local and national government, charities, private industry and those directly affected to work together to ensure more homes are adapted to allow us to live well in later life.

**Dr Anna Dixon, Chief Executive, Centre for Ageing Better**



Dr Anna Dixon

## EXECUTIVE SUMMARY

To live with arthritis or a related musculoskeletal condition is to live in pain. It is to live with physical limitations. For many people with arthritis this makes life at home challenging and everyday tasks slow, painful or impossible. But it doesn't have to be this way. We know that home aids and adaptations - from a lever tap and a jar opener, to a grab rail and a stair lift - can have a hugely positive impact on the lives of people with arthritis. They can be the difference between depending on another person and independence.

This report aims to understand the impact aids and adaptations in the home can have on the quality of life of people with musculoskeletal conditions; and the barriers that can prevent people from accessing and using them. To achieve this, Versus Arthritis has undertaken qualitative and quantitative research, alongside exploration and analysis of the policy landscape in this area. Our report sets out recommendations for local and national government on how the current system of providing aids and adaptations should be improved.

## OVERVIEW OF FINDINGS

The debilitating impact that arthritis can have on the lives of people with the condition is stark. The impact of someone's condition can be assessed by how difficult they find it to achieve activities of daily living. These are activities that most people take for granted; anything from washing and dressing, to getting around the home safely or using the toilet. In our study, 55% of adults with a musculoskeletal condition could not achieve two outcomes of daily living and almost half said they struggled to achieve three of these. In addition, we know these conditions don't only impact people's physical well-being but can result in a loss of independence that can affect people's emotional and mental well-being too.

Take the example of Simon, aged 39. He has lived with rheumatoid arthritis his entire life. During a flare up a few years ago, he was confined to his bed. He depended on family members to achieve the most basic of activities. 'You cannot imagine anything more degrading than relying on family members to clean you when going to the toilet,' Simon told us. He received aids from his local council including bespoke handles near the toilet, tailored to his height and hand size, a

bio-bidet to help him wash after using the toilet and a bath seat. Having a stairlift installed by the council has also been a huge benefit. It means Simon can put the children to bed when his wife Izzy is working late.

Home aids and adaptations can make a huge difference for people like Simon. Aids and adaptations are widely used by people with musculoskeletal conditions - in our research, 60% of people with a musculoskeletal condition used one. Of those, 95% felt that aids and adaptations have had a positive impact on their lives; 79% said they helped them maintain their independence; and for 14% of those people, aids and adaptations made the difference between dependence and independence.

Local authorities have a legal duty under the Care Act 2014 to provide community equipment (aids of any value and minor adaptations costing less than £1,000) free of charge to those who cannot complete two or more daily living activities. This is not means tested. Local authorities also have a legal duty, under the Housing Grants Construction Regeneration Act 1996, to meet the needs of people living with

disabilities, through the form of a means-tested Disabled Facilities Grant (DFG). Those who need an adaptation over the value of £1,000 such as ramps or wet rooms, can apply for a DFG.

Despite strong evidence of the positive impact of aids and adaptations, our research has found that many people with arthritis are not accessing support from their local authority. Only 16% of people we surveyed were getting their aids and adaptations from their local authority. This has two principal knock-on effects:

Firstly, 52% of people with arthritis who have eligible care needs that we surveyed had paid for items themselves. In our study, the average aid and adaptation cost £200 and even the costs of buying multiple smaller items can quickly add up.

***'95% of people with arthritis felt that aids and adaptations had a positive impact on their lives'***

Secondly, and more worryingly, many go without items that could help them lead more independent lives. In our study, 20% of people with eligible needs did not use any aids and adaptations, despite being entitled to them. These people may have unmet needs as a result.

The question remains: why do people not access aids and adaptations through their local authority? Fundamentally, there is a lack of awareness amongst people with arthritis of what support exists. People need information and advice to support them to make decisions and manage their own health and well-being. However, only 16% of the people with eligible care needs in our study knew of their local authority's duty to provide community equipment free of charge.

Furthermore, once accessed, the system is difficult to navigate. In our study, 54% of those who accessed aids and adaptations told us that they have had difficulty accessing aids and adaptations through their local authority.

Jennylyn was 31 when she was diagnosed with rheumatoid arthritis. Her diagnosis was sudden and she quickly started using crutches as both her knees needed replacing. She got in touch with her council and was offered a raised toilet seat. It was only when she contacted them a second time, at the suggestion of her sister who worked for the council, that she managed to get a full home assessment to ensure her needs were met.

She has since been provided with grab rails, a kettle tipper, raised plug sockets and other aids and adaptations. Most people without links to a council would not have known that they were entitled to more items that would fully meet their needs. Our study uncovered similar issues around the DFG. People are often unaware that it exists and face long waiting times when they do apply. Our findings also suggest that the means-test, which underpins access to the DFG, is outdated.

Aids and adaptations are important for people with arthritis and can play a key part in preventing or delaying care needs. There is much scope to improve local authority provision of aids and adaptations and ensure people with musculoskeletal conditions get better access to aids and equipment that can make so much positive difference to their quality of life.





# RECOMMENDATIONS

**1** Community equipment (aids of any value and minor adaptations up to the value of £1000) should be provided by local authorities to people with eligible needs free of charge. However, there is variation in provision of community equipment across local authorities. There are reports that some local authorities are introducing local pricing thresholds. **The Department of Health and Social Care (DHSC) should investigate and report on the reasons underlying the variation in local authority expenditure on community equipment.**

**2** Aids and adaptations are part of a preventative approach that can help reduce or delay care and support needs. They support quality of life and independence for people with musculoskeletal conditions. However, there is a lack of guidance illustrating what these services should look like and demonstrating their positive impact. **DHSC should commission an expert body to develop a centralised resource focused on home aids and adaptations. This should include updated best practice guidance for the provision of aids and adaptations, including information and advice, and evidence of return on investment.**

**3** Local authorities have a duty to provide accessible information and advice about the care and support services they provide. However, many local authorities are not meeting this duty and people with musculoskeletal conditions do not have access to the information on aids and adaptations that they need. **Local authorities should work with local partners to evaluate their information and advice services about aids and adaptations and housing, including the promotion of information and advice, in line with best practice guidance to ensure they meet the needs of people with musculoskeletal conditions.**

**4** Local authority housing departments have a legal duty to meet the needs of people living with disabilities. Provision of Disabled Facilities Grants (DFGs) is part of this duty. However, the process of means-testing, through which people access DFGs, has not been reviewed in over a decade. In addition to this, the grant is not well promoted. **We recommend that the Government implements the recommendations from the 2018 independent, expert review of the Disabled Facilities Grant, particularly those focussed on: future funding; information and advice for the general public; the means-test; and better analysis of local need.**

**5** Local authorities have a duty to plan and provide care and support services at both an individual and population level. However, there is a lack of data on major causes of care and support needs to enable effective provision of services. **DHSC should ensure that the remit to NHS Digital for 2020-21 and subsequent years includes activity to deliver closer integration of data from social care, health care and community health settings. Such data should also be made available for research purposes.**

**6** Responsibility for the provision of aids and adaptations is fragmented. Within local authorities, it is split across social care and housing departments. At a national level, responsibility is divided between the Department of Health and Social Care (DHSC) and the Ministry of Housing, Communities and Local Government (MHCLG). **Building on the joint working by the DHSC and the MHCLG around the Social Care Green Paper, the Departments should establish ongoing ways of integrated working around social care and housing policy. An initial workstream should be the provision of home aids and adaptations.**





Musculoskeletal conditions, including osteoarthritis and back pain, are typically painful and can cause functional limitations. They affect people's physical and mental well-being.

Aids and adaptations in the home may help people to overcome some of the functional limitations that can be caused by musculoskeletal conditions. However, many people don't use aids and adaptations which could improve their quality of life and empower them to live independently.

## 1.1 PURPOSE OF REPORT

This report aims to understand the impact of aids and adaptations in the home, on the quality of life of people with musculoskeletal conditions and the barriers that can prevent people from accessing

and using them. It also sets out recommendations for local and national government on how the current system of providing aids and adaptations could be improved.

## 1.2 DEFINITIONS

There are many different types of equipment and home modifications that can support people to maintain their quality of life and live independently. This report uses the following definitions:

### Aids

An aid helps people to manage everyday tasks such as bathing, dressing, and cooking (See Box 6, page 32).

### Adaptations

An adaptation is a more substantial addition or alteration that primarily helps someone to maintain freedom of movement around their home. Minor adaptations are defined as those costing less than £1000. Major adaptations cost more than £1000.<sup>1</sup> (See Box 6, page 32).

Community equipment is the name given to aids of any value and minor adaptations, costing less than £1000, in the Care Act 2014.

# 01. INTRODUCTION



## Box 1: Quality of life, well-being and independence

The positive impact aids and adaptations can have for people with musculoskeletal conditions, is underpinned by three interrelated concepts: quality of life, well-being and independence.

### Quality of life

In broad terms, quality of life is the concept that there is more to happiness and living well than the absence of sickness.<sup>2</sup> It is the sum of all the important elements that make up a person's life.

Versus Arthritis has investigated the factors that have most impact on the quality of life of people with musculoskeletal conditions. For people with these conditions pain has a significant negative impact on quality of life. Conversely, reducing pain is an important factor for improving quality of life.<sup>3</sup> Quality of life is underpinned by different forms of well-being.

### Well-being

There are many types of well-being including physical, mental and social well-being.<sup>4</sup> Well-being is a founding principle of the Care Act 2014. Well-being is defined within the Care Act as a broad concept. The elements of the definition that are most relevant to people with musculoskeletal conditions are:

- Physical and mental health and emotional well-being;
- Control by the individual over day-to-day life (including over care and support, or support, provided to the individual and the way in which it is provided);
- Suitability of living accommodation.<sup>5</sup>

See Annex 2 for the full definition.

### Independence

Independence refers to a person's ability to achieve the tasks of everyday living (sometimes referred to as daily outcomes) without the assistance of another individual. Independence is one element that contributes to a person's well-being and in turn to their overall quality of life.

Independence may be inextricably linked with other feelings of dignity, control, self-esteem and fulfilment. A reduction in a person's level of independence not only influences these feelings, but may negatively impact aspects of their well-being, and can also lead to an overall reduction in quality of life.<sup>6</sup>

***'Independence may be inextricably linked with other feelings of dignity, control, self-esteem and fulfilment'***

There are many ways of understanding independence, and it is not defined in the Care Act. However, the Care Act does hold independence up as a critical concept for individuals receiving care and support.

The Care Act emphasises the importance of people having choice and control over the care and support they receive so they can live the life they want to live. Choice and control are key aspects of independence.

The relationship between quality of life, well-being and independence is an important and recurring theme in this report. The impact of aids and adaptations on quality of life, well-being and independence is discussed in section 3.3.

## 1.3 IMPACT OF MUSCULOSKELETAL CONDITIONS

Musculoskeletal conditions are disorders of the bones, muscles and spine, as well as some autoimmune conditions such as lupus. Musculoskeletal conditions interfere with people's ability to carry out their normal daily activities. Common symptoms may include pain, joint

stiffness and a loss of mobility and dexterity. The symptoms can fluctuate over time. The pain and functional limitations that can be caused by these conditions reduce quality of life, can rob people of their independence and impair their ability to participate in family, social and working life.

## 1.4 PREVALANCE AND IMPACT

Around 17.8 million people in the UK have a musculoskeletal condition such as arthritis, back pain or neck pain.<sup>9</sup> The UK Global Burden of Disease study identifies musculoskeletal conditions as the largest single cause of years lived with disability (YLDs) and the third-largest cause of disability adjusted life years (DALYs).<sup>10</sup>

The prevalence of musculoskeletal conditions is increasing because the population is ageing, and levels of obesity and physical inactivity are growing. By 2050, arthritis is likely to affect one in five people in the UK.<sup>11</sup>

The impact of musculoskeletal conditions is felt across health and social care services, the economy and wider society. NHS England spending on these conditions totalled £4.7 billion in 2013/14 and makes up the third biggest spend annually.<sup>12</sup>

Musculoskeletal conditions are the most prevalent diseases in the working age population. In 2016, 30.8 million working days were lost in the UK due to musculoskeletal problems.<sup>13</sup>

People with musculoskeletal conditions are also likely to retire early and musculoskeletal conditions are a common reason for people seeking state support.

The combined cost to the UK economy of rheumatoid arthritis and osteoarthritis is estimated to be £14.8 billion per year, with back pain adding a further £10 billion of indirect costs.<sup>14</sup>

***'By 2050, arthritis is likely to affect one in five people in the UK'***

Musculoskeletal conditions are also an important but under-recognised contributor to health inequalities. People in the lowest income quintile are more likely to report persistent pain and the pain they experience is also likely to be more severe.<sup>15</sup>

# SIMON'S STORY

## 39 YEARS OLD, RHEUMATOID ARTHRITIS

Simon has been living with rheumatoid arthritis all his life and it affects every joint in his body. Four years ago, a flare up left him confined to bed for several weeks, during which time he required help with nearly every daily activity, including going to the toilet.

When Simon's second child was born, the family moved to a four-bedroom house which had in-built adaptations, including a spare room downstairs, a flat route from the front to the back garden, wide doorways to accommodate a wheelchair and high-level plug sockets. Simon also received aids from his local council including bespoke handles near the toilet, tailored to his height and hand size, a bio-bidet to help him wash after using the toilet, a bath seat and gradual steps and handrails leading up to the front door.

The aids and adaptations Simon has improved his quality of life. "You cannot imagine anything more degrading than relying on family members to clean you after going to the toilet," he says.

"The bio bidet has been fantastic in that regard." Having a stairlift installed by the council has also been a huge benefit. It means Simon can put the children to bed when his wife Izzy is working late.

***"You cannot imagine anything more degrading than relying on family members to clean you after going to the toilet."***

Despite knowing who to contact in his local authority, Simon found accessing major adaptations difficult. He and his wife applied for a Disabled Facilities Grant (DFG) to put in a downstairs bathroom. However, the family were told they would have to pay £78,000 towards the cost of the work, which they couldn't afford. Simon felt that the means test "never took into account our outgoings – my mortgage isn't cheap, and we're both working part-time."





**Table 1: Groups of musculoskeletal conditions**

Broadly, there are three groups of musculoskeletal conditions: inflammatory conditions, conditions of musculoskeletal pain and osteoporosis and fragility fractures.

Group	1: Inflammatory conditions	2: Conditions of musculoskeletal pain	3: Osteoporosis and fragility fractures
<b>Example</b>	Rheumatoid arthritis.	Osteoarthritis, back pain.	Fracture after a fall from a standing height. <sup>a</sup>
<b>Age</b>	Any.	More common with rising age.	Mainly affects older people.
<b>Progression</b>	Often rapid onset.	Gradual onset.	Osteoporosis is a gradual weakening of bone. Fragility fractures are sudden discreet events.
<b>Prevalence</b>	Common (e.g. around 400,000 adults in the UK have rheumatoid arthritis).	Very common (e.g. 8.75 million people in the UK have sought treatment for osteoarthritis).	Common (e.g. around 89,000 hip fragility fractures occur each year in the UK).
<b>Symptoms</b>	Common musculoskeletal symptoms include pain, joint stiffness and limitation of movement. Symptoms often fluctuate in severity over time.		Osteoporosis itself is painless. Fragility fractures are painful and disabling.
<b>Extent of Disease</b>	Can affect any part of the body including skin, eyes and internal organs.	Affects the joints, spine and pain system.	Hip, wrist and spinal bones are the most common sites of fractures.
<b>Main treatment location</b>	Urgent specialist treatment is needed, and usually provided in hospital outpatients.	Primary/community care for most people. Joint replacement requires hospital admission.	Primary care for prevention. Hospital for treatment of fractures.
<b>Medical treatment</b>	Medication to suppress the immune system.	Pain management. Support to maintain healthy body weight. For severe cases joint replacement may be necessary.	Bone-strengthening drugs. Fractures may require surgery.
<b>Physical activity benefits</b>	Generic, self-determined and prescribed exercises are important adjunct to medical therapy.	Generic, self-determined and prescribed exercises are main treatment approach.	Generic, self-determined and prescribed exercises prevent falls, strengthen bone and enhance recovery after a fracture.
<b>Modifiable risk factors</b>	Smoking.	Injury, obesity, physical inactivity.	Smoking, alcohol intake, poor nutrition including insufficient vitamin D, physical inactivity.

<sup>a</sup>Osteoporosis is a condition of bone weakening which in itself is painless. Fragility fractures caused by osteoporosis happen when frail bones break, causing pain and disability. Bone fractures can also occur due to trauma or injury.

## Box 2: What is disability?

The Equality Act 2010 sets out a legal definition of disability: 'a person has a disability if they have a physical or mental impairment and that impairment has a substantial and long-term adverse effect on that person's ability to carry out normal day-to-day activities'.<sup>7</sup>

The Housing Grants, Construction and Regeneration Act 1996 sets out a different definition of disability (see annex 7), which is used as a basis to determine whether a person qualifies for a Disabled Facilities Grant (DFG).

Despite musculoskeletal conditions being a leading cause of disability, not everyone living with a musculoskeletal

condition will meet either of these definitions of disability or consider themselves disabled.

Another way of understanding disability is the social model of disability. This argues that whilst people live with physical or mental impairments, society is the disabling factor because social environments are not easily accessible for people with physical or mental impairments.<sup>8</sup>

The social model of disability can be a helpful concept in policy work. Aids and adaptations can mitigate the disabling societal effect, by making the home environment more easily navigable, and empowering people to move around their home more freely and independently.

## 1.5 RESEARCH APPROACH AND USE OF REPORT

Versus Arthritis has commissioned both qualitative and quantitative research to understand the positive impact aids and adaptations in the home have on quality of life for people with musculoskeletal conditions (see Methods, Annex 8). This report offers key findings about people's experiences of accessing

aids and adaptations from their local authority. It also provides examples of best practice in the ways local authorities deliver home aids and adaptations. We hope this report prompts local authorities to examine their provision of aids and adaptations, and take action to better support people with musculoskeletal conditions.


Local authorities have duties to provide care and support to those with eligible care needs, including aids and adaptations in the home, as well as housing services. These duties are set out in the Care Act 2014<sup>16</sup>, the Housing Grants, Construction, and Regeneration Act 1996<sup>17</sup> and their supporting regulations and guidance.

The policy landscape setting out these duties is complex and, because a number of different pieces of legislation and bodies are involved, the system for the provision of aids and adaptations can be difficult to understand and navigate.

The Care Act places two broad duties on local authorities: promoting well-being; and preventing, reducing or delaying care needs. The duties are universal and apply to everyone in the local authorities' local population.

There are also four specific responsibilities relevant to the provision of aids and adaptations in the Act. These duties relate to the provision of community equipment, information and advice services, and the duties to assess and to ensure that people's care needs are met.

Housing authorities have duties to meet the housing needs of people with disability, including the provision of Disabled Facilities Grants.

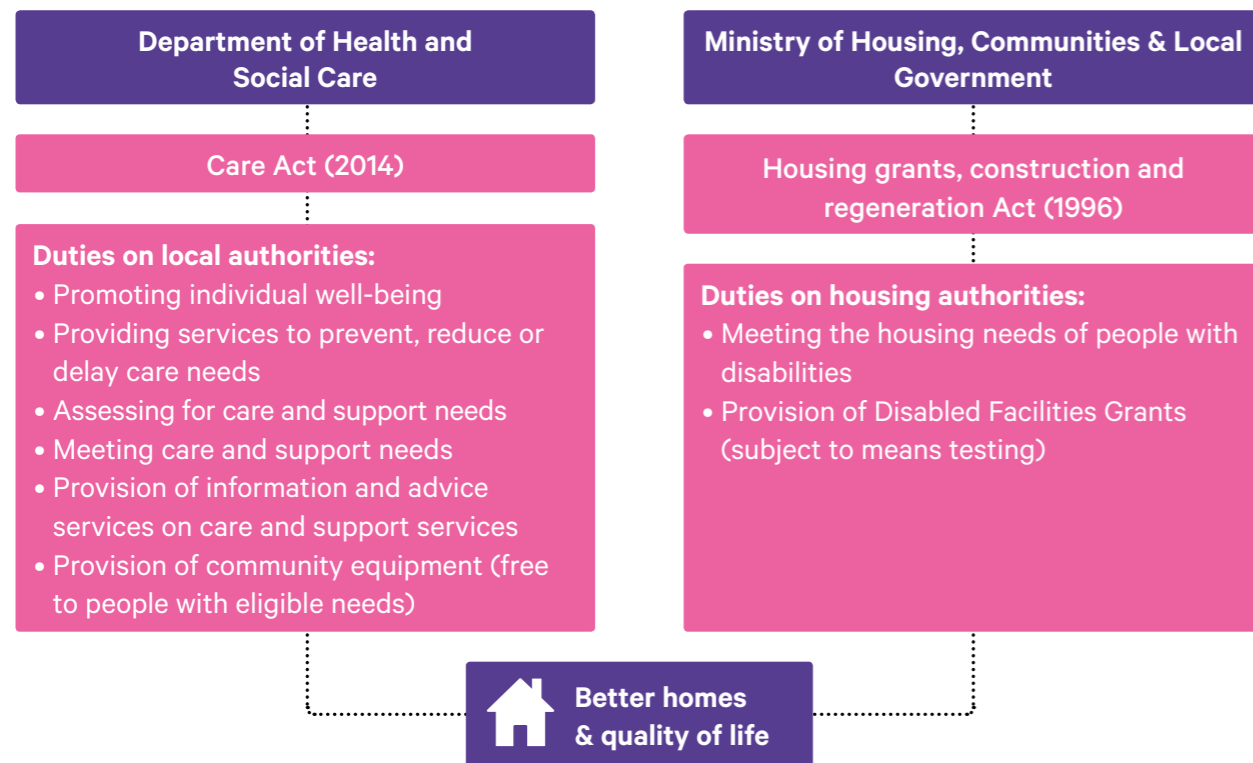


# 02.

## LOCAL AUTHORITY DUTIES AND PROVISION



## Policy covering aids and adaptations provision



### 2.1 THE DUTY TO PROMOTE WELL-BEING

Local authorities have a legal duty, under the Care Act, to ‘promote... an individual’s well-being’<sup>18</sup> (See Annex 2 for a full definition of well-

being). The well-being principle recognises that a person’s ambitions to achieve certain outcomes should shape the care and support they receive.<sup>19</sup>

### 2.2 THE DUTY TO PREVENT CARE AND SUPPORT NEEDS

Local authorities have a second duty under the Care Act to ‘provide or arrange for services intended to prevent, reduce or delay care and support needs for adults and carers’.<sup>20</sup> This applies to many different types of support, services, facilities and other resources, not just in social care but also in the housing and public health services. Prevention is an ongoing consideration rather than a single activity.

There are three broad approaches to prevention:

- Primary prevention aimed at preventing

- people developing needs;
- Secondary prevention focused on reducing further deterioration; and
- Tertiary prevention to delay the impact of an existing disability.<sup>21</sup>

The prevention duty is universal and applies whether or not someone has an existing care and support need (see Annex 3).

Home aids and adaptations are important to people with musculoskeletal conditions because they can help to reduce or delay care needs,

which may arise because of the functional limitations associated with their condition. These interventions can help people with musculoskeletal conditions to live well and

remain independent in their own homes. In a 2015 survey, 96% of occupational therapists agreed that home adaptations reduce the need for formal social care.<sup>22,23</sup>

### 2.3 ELIGIBILITY FOR SOCIAL CARE

Local authorities are responsible for determining whether an adult has needs for care and support, what those needs are, and whether an adult’s needs are eligible for their local authority to meet them.<sup>25</sup> To fulfil this responsibility local authorities have a legal duty to provide needs assessments. Anyone can request a needs assessment from their local authority. The needs assessment also determines eligibility for community equipment. Adults are eligible for community equipment if as a result of a physical or mental illness or injury they are unable to achieve two or more outcomes of daily living (for example, washing and dressing – see box 5) and this has a significant impact on their well-being. Local authorities must consider the fluctuating nature of conditions such as inflammatory forms of arthritis when determining eligibility.<sup>26</sup>

When an adult has needs eligible for care and support, the local authority must ensure that these needs are met.<sup>27</sup> If an adult doesn’t meet the eligibility criteria, the local authority must provide easily accessible, written, personalised feedback. It must also provide that person with information and advice about where they can access support and services in the local community.<sup>28,29</sup> People

living with musculoskeletal conditions who have needs that meet the eligibility criteria should receive community equipment (aids and minor adaptations) free of charge. For other care and support services, such as care in the home, the local authority will undertake a financial assessment to decide if an adult must pay for care and support (see Box 3).

#### Box 3: Financial assessment for social care

The financial assessment for social care is carried out by the local authority and is designed to ensure people only pay what they can afford for the care and support they need.<sup>30</sup> Some people may be entitled to a degree of financial support based on means testing. Others may be entitled to free care. The needs assessment and financial assessment can be carried out simultaneously, but their outcomes must be independent of each other. For further information on needs and financial assessments see Annex 5.

### 2.4 COMMUNITY EQUIPMENT

Community equipment (aids of any value and minor adaptations costing less than £1000) includes hand rails, specially designed cutlery and other items that help people manage daily living (see Annex 4). Community

equipment should be provided for free by local authorities to people with eligible needs.<sup>24</sup> This is an important service for people with musculoskeletal conditions and can help to meet, reduce or delay care needs.



# DEBORAH'S STORY

## 72 YEARS OLD, OSTEOARTHRITIS

"I've had lever taps put in, and I've never looked back". Deborah has adapted her home with 'everyday' products that help with her osteoarthritis. Deborah's osteoarthritis set in five years ago and she can no longer make a fist with her hands. This means she finds daily tasks that require gripping objects impossible.

Carrying things is more of a challenge these days. For Deborah, lever taps have made a huge difference. "My old kitchen had these old-fashioned taps. They certainly used to upset me – not being able to turn them. Having them replaced has made a difference."

Deborah moved to her bungalow because she felt her previous home was no longer practical. The feeling that she couldn't spend all day "going up and down" stairs is what shaped her decision to move. As well as lever taps and a stair-free home, Deborah loves her handle-free wardrobe. She likes the way it looks;

the positive impact it has on her arthritis is an added benefit. In the kitchen she has a verity of different gadgets, including a soft-handled knife and jar opener. Deborah is a pragmatist when it comes to aids and adaptations. She sees herself as too young for them at the moment, but is open to change.

***"Information is a really good thing, the more you know the better"***

"I hope it doesn't get to the point where I need handles in the house – but I suppose if I did I would do it." Deborah's daughter works for DIAL Leeds (a disabled people's social enterprise), so she has a good source of information. "Information is a really good thing, the more you know the better". However, Deborah wasn't aware that she should be able to get information and advice from her council.



## 2.5 INFORMATION AND ADVICE SERVICES

Local authorities have a legal duty to establish and maintain information and advice services relating to care and support for adults and carers in their local area.<sup>31</sup> This includes information and advice on the provision of home

aids and adaptations. Good information and advice is essential in empowering people with musculoskeletal conditions to be independent and in control of their care and support.<sup>32,33,34</sup>

## 2.6 DISABLED FACILITIES GRANTS AND MAJOR ADAPTATIONS

Major adaptations (costing more than £1000) include level floor showers, stairlifts, and structural alterations like widening doorways.<sup>35</sup> People with musculoskeletal conditions may be eligible for Disabled Facilities Grants to pay for major home adaptations. These grants are designed to help people living with disabilities to meet the cost of making major adaptations to their home.

DFGs are underpinned by the legal duty housing authorities have, under the Housing Grants, Construction and Regeneration Act 1996, to meet the needs of people with disabilities.<sup>36</sup> The grants were introduced because of the link between disability and low income.<sup>37</sup> Funding for DFGs comes from the improved Better Care Fund (iBCF) and is delivered through local authorities (see section 4.2).

Eligibility for DFGs differs from eligibility for community equipment in two important ways. Firstly, the legal definition of disability used in the provision of DFGs is set out in the Housing Grants, Construction, and Regeneration Act (rather than the definition in the Equality Act which underpins the Care Act). Secondly, unlike community equipment, which should be

provided free of charge to those with eligible care needs, DFG eligibility is means-tested. The means-test criteria are set out in the related Housing Renewal Grants Regulations which are intended to ensure resources go to those most in need. (See Annex 7).<sup>38</sup>

***‘Major adaptations (costing more than £1000) include level floor showers, stairlifts, and structural alterations’***

Under the Housing Grants Construction and Regeneration Act 1996, DFGs are given directly to individuals. However, the Regulatory Reform (Housing Assistance) (England and Wales) Order 2002 (RRO) allows local authorities to be more flexible around offering housing assistance.<sup>39,40</sup> Since 2008, DFG funding has been included in the RRO’s remit. This means local authorities can use DFG funding more widely so long as it is being used to promote prevention through home aids and adaptations, for example through a home safety grant to fix trips and fall hazards, heating systems or minor repairs.<sup>41</sup>

### Box 4: 2018 external review of the Disabled Facilities Grant and other adaptations

In February 2018 the DHSC commissioned an independent review of the DFG. In December 2018 the finalised external review was published, written by the University of the West of England, Foundations, the Building Research Establishment (BRE) and Ferret Information Systems.<sup>42</sup> The review made recommendations that seek to make the DFG fit for purpose.

#### The review had two aims:

1. To support more people to live in suitable housing so they can stay independent for longer.
2. To make the case for more joined up action across housing, health and social care.

#### Findings

The review found that the system governing the DFG was overly complex with responsibility split between various departments at the local authority level. Furthermore, it found that the means test that underpins access to the grant is overly bureaucratic and out of date. The test doesn’t take into account outgoings such as mortgage repayments; and the calculation to determine projected costs hasn’t been updated since 2008, since when costs have risen by 30% due to inflation.

The review also revealed that one third of people drop out during the process of applying for a DFG. Often, this is because the means-tested grant does not cover the full costs of the adaptations, and people are unwilling or unable to provide their own contributions. There is also significant regional variation in the delivery of home adaptations provided by the DFG, particularly in the number of people who drop out part way through the process. The review also found that guidance on the delivery of DFGs is, in practice, made up of

a series of court judgements, Ombudsman reports and letters of guidance. The review recommends that bringing together updated information on best practice would help local authorities to better deliver DFGs.

#### Recommendations

The external review of the DFG made 45 recommendations about how the DFG and the wider housing system should change. They aim to improve the delivery of the grant and make the process simpler; integrate the DFG more closely with housing, health and social care; and to provide more strategic oversight, with the hope of providing a more person-centred approach to delivering home adaptations.

Some of the key recommendations are:

- A further five-year funding programme for the DFG to improve certainty and enable local authorities to invest in better procurement.
- A Housing and Health Partnership Board in each area as a requirement of DFG funding with representatives from housing, health and social care.
- Better analysis of local need to develop preventative strategies and determine levels of revenue and capital funding.
- Use of NHS number on all files, data sharing protocols, aligned IT systems and improved local reporting focussed more on outcomes.
- That including assessment for the DFG within Care and Support Charging Regulations is part of the Social Care Green Paper. Alternatively, the existing means testing regulations are updated.
- That the national advice line is updated and improved to give people support with housing options.

# 03.

## EXPERIENCES OF ACCESSING AIDS AND ADAPTATIONS

This study is based on qualitative and quantitative research involving people with musculoskeletal conditions. The research explores the impact of home aids and adaptations; and the experiences of people with musculoskeletal conditions in accessing them from their local authority. This study reveals how musculoskeletal conditions affect people's everyday lives and highlights the positive impact aids and adaptations can have on their quality of life.

## PART 1: IMPACT

### 3.1 MUSCULOSKELETAL CONDITIONS LIMIT DAILY LIFE

Musculoskeletal conditions limit people's ability to carry out ordinary activities of daily living. It can be difficult, or even impossible, for someone with a musculoskeletal condition to do everyday tasks such as dressing, preparing meals or washing themselves. This is because of the pain, joint stiffness, and functional limits caused by musculoskeletal conditions. Within the Care Act, core activities of daily living are defined as 'outcomes' (see Box 5). The guidance defines being unable to achieve an outcome as:

- 'Being able to do something without assistance, but doing so causes significant pain, stress or anxiety;
- Being able to do something without assistance, but doing so endangers or is likely to endanger health and safety of the individual or others;
- Being able to do something with the supervision of another adult;
- Not being able to do something at all.<sup>43</sup>

More than half (55.1%) of adults with musculoskeletal conditions in our study are unable to achieve two outcomes of daily living and almost half (48.0%) are unable to achieve three or more outcomes. Under Care Act eligibility criteria, these people would qualify for community equipment, free of charge, from

their local authority. The most common outcome people with musculoskeletal conditions are unable to achieve is accessing and engaging in work, education, volunteering or training (15%).

#### Box 5: What is an outcome?

The Care Act defines several core activities of daily living as outcomes, these include:

- Managing and maintaining nutrition
- Managing personal hygiene
- Managing toilet needs
- Being appropriately clothed
- Being able to make use of an adult's home safely
- Maintaining a habitable home environment
- Developing or maintaining family or other personal relationships
- Accessing and engaging in work, training, education or volunteering
- Making use of necessary facilities or services in the local community including public transport and recreational facilities or services
- Carrying out caring responsibilities the adult has for a child.<sup>44</sup>










### 3.2 MANY PEOPLE WITH ARTHRITIS USE AIDS AND ADAPTATIONS

In this study, six in ten (60.2%) people with a musculoskeletal condition say they use an aid or adaptation. People with musculoskeletal conditions use many different kinds of aids and adaptations. These range from something as simple as a shoehorn, to major structural changes to their home. (see Box 6).

In our study, regardless of the type of musculoskeletal condition someone has, their age, or gender, more people use aids and adaptations than not. However, the type of aid or adaptation people may use varies according to their level of need and the type of musculoskeletal condition they have. (see Fig 1).

#### Box 6: Common aids and adaptations

##### Aids

-  **Aids for dressing:** shoehorns, boot grips, knee supports.
-  **Kitchen aids:** soft or wide handled cutlery, adapted kettles, two-handed saucepans, dishwashers, microwaves, electric can openers, food processors.
-  **Aids for resting and standing:** perching stools, banisters, rails or handles, high stools.
-  **Aids for assisting with housework:** 'grabbing' tools, a trolley for moving items, upright hoovers, lever handles on doors, touch lamps.
-  **Aids to help with washing:** tap turners/lever taps, bath seats, raised toilet seats, shower seats, electric 'raise and lower' seats.
-  **Aids for staying mobile around the home:** portable ramps, slide sheets, soft knee pads.
-  **Aids for sleeping:** adjustable beds, beds that raise you up, hot water bottles, gloves to reduce pain when sleeping, specialist mattresses.

##### Adaptations



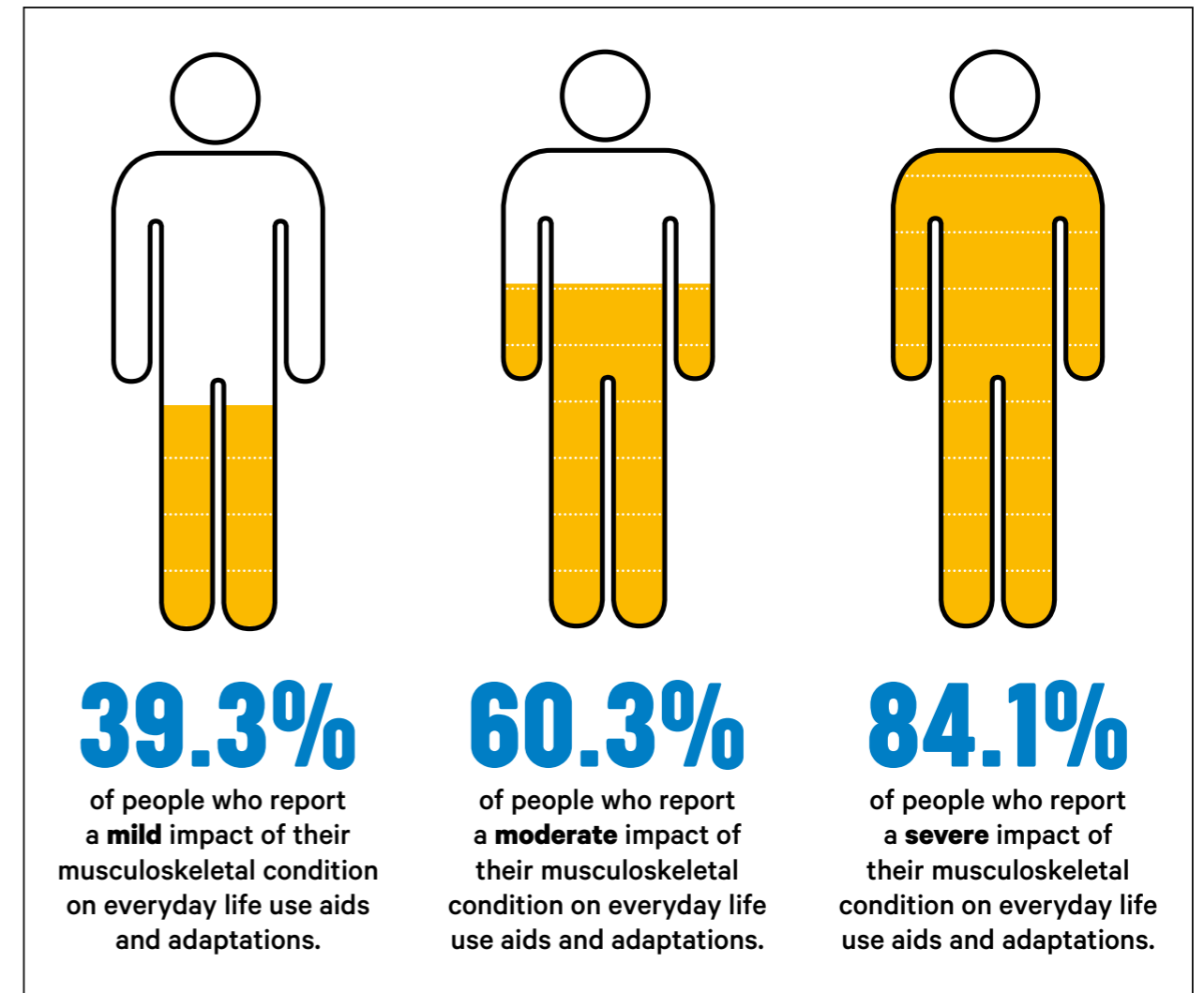
-  **Adaptations to help with mobility around the home:** automatic doors for wheelchairs, doorways widened for wheelchair access, fixed ramps, graded/sloping front drive, stair lifts, wheelchair lifts.
-  **Adaptations to help with bathing:** baths with built-in handles, fixed hoists, major permanent bathroom changes e.g. walk-in bath/wet room.

Figure 1: Use according to severity of condition



In this study, over seven in ten (73.4%) of people with eligible care needs are using aids and adaptations, compared with almost four in ten (35.7%) people without such care needs. In other words, people with musculoskeletal conditions who need more care and support are more likely to use aids and adaptations.

Aids and adaptations can be helpful for people with dexterity and mobility issues across a range of musculoskeletal conditions. For example, grab rails can be useful in helping people with pain and stiffness in their legs and feet move safely around their home; and kitchen aids can support people with limited dexterity in their

hands, wrists and fingers, to be able to prepare meals for themselves.

***'73.4% of people with eligible care needs are using aids and adaptations'***

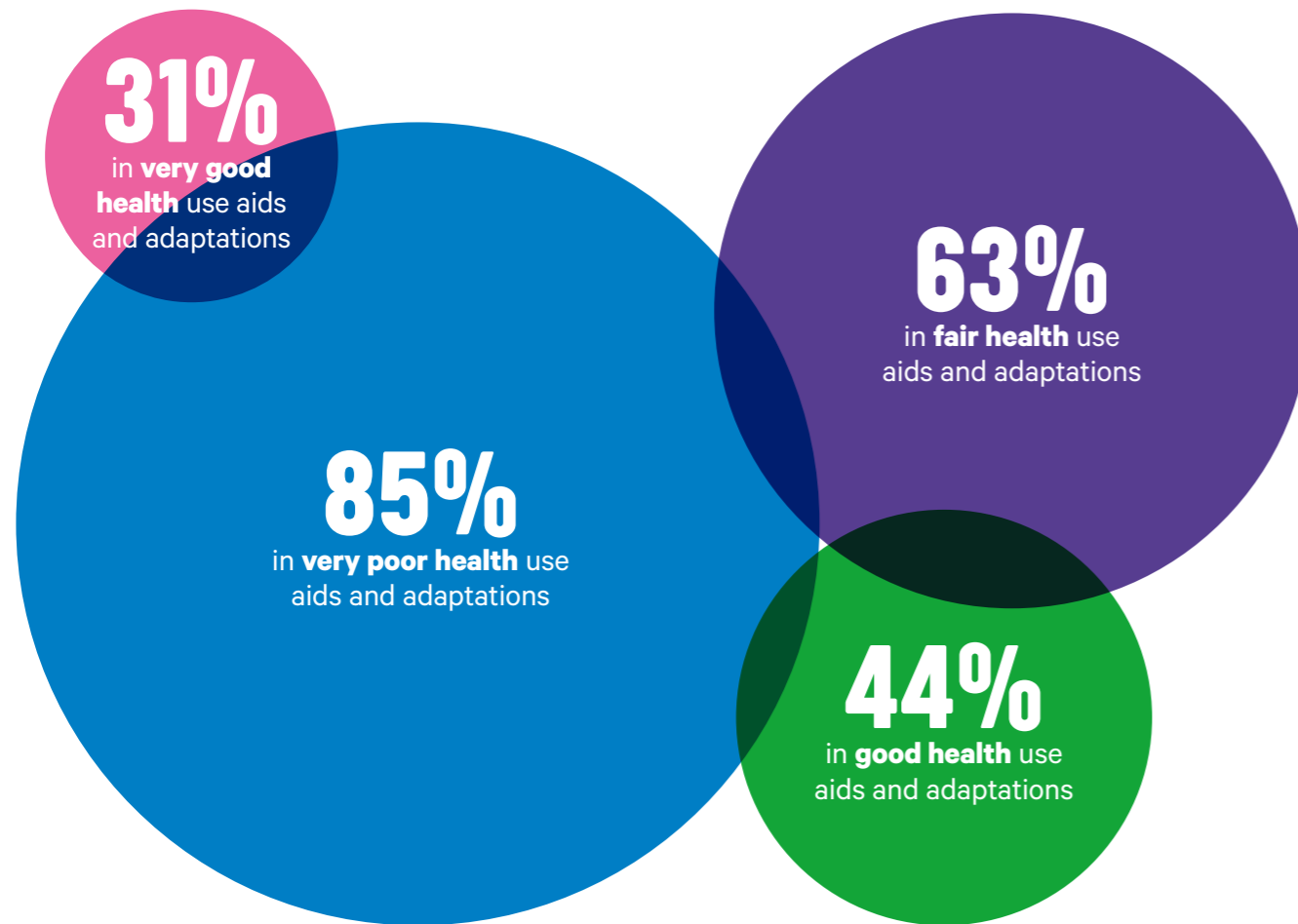
People with all types of musculoskeletal conditions agree that the most useful aids and adaptations often aren't specifically designed for those with musculoskeletal conditions, but can be everyday features that help, including downstairs bathrooms and dishwashers.

**Health status**

Health is a key aspect of quality of life – and musculoskeletal health is an important part of this. A person’s health status includes aspects such as pain, mood, self-efficacy, fatigue, dexterity and mobility.<sup>45</sup> In this study, we examine the impact a person’s overall health status has on their use of aids and adaptations in the home and the impact a person’s musculoskeletal health in particular has on their use of home aids and adaptations. In this study people with self-reported poor health are more likely to be using aids and adaptations than those in better health (see Fig 2).

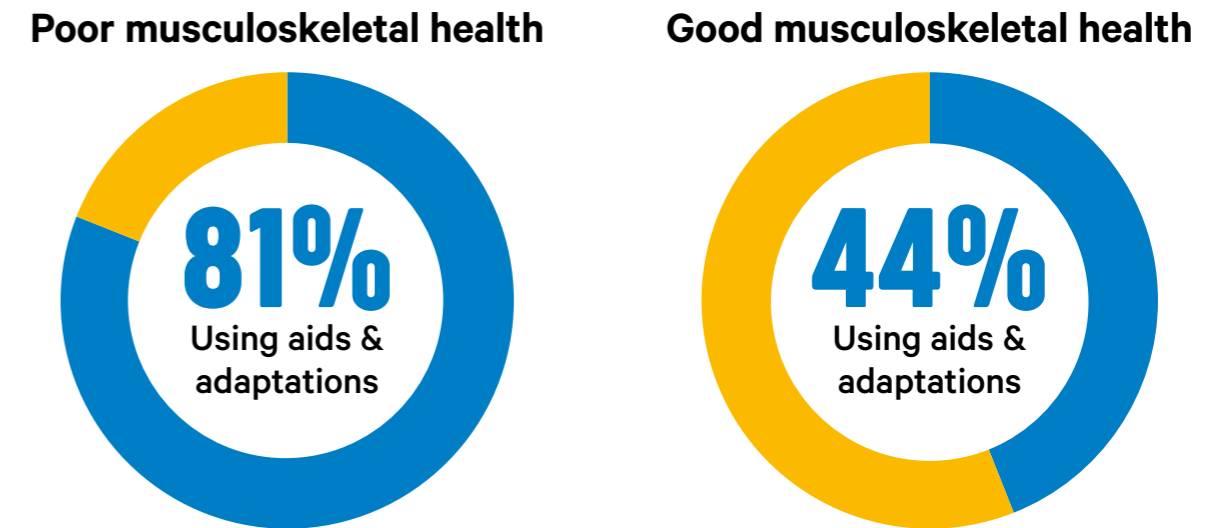
To explore the relationship between musculoskeletal health and the use of aids and adaptations, some people in the study completed the Musculoskeletal-Health Questionnaire (MSK-HQ). The MSK-HQ is a patient reported outcome measure. It uses a series of questions to quantify the impact a person’s musculoskeletal health has on their life.<sup>46</sup> The lower a person’s score, the worse their musculoskeletal health. The MSK-HQ results in this study show that people with poorer musculoskeletal health are more likely to use aids and adaptations (see Fig 3).

**Figure 2: Use according to self-reported health status**



The survey looked at people’s self-reported overall health, and how this affected their use of aids and adaptations. People with musculoskeletal conditions were asked ‘How is your health in general, would you say it was ... very good/good/fair/bad/very bad?’. (Total number of respondents = 1059).

**Figure 3: Use according to musculoskeletal health status**



A sub-sample of the people in the survey answered the musculoskeletal health questionnaire. This uses a series of questions to identify the impact a person’s musculoskeletal health has on their life. The same people were also asked ‘Do you currently have any of the following aids or adaptations in your home?’ (Number of respondents with an MSK-HQ score of < 30 = 63; Number of respondents with an MSK-HQ score of > 30 = 91)

**People not using aids and adaptations**

In this study, almost four in ten (39.8%) with a musculoskeletal condition don’t use an aid or adaptation. Their reasons for not using aids and adaptations vary. People may be satisfied with their pain relief or feel their condition isn’t

bad enough to need to use an aid. However, six in ten (64.7%) of people with musculoskeletal conditions currently not using aids and adaptations say they will consider getting them in future.

**Box 7: Ezi-Plug - the plug for people with low dexterity**

The Ezi-Plug is a plug and socket system, designed to enable people with dexterity issues caused by musculoskeletal conditions like arthritis, to plug electrical appliances into the mains with ease. It is designed so people can guide a plug into the correct position using the shape of the socket. Once the top part of the plug is as far in as it can go, the plug pins will automatically be in line, and the person can gently push the lever handle to insert the plug. The plug is held in the hand with a loose grip. There is no pressure on the joints of the fingers.<sup>47</sup> This means that even people with advanced hand problems are able to use a plug and socket when they need to use key electrical

appliances. The plug has an inclusive design with an attractive appearance; it doesn’t look like a disability aid. The overall system is also extremely safe. If there is any pressure on the lead, the plug will disengage. This means that people won’t trip over the cable and the connections aren’t stressed. Ezi-Plug was designed by William Dolman. His mother has rheumatoid arthritis, and it was her struggle with conventional plugs and sockets that inspired him to create Ezi-Plug.<sup>47</sup>







# JACK'S STORY

## 68 YEARS OLD, OSTEOARTHRITIS AND OTHER LONG-TERM CONDITIONS

"I've had a very active, outdoor life. I've been all over the world. I used to work with horses and dogs; I bred dogs, and even won a prize at Crufts and judged competitions. Now I'm 68 and have multiple health conditions.

It's just impossible to do the things I used to do, but I live alone and am very independent which I don't want to give up. I was diagnosed with osteoarthritis in my hips and spine three years ago, and it has really affected my mobility.

The arthritis in my spine caused progressive paralysis and I've had operations to stop it getting worse. I also had a fall, which really knocked my confidence. The doctor suggested I get myself some crutches, which have made me feel much more stable and steady. They're definitely my most important aid, but I use many others.

I love cooking, but I find it difficult because I don't have any feeling in my fingers, so they are

vulnerable to nicks and burns. Even slicing a carrot can be quite dangerous and I often end up cutting my fingers.

***"Using these aids has helped my independence and meant I can carry on as normally as possible"***

I've managed to find kitchen implements that help, including special knives, a chopping board that grips vegetables, a one handed tray which I can carry while using my crutch, and a long grabber to reach the top shelf of my cupboards.

Overall, using these aids has helped my independence and meant I can carry on as normally as possible. Going out and socialising would be impossible without them; I would be housebound."

### 3.3 IMPROVING QUALITY OF LIFE AND INDEPENDENCE

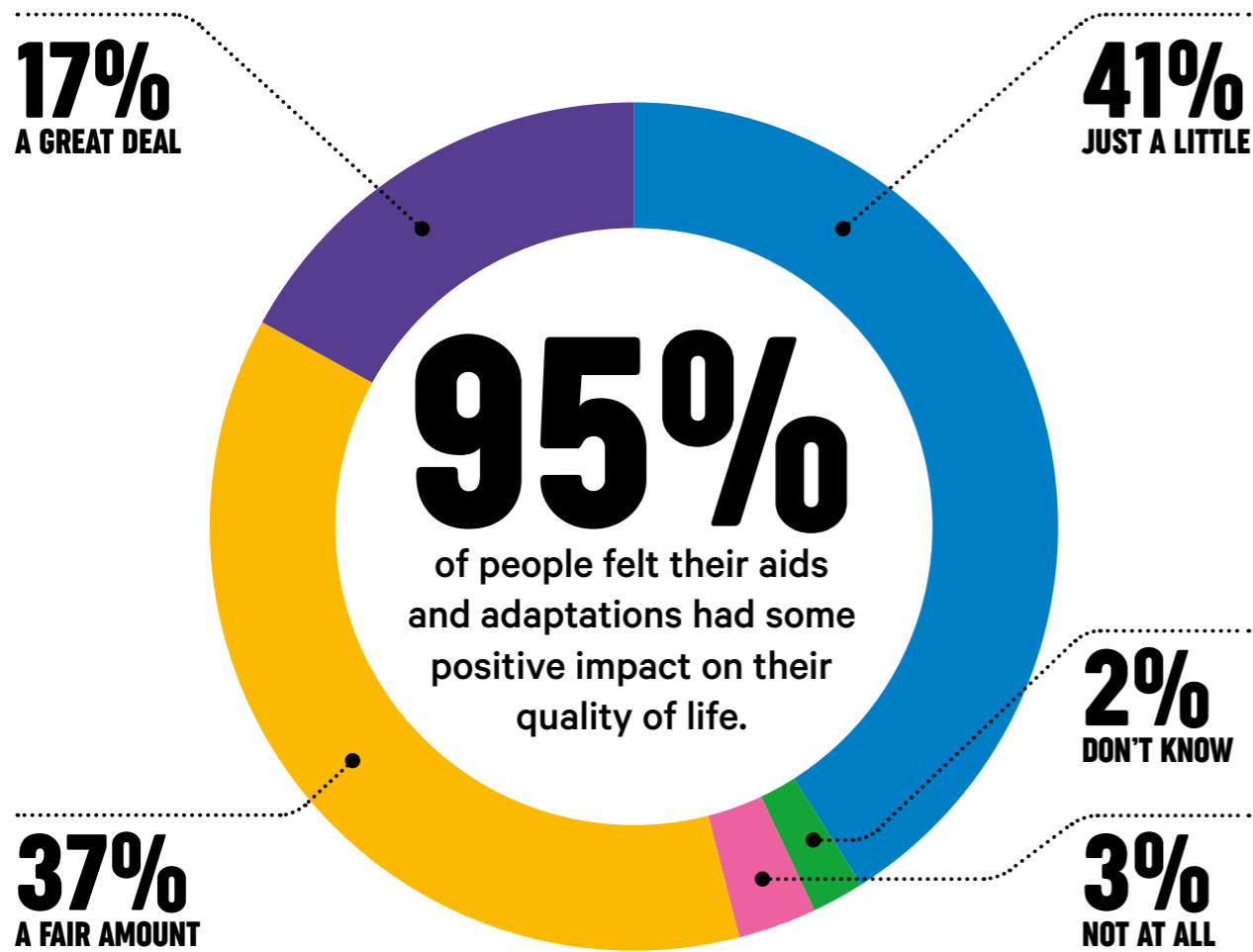
#### Quality of life

Aids and adaptations are important for people with musculoskeletal conditions because they make everyday life at home easier and this has a positive impact on quality of life. In this

study more than nine in ten (95%) people with a musculoskeletal condition who are using aids and adaptations feel these have a positive impact on their quality of life (see Fig 4).

**Figure 4: Impact on quality of life**

People with musculoskeletal conditions using aids and adaptations say they have some positive impact on their quality of life.



People with musculoskeletal conditions were asked 'Overall, what impact do aids and adaptations you have in your home have on your quality of life?'. (Total number of respondents = 637)

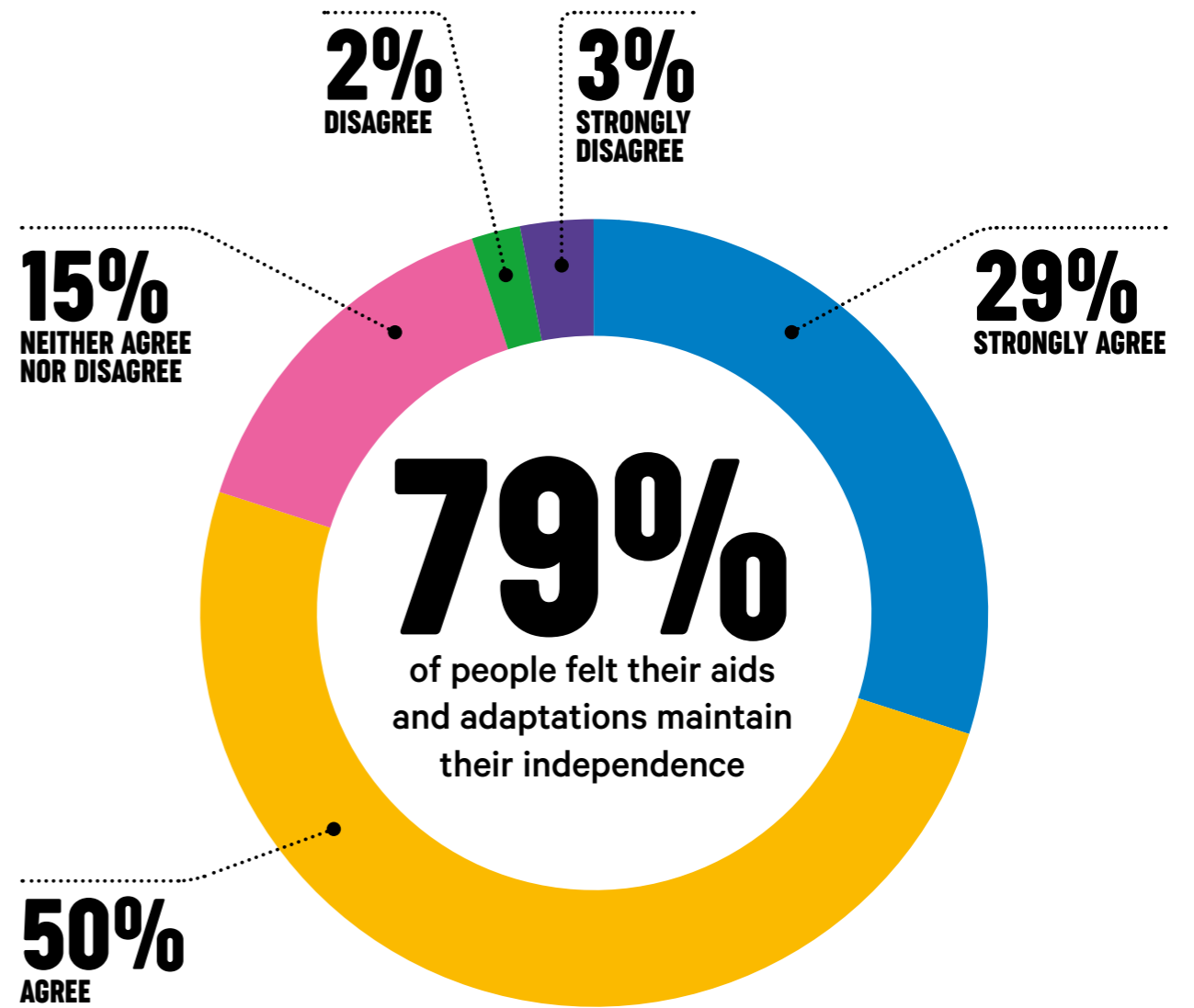
#### Independence

Independence is an important contributor to well-being and quality of life. Many people highly value their independence and want to maintain it for as long as possible. In this

study, almost eight in ten (79%) of people with musculoskeletal conditions say aids and adaptations help them maintain their independence (see Fig 5).

**Figure 5: Impact on independence**

People with a musculoskeletal condition using aids and adaptations say they help them maintain independence.



People with musculoskeletal conditions were asked 'How much do you agree or disagree that the aids and adaptations you have in your home help you maintain your independence?'. (Total number of respondents = 637)



### 3.4 OVERCOMING FUNCTIONAL LIMITATION

Musculoskeletal conditions can limit people's movement and dexterity in their joints. People with musculoskeletal conditions can experience difficulties with activities like writing, using cutlery or dressing. If someone's spine, legs and feet are affected, they can find walking, moving from sitting to standing or stair climbing painful, difficult or impossible. In our study, one in ten (13.6%) say aids and adaptations enable

them to overcome these kinds of limitations. For this group, aids and adaptations can make the difference between dependence and independence. The activities that aids and adaptations are most useful in helping people with musculoskeletal conditions to achieve are mobility in the home (9.4%), using the toilet (6.1%), washing (5.5%) and doing housework (5.5%) (see Box 8 and Table 2).

#### Box 8: Activities only achieved with help of an aid or adaptation



Table 2: Activities only achieved with help of an aid or adaptation

Impact of aids and adaptations on outcomes of daily living	% of people only able to achieve this outcome with an aid or adaptation
Mobility within the home	9.4
Toileting	6.1
Washing	5.5
Housework	5.5
Personal hygiene and grooming	4.5
Dressing	4.5
Preparing meals	4.4
Caring responsibilities	3.2
Taking medication	2.8
Self-feeding	2.7
Use of telephone or other communication devices	2.7
Access to sources of heat, power and light	2.5
Maintaining or developing relationships	2.2

All respondents answering, "Thinking of the following activities (i.e. washing, dressing, toileting...) please select the option which is most appropriate to you" with the option "Can do with aid". (Total number of respondents = 1059).

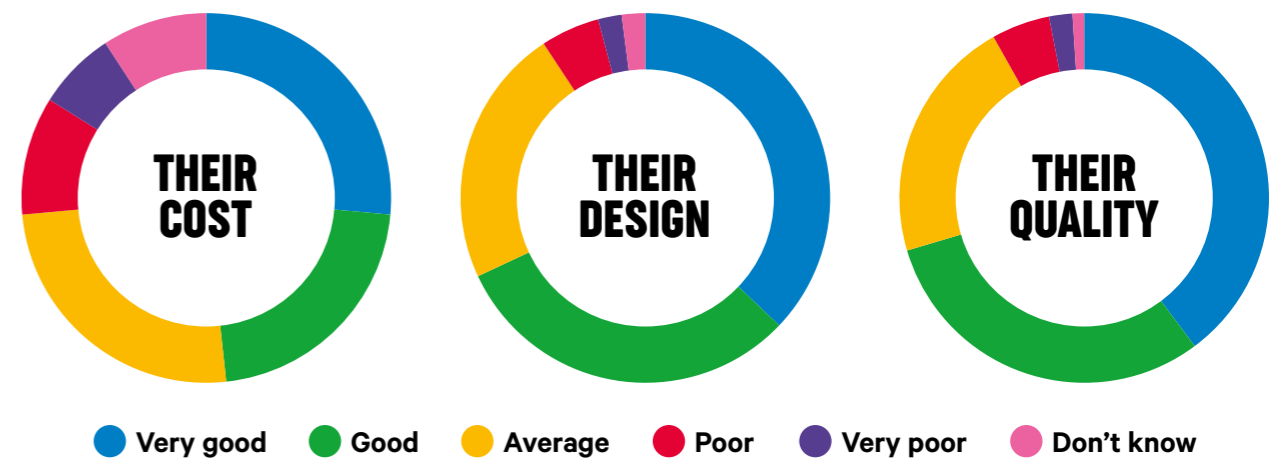
## PART 2: CHALLENGES

### 3.5 COMMON PROBLEMS WITH AIDS AND ADAPTATIONS

Well-designed, good quality aids and adaptations empower people to live well and independently. However, inappropriate or poorly-designed aids and adaptations can leave people with unmet need. In the quantitative part of the study, people with musculoskeletal conditions rate their aids or adaptations on

cost, aesthetics, design and quality. Most people describe their aids and adaptations as good, but some report dissatisfaction with high cost and poor aesthetics (see Fig 6). Qualitative work also highlighted concerns with the placement of aids in the home and a lack of availability of some types of aids and adaptations.

Fig 6: Evaluation of aids and adaptations



People with musculoskeletal conditions, using aids and adaptations were asked 'Overall, thinking about all the aids and adaptations you currently have in your home, how would you rate the following... their cost; their design; their quality; their aesthetics. (Total number of respondents = 637).

#### Cost

Cost is one of the most common reasons why people in our study say they don't have an aid or adaptation. Nearly one in ten (7.6%) in our study who say they don't have an aid or adaptation say they don't want to spend money on them. Some people don't realise they may be entitled to items for free from their local authorities. Among people that are aware of shops selling aids and adaptations, some say they feel that products are expensive because 'sellers know how much people rely on them'. In this study, the average cost of an aid and adaptation was around £200.

The cost of major adaptations is also cited as a barrier for many people. People often aren't aware of financial support such as Disabled Facilities Grants that could help meet the costs of major adaptations. Instead, some people have considered funding adaptations – including stair lifts or downstairs toilets – themselves. Some have been given quotes and feel they can't afford them. Another reason that can stop people applying for a DFG is concern that major structural changes will affect the potential sale of their home.

**Aesthetics and design**

The physical appearance of aids and adaptations provided by local authorities can deter some people with musculoskeletal conditions from using them. Some feel local authority aids and adaptations look medicalised and share the same design as equipment found in hospitals and care homes. There is also a sense that some useful aids – such as those that could help with parenting tasks – just don't exist. Additionally, some people with musculoskeletal conditions feel their families would not like having aids

and adaptations in their home because of their medicalised appearance. A Centre for Ageing Better report looked at the lived experience of those who access aids and adaptations. They found that for some, adaptations signalled vulnerability and incapacity, reminding them of the mobility they had lost rather than the freedom they had gained.<sup>48</sup>

**Quality and safety**

Some people say they have concerns about the quality of local authority provided aids

**Table 3: Emotions acting as motivation and deterrent**

Emotion	As motivation	As deterrent
<b>Understanding and empathy from others</b>	Using aids and adaptations in front of others may encourage people to see my condition as severe and treat it seriously.	My partner/family would lack empathy if I had to make changes to our shared home. People will think I am putting it on or judge me if they see me using an aid or adaptation.
<b>Having face-to-face human contact</b>	Aids and adaptations will enable me to get around and see people in person.	Having an aid or adaptation will make me too embarrassed to invite people over. Using aids and adaptations to get around might mean people choose to take advantage of me.
<b>To be seen by others as myself and not as my condition</b>	I want people to see me as capable and look past what I can't do.	I don't want to draw attention to my condition.
<b>Being able to meet the needs of others</b>	Making changes will enable me to carry on interacting with others in the way I am used to.	Aids and adaptations will not meet the needs of others in our shared home environment – and may even detract from their needs (e.g. by taking up room).
<b>Being able to engage in sexual intimacy</b>	Making changes will enable me to carry on interacting with my partner in a way that I am used to.	Getting aids and adaptations may reduce our ability to be sexually intimate (e.g. single hospital bed).
<b>To have shared experiences with my family and friends</b>	Making changes will enable me to carry on interacting with my family and friends in the way I am used to.	Aids and adaptations may isolate me from my family and friends.
<b>Feeling 'normal'</b>	Using an aid or adaptation will enable me to carry on as normal.	Using aids and adaptations makes me feel different and abnormal.
<b>To maintain my pride and dignity</b>	It will increase my dignity to be able to do daily activities myself.	Aids or adaptations are embarrassing, they are for old people, not people like me.

and adaptations, which stops them from using or requesting them. For example, some people feel that aids and adaptations with an electronic component (e.g. an electric bath seat) can be unreliable or unsafe, and don't want to use them.

**Placement of aids in the home**

There can be issues around where aids and adaptations are placed in the home. Some people experience local authority-provided aids, like grab rails, being installed inappropriately

such as on the wrong side of the bed. This leaves people's needs unmet and could stop people from seeking further help. Shared decision making throughout the adaptation process has been found to improve outcomes.<sup>49</sup>

**Availability**

Some items that could be extremely useful in meeting everyday needs simply don't exist. For example, one participant in the qualitative research felt that there was a lack of adaptations to enable intimacy.

Emotion	As motivation	As deterrent
<b>Feeling in control of my condition</b>	Having an aid or adaptation helps me to manage and enables me to feel like I am in control of my arthritis.	Having an aid or adaptation (particularly aimed at future needs) worries me that I will slowly lose control of my condition; that I have reached the point of no return.
<b>Feeling independent and autonomous</b>	Having aids or adaptations will enable me to get around and do daily activities without relying on others.	Using aids and adaptations will mean I have given up; that I am not self-reliant anymore. An aid or adaptation may disable me rather than enable me.
<b>Feeling valuable and having a purpose</b>	Making changes to enable me to carry on will stop me feeling so useless.	Having to make a change to my home will make me feel useless.
<b>To feel proud of my home and home environment</b>	Aids and adaptations can help me take better care of my home.	Aids and adaptations are ugly and embarrassing. Getting aids and adaptations make cleaning and DIY more difficult – e.g. by cluttering the home.
<b>Ability to engage in activities that keep me healthy</b>	Aids may help me do activities to boost my health and fitness.	Aids and adaptations will stop me keeping healthy and fit (e.g. a stair lift).
<b>Ability to keep busy and stave off boredom</b>	Aids and adaptations will enable me to do things I love and stop me feeling so bored.	Aids and adaptations may clutter the house and make it harder to do things I enjoy.
<b>To be able to relax and destress-</b>	Aids and adaptations will give me space and time at home to relax.	Aids and adaptations and the process of having them installed may be more hassle.
<b>Feeling refreshed as if you've had a good night's sleep</b>	Aids may help me sleep better.	Aids or adaptations attached to my bed may get in the way.



### 3.6 EMOTIONAL ASPECTS OF AIDS AND ADAPTATIONS

A person's relationship with their musculoskeletal condition and the functional limitations it may cause can be very complex and can include an emotional component that aids and adaptations cannot address and may even worsen. People's emotional responses to aids and adaptations vary. For some, an emotion may motivate them to access aids and adaptations. For others, the same emotion acts as a deterrent. Table 3 explores this in more detail.

One common myth is that musculoskeletal conditions are a natural part of ageing and only affect older people. Younger people with musculoskeletal conditions told us they felt shock at experiencing symptoms, as they feel too young to be affected. This affects their attitude towards aids and adaptations. One person in her 20s we talked to was concerned by the fact that lots of products were aimed at older people. This put her off. Younger people in our study said they are less likely to want to admit or publicise their condition to others: this makes them less likely to use aids and adaptations. In contrast, some older individuals may be more prepared to accept that their condition could get worse and are more open to the idea that aids and adaptations might make a difference to their

day to day life. Some people who have functional limitations in a particular joint may believe that using an aid or an adaptation will speed up that joint's decline. For people who believe this, aids and adaptations can feel disabling rather than enabling and this acts as a barrier. One person with arthritis told us, 'To have to ask for help is quite embarrassing. Even though I try to adapt, it brings home that there are certain things I can't do. It reminds me I have a problem'.

In some situations, this may be true. For example using a stairlift can help a person get up and down stairs in their home safely but may reduce a person's muscle strength in their legs. In other situations, an aid may make the difference between being able to do something and not being able to do something without leading to loss of strength, such as using an aid to remove a jar lid or the cap of a bottle. High quality occupational therapy assessments are important in empowering people to identify and access aids and adaptations that will improve their lives and help them maintain independence. Finally, some people become so used to struggling with their day-to-day life that they don't recognise the impact of their condition on their quality of life or that their needs are unmet.

### 3.7 IMPACT OF PERSONAL EXPERIENCE OF ARTHRITIS

People with poorer overall health and musculoskeletal health are more likely to use aids and adaptations (see section 3.2). However, it is not just the actual severity of a person's condition but also their *experience of their condition* that is important and the two may interact. In our study, whether a person is managing or struggling with their condition is important in determining whether they use aids or adaptations. People who struggle with their health are more likely to use aids

and adaptations whether the impact of their condition is mild or severe. Some people don't use aids and adaptations because they feel they are managing well without them.

In the study, six in ten people (65%) without an aid or adaptation say they don't think their condition is bad enough to get one. Almost two in ten (16%) feel they can cope on their own, and two in ten (20%) of those without aids and adaptations feel they don't need one.

### Box 9: Exploring the needs of different groups of people with arthritis

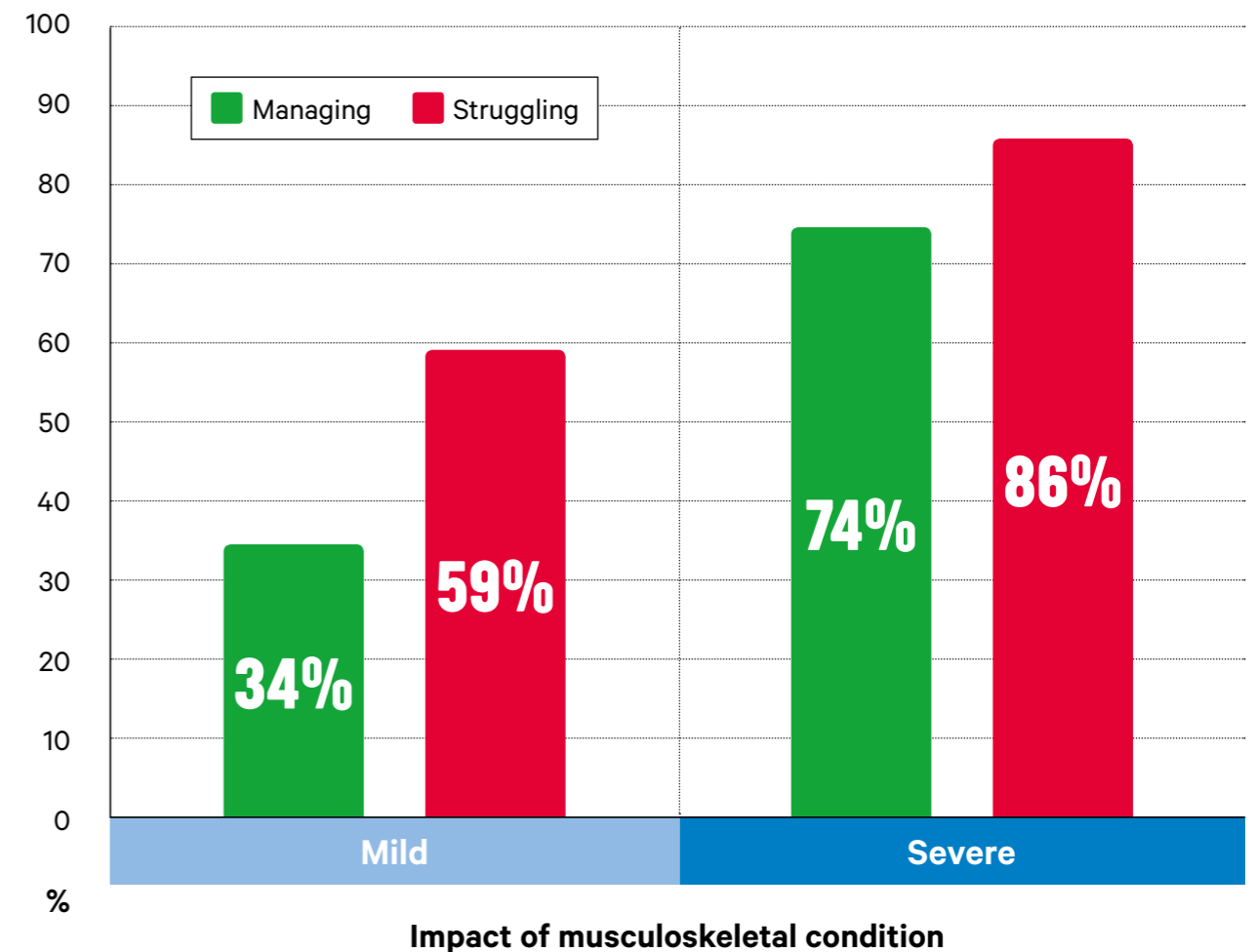
Research by Versus Arthritis into unmet need, shows a diversity of experience among people with musculoskeletal conditions.

Some people (with both mild and severe conditions) report being able to manage the pain of their musculoskeletal condition. In contrast, others are controlled by their pain.

The work identifies six groups of people with musculoskeletal conditions, regarding their experiences of their condition:

- Severe symptoms but managing
- Severe symptoms and struggling
- Moderate symptoms and managing
- Moderate symptoms and struggling
- Mild symptoms and managing
- Mild symptoms but struggling.<sup>50</sup>

Fig 7: How experience of condition impacts use



People with musculoskeletal conditions were asked 'You said that you have aids or adaptations in your home. What made you get these aids and adaptations?' Total number of respondents = 637; People with musculoskeletal conditions were also asked 'Overall, how do you rate the impact of [condition 1/2/3] on your day-to-day life?' (Total number of respondents = 1059).

# CHRISTINE'S STORY

## 76 YEARS OLD, OSTEOARTHRITIS

"I've had osteoarthritis since the age of 19 and took the attitude that it wouldn't beat me. Over time it's affected different parts of my body, including my hands, hips, knees and neck. Just making a cup of tea and other tasks around the kitchen can be complicated.

Over the years, I've bought various aids and gadgets to manage my arthritis. I didn't realise how much an electric tin opener or gripping plastics could revolutionise my life. I recently thought about getting an adapted bread knife so I can cut bread more easily, but I have held off until I have a bit of spare money as I also need to install some expensive quarter turn taps in my kitchen.

To continue gardening, I've bought knee pads and sprung secateurs. When we were able to afford it we adapted the bathroom with a walk-in shower so that I can wash without fear of falling. I also have lever taps on the hand basin and replaced the toilet with one that has a button flush instead of a handle.

The cost has really mounted up; the adaptations in the bathroom alone came to over £3,000, but it was necessary so we just had to get on with it. I was shocked to discover, after talking to Versus Arthritis, that I might be entitled to some of these items free of charge from my local authority.

***"I was shocked to discover, after talking to Versus Arthritis, that I might be entitled to some of these items free of charge from my local authority."***

I know councils are under financial pressure, but these aids and adaptations are invaluable, helping people like me to manage my condition at home. Having access to them may mean I need to rely less on services provided by the council or the NHS. It is quite sad that I only found out about local authority support after spending so much of my own money."





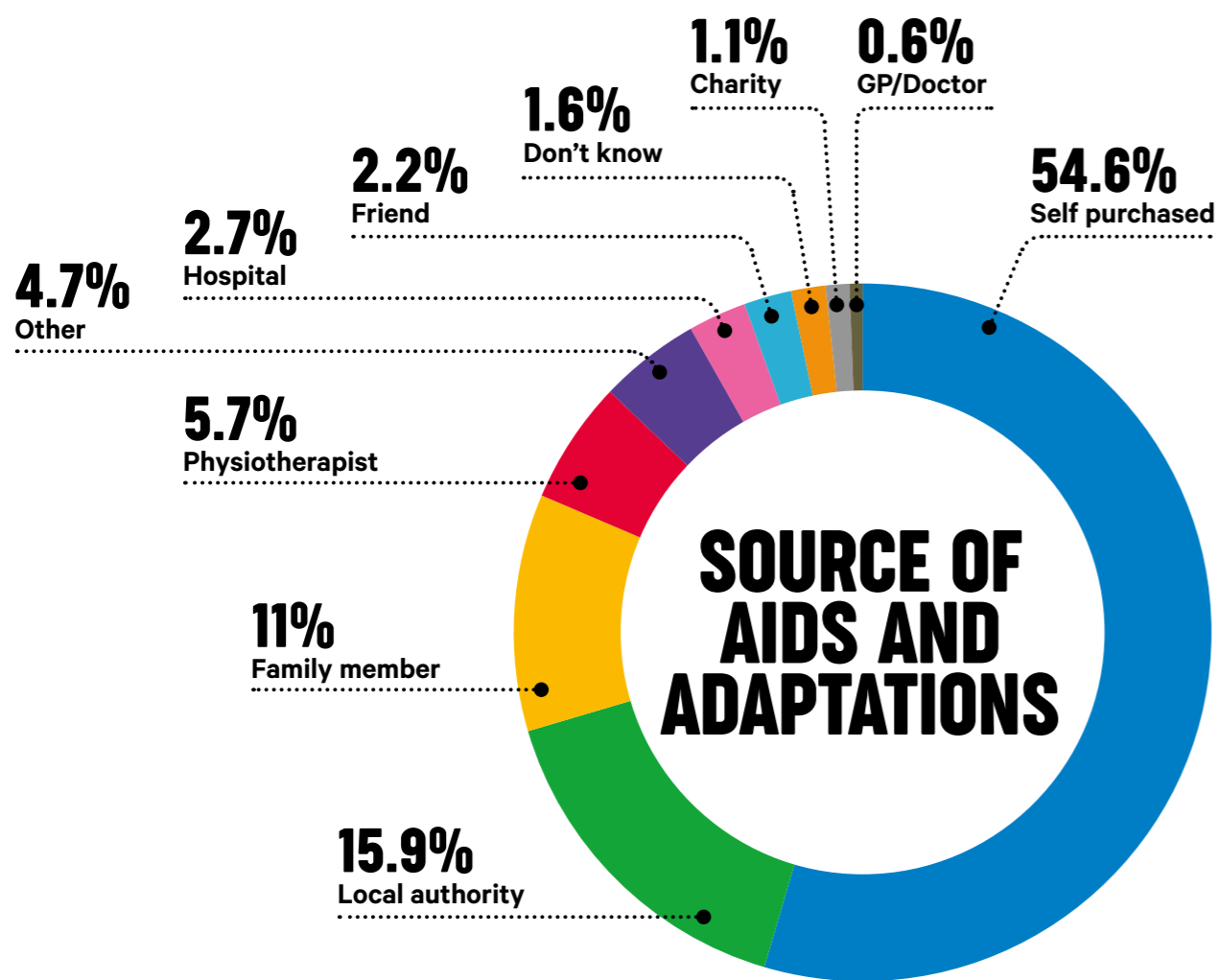
# PART 3: ACCESS

## 3.8 PEOPLE OFTEN PAY FOR THEIR OWN AIDS AND ADAPTATIONS

In this study, over half (54.6%) of all those with an aid or adaptation paid for it themselves. The same is true of people with musculoskeletal conditions and eligible needs; over half (52%) are paying for their own aids and adaptations. Overall, our study shows that nearly one in five (15.9%) people with a musculoskeletal condition are getting aids and

adaptations from their local authority. Two fifths (40%) of people with a musculoskeletal condition have had difficulty acquiring aids and adaptations from their local authority. Other sources of aids and adaptations that are used include physiotherapists, occupational therapists, hospitals, charities, and friends and family (see Fig 8).

Fig 8: Sources



People with musculoskeletal conditions were asked "Where did you get your most recent aids or adaptations from?" (Total number of respondents = 637)

## 3.9 ELIGIBLE CARE NEEDS

More than half the people (55.1%) with a musculoskeletal condition in this study have eligible needs. A large majority of this group, four fifths (80%), use aids and adaptations. However, less than one fifth (17.3%) of people who have eligible needs receive aids and adaptations from their local authority. This means that many people are paying

for equipment which they would be entitled to for free. One fifth of people (19.9%) with musculoskeletal conditions and eligible care needs do not use aids and adaptations and may have unmet care needs. Over four fifths (86.2%) of people in this group do not know that their local authority has a duty to provide community equipment.

### Box 10: Ealing Council's repairs and adaptations agency

Ealing Council's in-house repairs and adaptations agency offers an interesting example of integrated working and innovation in adaptation provision. The agency offers an adaptations service, a handy-person service, minor works and repairs, a fast-track stairlift service and a social care call centre. The call centre routes calls to the relevant services and takes referrals from other council departments, voluntary organisations and hospitals. This helps reduce waiting times for the social care occupational therapist, as not all services require their intervention. For example, if a person with an eligible need requires a home a home repair, they can inform the social care call centre, who in turn can email a referral to the handy-person service. This is checked and passed to a contractor, maintaining clear lines of communication between social care and housing departments. Hospitals can also call the handy-person service to ensure speedy discharges.

Occupational therapists and contractors work closely to deliver a fast-track stairlift service. If an occupational therapist identifies a need for someone to have a stairlift installed, once they've discussed this work with the individual and checked this need with a manager, they can go directly to an approved contractor. Designed to prevent people who can't manage the stairs

anymore from falling, this rapid response approach is possible because the council doesn't require those who need it to be means tested.

Ealing's repairs and adaptations agency has hugely simplified the DFG process for home adaptations, by employing the Regulatory Reform Order (see 2.6). This allows the council to be flexible in its funding model. A caseworker checks if the test for resources is applicable to the individual. If not, a home visit is arranged, during which a four-page form is completed, and documents are checked. In DFG cases, an occupational therapist and a surveyor make the visit together to ensure the assessment and specification are completed in one trip. The next step is for the occupational therapist to confirm the work plan with the customer before it goes out to tender with approved contractors. People who don't qualify for a DFG still have the option of accessing the integrated service for a fee and have access to the council's pool of contractors. In council-provided DFG services, Ealing Council only allows the use of approved contractors, so they can monitor and control the quality of work. For both the handy-person and DFG services, the council evaluates the work completed. In 2014 they achieved 98% and 100% satisfaction (respectively).

### 3.10 LACK OF INFORMATION AND ADVICE

People with musculoskeletal conditions need information and advice to support them to make decisions and manage their own health and wellbeing. One person in our qualitative study highlighted that ‘information is a really good thing-the more you know the better’. Knowledge of what is available may help people get access to aids and adaptations. Under the Care Act, local authorities have a legal duty to provide information and advice on care and support, including aids and adaptations. However, many local authorities don’t adequately fulfil this duty, particularly in relation to informing and advice about aids and adaptations.

**‘Nobody tells you what’s available – you have to ask for it or find out by yourself’**

In this study, one third of people (35%) with musculoskeletal conditions have sought information and advice, although one in ten (11.8%) choose their local authority as their main source. One participant complained that ‘Nobody tells you what’s available – you have to ask for it or find out by yourself’. People who succeed in getting information and advice about aids and adaptations from their local authority may have insider knowledge of how the system works, for example through their personal experience of being care worker or having a relative working in the social care sector. Overall, fewer than two in ten (16.1%) of people with eligible needs are aware of their local authority’s duty to provide community equipment.

#### Difficulty accessing aids and adaptations

Within the study, over half of those (54%) who access aids and adaptations through sources other than their local authority, said they have had difficulty accessing aids and adaptations from their local authority. Small setbacks often act as deterrents to accessing aids and

adaptations from local authorities. Some who have tried have not persisted, because they feel the person they have spoken to at their local authority is best placed to know who may be eligible for support and often a person won’t recontact the council if they have been told they aren’t eligible for support, even if their circumstances change. ‘I can’t imagine anything will have changed since I called up a few years ago...they told me our income was too high’.

Many people who try to search online for information and advice about aids and adaptations struggle to find any. They feel what little information and advice that is available focuses on products tailored towards older people. ‘Most support is geared towards older people, I am not in that category’. Other research points to a system that is difficult to understand. A report by the Centre for Ageing Better found that the process of getting the right adaptations in place can be so complex that even practitioners themselves struggle to navigate it.<sup>51</sup>



**2 IN 10**

**people with eligible needs are aware of their local authority’s duty to provide community equipment.**

### 3.11 BARRIERS TO ACCESSING AIDS AND ADAPTATIONS

Other barriers which prevent people with musculoskeletal conditions from accessing aids and adaptations occur in relation to healthcare professionals; budget restrictions impacting on provision; and a lack of best practice guidance.

#### Healthcare professionals

Some people with arthritis suggested that some health care professionals use medicalised language and that this can put people off a discussion about aids and adaptations. For example, they may use language such as ‘prescribing’ aids and adaptations. Some healthcare professionals described working from a prescribed list to help them navigate the wide range of potential equipment that is available and to prevent them from being overwhelmed by choice. This approach has the potential to leave needs unmet if individuals have a need for an aid or adaptation that isn’t on the list.

#### Budget restrictions impacting provision

Some occupational therapists that took part in the qualitative research suggested that due to pressures on adult social care budgets, there may be less resource for aids and adaptations in the future. As a result, occupational therapists said they are prescribing aids and adaptations to meet future needs now. But this can feel disempowering for people with musculoskeletal conditions who are given aids and adaptations they feel they are not ready to use.

#### Lack of best practice guidance

Aids and adaptations could be an important part of high quality, effective preventative services. Unofficial best practice guidance does exist, notably the Home Adaptation Consortium’s ‘Home Adaptations for Disabled People’<sup>52</sup>, last updated in 2015, and the Centre for Ageing Better’s ‘Adapting for ageing: good practice and innovation in home adaptations’.<sup>53</sup>

However, there is no official national best practice guidance to describe effective preventative services, or what good provision of aids and adaptations should be. As a result, local authorities may be missing the opportunity to reduce or delay care needs due to a lack of

**‘Information is a really good thing-the more you know the better’**

understanding of the potential value of services on individual and population level outcomes, and in terms of a return on investment. The Department of Health and Social Care must play a greater role in spreading good practice, which could be beneficial in helping local authorities to utilise and provide aids and adaptations as part of preventative approaches.

**54%**

**who use aids and adaptations said they had difficulty accessing them from their local authority.**







# JENNYLYN'S STORY

## 50 YEARS OLD, RHEUMATOID ARTHRITIS

"I was 31 and a teacher when I was diagnosed with rheumatoid arthritis. My diagnosis happened very quickly and out of the blue. It was a big shock and a lot to take in. I had to start using crutches because both my knees needed replacing.

I got in touch with the occupational therapy team at the council, and a lady came round and offered me a raised toilet seat. I was sort of happy enough with that. Even though I was finding it very difficult, I didn't really know what I needed or what I should be asking for.

Luckily for me my sister works for a council, and when she heard about the toilet seat she said: "Jenny, that's rubbish, you need to get hold of the right person". I got in touch again and managed to get a full home assessment this time. As soon as the second occupational therapist saw me struggling to walk, I knew she

was going to help me. Over the years I've been assessed by various professionals and have been provided with grab rails in my bathroom, a kettle tipper, a jar opener, a ring pull gadget to open cans, and raised plug sockets around my house. I've also bought lots of aids myself.

***"It's all at the discretion of the person who comes to your home. I feel if I hadn't asked and pushed for these things, I wouldn't have got them."***

I think it's all at the discretion of the person who comes to your home, which shouldn't be the case. I feel if I hadn't asked and pushed for these things, I wouldn't have got them."



### 3.12 DIFFICULTIES ACCESSING THE DISABLED FACILITIES GRANT

Disabled Facilities Grants (DFGs) provide crucial funding for major home adaptations (see section 2.6). Our qualitative research highlighted five main challenges around the provision of DFGs:

- 1** People with musculoskeletal conditions that could benefit from DFGs, often don't know the grants exist.
- 2** Some people face a long wait for grants and applications to be approved. In some councils, people can wait for years to get a major adaptation. Councils may have a huge backlog of applications to process and deliver.
- 3** The means-test which is used to assess eligibility for DFG does not take all outgoings into account. This may disadvantage people who have high monthly

outgoings like mortgage payments, or whose expenses are higher because they have young children. The mean-test criteria have not changed significantly since its introduction of the DFG in 1996, even though the cost of living has risen greatly since then (see Simon's story).

**4** Some items that cost more than £1000 (such as some types of hospital-style beds) are not covered by the Housing Grants, Construction, and Regeneration Act 1996. This leaves a potential gap in provision which cannot be met through community equipment or DFGs.

**5** There is variation between local authorities in provisions DFGs. In some cases, provision, even within the same county, may vary.



### Box 11: Sunderland Care and Support – Integrated Services

Preventing care needs is a key aim for Sunderland City Council. To facilitate this, the Council set up a trading company that provides all their care and support services.

Sunderland City Council and Sunderland Care and Support aim to ensure that if someone has an identified need, this is not left unmet. To promote integration across care and support services, one manager takes responsibility for:

- Home improvement agencies
- Equipment
- Telecare
- Home adaptations/DFG services.

To improve integration, teams from each service shadow each other to ensure that they take a holistic approach when assessing needs for home aids and adaptations. This integrated way of working has another benefit. It builds resilience in the services as staff can cover for each other when necessary. Integrated services have also led to upskilling of staff, higher levels of job satisfaction and, lower staff turnover – which also boosts service resilience.

Occupational Therapists are not part of the integrated service, but they work closely with the integrated team.

The process for providing community equipment is simple. Customer service phoneline staff take people through a triage system of questions and direct them to the most appropriate service. The equipment service is open 24/7, enabling people's needs for aids to be met quickly and efficiently. This has a particularly positive impact on local hospitals, relieving pressure by ensuring that people who need community equipment can be discharged quickly, reducing bed-blocking. Sunderland Care and Support also has a van which operates as a one-stop-shop for community equipment and which can help people in immediate need.

The service has also improved efficiency in delivering major home adaptations. During assessments, occupational therapists are accompanied by surveyors to speed up the process. For major adaptations, the Council sometimes offers discretionary loans to those who are ineligible for a Disabled Facilities Grant. This is a home equity loan, which means that when the property is sold, the Council can recover its costs. Sunderland City Council is also attempting to move to a financial assistance model based on self-declaration, whereby anyone with less than £20,000 can apply for support.



The provision of aids and adaptations exists within a much wider context and is impacted by changes in the health, social care and housing landscape.

These include: the impact of cuts to local authority budgets; the health and social care integration agenda; the quality and quantity of accessible housing stock.

#### 4.1 LOCAL AUTHORITY SOCIAL CARE BUDGETS

Aids and minor adaptations are funded from local authority adult social care budgets. Overall local authority budgets have been cut by 26% in real terms since 2009/10.<sup>54</sup> Adult social care budgets account for about 36.9% of overall local authority budgets and planned savings in adult social care accounts for about 27% overall local authority savings.<sup>55</sup>

The impact of these cuts and savings on aids and adaptations is likely to be an ongoing reduction in quality and availability of items. Despite local authorities having a legal duty to provide community equipment, some local authorities have been reported to be reducing the limit for community equipment from £1000 to £500.<sup>56</sup>

Good provision of aids and adaptations hinges on well-funded and sustainable local authority budgets. The national government should be doing all it can to maintain these budgets, in the context of the much wider debate around the development of a fair and sustainable funding model for social care services. Furthermore, increased funding can result in significant innovations and improvements in some local areas.<sup>57</sup>

***‘Overall local authority budgets have been cut by 26% in real terms since 2009/10’***

#### 4.2 INTEGRATION OF HEALTH AND SOCIAL CARE

Provision of aids and adaptations is complex because the development of legislation and policy has led to multiple bodies having responsibility. For example, funding for DFGs comes from the improved Better Care Fund (iBCF) but is delivered through local authority housing departments. However, assessments and work are conducted by both local authority social care and housing departments. This creates barriers for service users because communication can become confused or delayed.<sup>64</sup>

However, wider integration of health and social care at a local level is being pursued across the country.<sup>65</sup> The purpose of integration is to put patients at the heart of service design and delivery, whilst improving value for money alongside patient outcomes and satisfaction. The integration agenda aims to overcome barriers within the system, including organisational, professional, legal and regulatory barriers.<sup>66</sup> There are some existing links between housing policy and social care. For example, housing

# 04. WIDER CONTEXT

authorities should seek advice from social care departments when determining if home adaptations are ‘necessary and appropriate’.<sup>67</sup>

The only mandatory policy to facilitate integration is the improved Better Care Fund (iBCF). The iBCF is a pool of money designed to join up health and care services. It requires clinical commissioning groups (CCGs) and local authorities to have shared budgets underpinned by integrated spending plans.<sup>68</sup> For 2017/18 the iBCF totals £5.1 billion and in 2018/19 this will rise to £5.6 billion.<sup>69,70</sup>

There is no legal requirement for local authorities to consider housing issues as part of their integration of health and social care. This is despite the evidence demonstrating that housing is a social determinant of health, and that bad housing conditions, including

housing that is in poor physical condition, constitute a health risk.<sup>71</sup> Aids and adaptations have an important role to play in the context of integration as increased investment in housing adaptations could have a direct impact on relieving pressure on health and social care.

The inclusion of the Disabled Facilities Grant within the iBCF is a welcome step towards recognising the importance of home adaptations and good housing environments. However, for integration to be successful, it must not only recognise the importance of housing as a wider determinant of health but take this further by introducing policy to underpin it.

Local authorities must also move more towards integrating their own departments and being more collaborative (see Box 10: Ealing Council case study).

## 4.3 HOUSING

The housing landscape demonstrates why some issues exist around the provision of aids and adaptations as well as why their importance is increasing. Current housing stock is not fit for purpose. Only 6% of existing housing stock meets the four minimum access features allowing people with disabilities even to visit, let alone live in them.<sup>72</sup>

The concept of universal or inclusive design aims to change this. This design movement aims to produce products and spaces that are accessible to all people as standard. Features can include level entrance, automatic doorways, and passageways wide enough for wheelchairs to move and turn.

However the problem remains. 1.8 million people with disabilities are currently living with unmet housing needs. Aids and both minor and major adaptations are critical for meeting the unmet

housing needs of people with disabilities, particularly people with musculoskeletal conditions. In this context, home aids and adaptations will become more significant as current housing stock will have to be adapted so people can live well with disabilities. Housing becomes important when considering independence as a person’s living environment, if well adapted, can foster and improve a person’s independence. However, poor home environments can compound dependency.<sup>73</sup>

Increases in DFG funding represent some recognition by the Government of the importance of aids and adaptations, and the increase is designed to enable greater access for people requiring home adaptations. However, a large number of people aren’t getting access to DFGs.<sup>74</sup> This is in part due to the complexity of the process of accessing DFGs.

## Box 12: Return on investment of aids and adaptations

There is limited evidence on the return-on-investment potential of aids and home adaptations at the national level. What research does exist indicates that housing interventions are overwhelmingly cost-effective. There are also a number of smaller-scale studies on individual schemes that show high return on investment.

- In Wales, the Rapid Response Adaptations Programme has estimated that £7.50 of health and care costs are saved for every £1 spent on adaptations.<sup>58</sup> This scheme allows care and repair services to provide timely adaptations to facilitate people returning home after being discharged from hospital. Adaptations are usually completed within 15 days but can be installed immediately in urgent cases.

***‘In one scheme £13,500 was saved in hospital bed days for a spend of £1,000.’***

- In Bristol, West of England Care and Repair, with funding from Dolphin Society charitable foundation, delivers minor repairs and adaptations for those returning home from hospital. An independent review showed that for a spend of £1,000, £13,500 were saved in hospital bed days.<sup>59</sup>
- Public Health England published a report in 2018 on falls prevention which also showed the effectiveness of home

adaptations. Hospital admissions were cut by 23%; there was a social return on investment of £7.23 for every £1 spent; and a purely financial return on investment of £3.17 for every £1 spent.<sup>60</sup>

- In 2012 the London School of Economics and the British Healthcare Trades Association produced a report that estimated that a spend of £270 million on DFGs is worth up to £567 million in health and social care savings and quality of life gains.<sup>61</sup>
- The Building Research Establishment modelled the impacts of preventive home adaptations among those with long-term illness or disability. The report estimated that the overall payback time in terms of NHS cost reductions was 15.2 years. For adaptations such as grab rails that reduce falls, payback was estimated at 5 to 6 years.<sup>62</sup>
- Bristol University conducted research into the cost-effectiveness of equipment and adaptations on behalf of the Office for Disability Issues in 2007. The report’s authors concluded that whilst not all adaptations provided a financial return on investment, where interventions prevent the need for further care; prevent hip fractures; or expedite hospital discharge; and where they improve the mental health of the household as a whole, they do save money, and sometimes substantially.<sup>63</sup>





# ANISSA'S STORY

## 49 YEARS OLD, RHEUMATOID ARTHRITIS

Anissa's age dominates her relationship with her condition. She says: "I'm the youngest person I know with arthritis, I'd not heard of people getting it this young. You always think of old people getting it".

Anissa's rheumatoid arthritis means she is unable to do most daily tasks. She first noticed pain in her hands whilst gardening but didn't think it could be arthritis because at 49, she felt she was too young.

Anissa's condition has progressed, causing her hand and knee joints to swell up. Because of pain and weakness in her hands, she finds gripping things difficult, and struggles with personal grooming tasks like brushing her hair and putting on her shoes. The impact of this prevented Anissa moving to Spain as she had planned. Anissa has a raised sofa, to enable her to get up and down more easily, along with rails by her bathroom and toilet to aid her with washing.

Anissa is house-proud, but her rheumatoid arthritis prevents her from being able to manage general housework and maintenance. This leaves her feeling constantly like she has a backlog of tasks she can't complete. "No matter what I do I just can't get through everything! I can't keep on top of things."

***"I'm the youngest person I know with arthritis. you always think of old people getting it"***

Anissa accessed help through social services, who sent an occupational therapist to see her – something that she knew about through her own career in social care. However, she felt it took quite a lot of effort on her part to access this help. "Nobody tells you what's available – you have to ask for it or find out by yourself".



# 05. RECOMMENDATIONS

There is much scope to improve local authority provision of aids and adaptations to ensure people with musculoskeletal conditions get better access. To facilitate this, Versus Arthritis recommends:

**1** Community equipment (aids of any value and minor adaptations up to the value of £1000) should be provided by local authorities to people with eligible needs free of charge. However, there is variation in provision of community equipment across local authorities. There are reports that some local authorities are introducing local pricing thresholds.

**The Department of Health and Social Care (DHSC) should investigate and report on the reasons underlying the variation in local authority expenditure on community equipment.**

**2** Aids and adaptations are part of a preventative approach that can help reduce, or delay care and support needs. They support quality of life and independence for people with musculoskeletal conditions. However, there is a lack of guidance illustrating what these services should look like and demonstrating their positive impact.

**DHSC should commission an expert body to develop a centralised resource focused on home aids and adaptations. This should include updated best practice guidance for the provision of aids and adaptations, including information and advice, and evidence of return on investment.**

**3** Local authorities have a duty to provide accessible information and advice about the care and support services they provide. However, many local authorities are not meeting this duty and people with musculoskeletal conditions do not have access to the information on aids and adaptations that they need. **Local authorities should work with local partners to evaluate their information and advice services about aids and adaptations and housing, including the promotion of information and advice, in line with best practice guidance to ensure they meet the needs of people with musculoskeletal conditions.**

**4** Local authority housing departments have a legal duty to meet the needs of people living with disabilities. Provision of Disabled Facilities Grants (DFGs) is part of this duty. However, the process of means-testing through which people access DFGs has not been reviewed in over a decade. In addition to this, the grant is not well promoted.

**We recommend that the Government implements the recommendations from the 2018 independent, expert review of the Disabled Facilities Grant, particularly those focussed on: future funding; information and advice for the general public; the means-test; and better analysis of local need.**

**5** Local authorities have a duty to plan and provide care and support services at both an individual and population level. However, there is a lack of data on major causes of care and support needs to enable effective provision of services.

**DHSC should ensure that the remit to NHS Digital for 2020-21 and subsequent years includes activity to deliver closer integration of data from social care, health care and community health settings. Such data should also be made available for research purposes.**

**6** Responsibility for the provision of aids and adaptations is fragmented. Within local authorities, it is split across social care and housing departments. At a national level, responsibility is divided between the Department of Health and Social Care (DHSC) and the Ministry of Housing, Communities and Local Government (MHCLG). **Building on the joint working by the DHSC and the MHCLG around the Social Care Green Paper, the Departments should establish ongoing ways of integrated working around social care and housing policy. An initial workstream should be the provision of home aids and adaptations.**



## 6.1 ANNEX 1 – EXAMPLES OF AIDS AND ADAPTATIONS PROVISION

- **Cornwall Home Solutions** – In-house home improvement agency of Cornwall Council, providing minor aids and equipment, major adaptations, handyperson services, access to finance such as loans and grants, and information and advice services, amongst others. For more information [homeadaptationsconsortium.files.wordpress.com/2013/10/cornwall-dfg-case-study.pdf](http://homeadaptationsconsortium.files.wordpress.com/2013/10/cornwall-dfg-case-study.pdf)
- **Knowsley Centre for Independent Living** – a one stop shop with an in-house DFG team, care and repair and handyperson services, Knowsley Housing Trust adaptations team and Occupational Therapist services. For more information [homeadaptationsconsortium.files.wordpress.com/2013/10/cameo-of-good-practice-knowsley-centre-for-independent-living.pdf](http://homeadaptationsconsortium.files.wordpress.com/2013/10/cameo-of-good-practice-knowsley-centre-for-independent-living.pdf)
- **Lightbulb Leicestershire** – aims to integrate housing support into one easy access service across Leicestershire. Experts from different agencies work together to improve how adaptations in the home are assessed and carried out. Lightbulb Leicester aims to enable people to remain independent in their own home, reduce pressure on hospital services and providing more preventative services in the home. For more information [leicestershire.gov.uk/news/lightbulb-to-transform-housing-support](http://leicestershire.gov.uk/news/lightbulb-to-transform-housing-support)
- **Middlesbrough Staying Put** – a council-managed agency based within the adult social care department of Middlesbrough Borough Council, focused on reducing demands on A&E services and facilitating rapid hospital discharges. For more information [homeadaptationsconsortium.files.wordpress.com/2013/10/cameo-of-good-practice-middlesbrough-staying-put.pdf](http://homeadaptationsconsortium.files.wordpress.com/2013/10/cameo-of-good-practice-middlesbrough-staying-put.pdf)
- **Somerset My home, my life** – A service supporting vulnerable people in need of housing-related support to promote their independence, health and well-being in their chosen home. It offers DFG services, information and advice, signposting and advocacy. For more information [homeadaptationsconsortium.files.wordpress.com/2013/10/somerset-dfg-case-study.pdf](http://homeadaptationsconsortium.files.wordpress.com/2013/10/somerset-dfg-case-study.pdf)
- **Staffordshire Revival** – a home improvement agency based in Stafford that provides a single point of contact for all their services along with an information and advice service on housing options. For more information [homeadaptationsconsortium.files.wordpress.com/2013/10/revival-hia1.pdf](http://homeadaptationsconsortium.files.wordpress.com/2013/10/revival-hia1.pdf)
- **West of England Care and Repair** – A not-for-profit home improvement agency providing information and advice, handyperson services, needs assessments, casework and technical support. For more information [homeadaptationsconsortium.files.wordpress.com/2013/10/cameo-of-good-practice-west-of-england-care-repair.pdf](http://homeadaptationsconsortium.files.wordpress.com/2013/10/cameo-of-good-practice-west-of-england-care-repair.pdf)
- **Wigan home adaptations pilot** – Wigan has piloted a non-means-tested grant service for major adaptations to reduce delayed transfers of care. For more information [homeadaptationsconsortium.files.wordpress.com/2013/10/cameo-wigan1.pdf](http://homeadaptationsconsortium.files.wordpress.com/2013/10/cameo-wigan1.pdf)



# 06.

# ANNEXES & REFERENCES

## ANNEX 2 – WELL-BEING

The definition of well-being within the Care Act is: ‘Well-being’, in relation to an individual, means that individual’s well-being so far as relating to any of the following—.

- (a) personal dignity (including treatment of the individual with respect);
- (b) physical and mental health and emotional well-being;
- (c) protection from abuse and neglect;

- (d) control by the individual over day-to-day life (including over care and support, or support, provided to the individual and the way in which it is provided);
- (e) participation in work, education, training or recreation;
- (f) social and economic well-being;
- (g) domestic, family and personal relationships;
- (h) suitability of living accommodation;
- (i) the individual’s contribution to society.<sup>75</sup>

## ANNEX 3 – PREVENTION

The Care Act<sup>76</sup> is founded on ‘prevention’ of care and support needs. It sets out a preventative duty for local authorities in regard to care and support. It states that ‘a local authority must provide or arrange for the provision of services, facilities or resources...’ and that provision of these services in a preventative context must consider:

- Services contributing to preventing or delaying care and support needs from developing in both adults and carers.
- Services contributing to reducing care and support needs for adults and their carers.

The Care Act does not include a formal definition of ‘prevention’ or ‘preventative’ measures, and these can include a broad range of types of support, services, facilities or other resources. ‘Prevention’ is generally broken down into three approaches, although services can cut across any and all of these. It is not considered as a single intervention or activity, but as an ongoing consideration.

- Primary prevention includes interventions aimed at people with no current health or care and support needs. Services, facilities or resources provided or arranged at this level tend to be universal and available to everyone.

- Secondary prevention includes services aimed at people with existing health conditions or disabilities, and these services are important for people with musculoskeletal conditions. They are targeted interventions to prevent people developing further needs such as:
  - Fall prevention clinics
  - Adaptations to housing to improve accessibility
  - Handyperson services
  - Short-term provision of wheelchairs.
- Tertiary prevention minimises the effect of disability or deterioration for people with established or complex needs. Tertiary prevention includes services provided in people’s own homes; rehabilitation/reablement services; and community equipment such as minor aids. People with more severe forms of musculoskeletal conditions (e.g. severe osteoarthritis) may use tertiary prevention services.

Prevention plays a critical part in promoting well-being and independence. Aids and adaptations can act as a preventative social care service.<sup>77</sup>

## ANNEX 4 - COMMUNITY EQUIPMENT

Community equipment is defined in regulations which support the Care Act. These state that: ‘Community equipment (aids and minor adaptations) means an aid, or a minor adaptation to property, for the purpose of

assisting with nursing at home or aiding daily living and, for the purposes of these Regulations, an adaptation is minor if the cost of making the adaptation is £1,000 or less.<sup>78</sup>

## ANNEX 5 - NEEDS ASSESSMENT AND FINANCIAL ASSESSMENTS

Under the Care Act there are two kinds of assessment relevant to the provision of aids and adaptations:

- **Needs assessments** identify the needs of individuals and how those needs might be met, including whether they are eligible for the local authority to meet them.
- **Financial assessments** determine who pays for an individual’s care and support needs, whether that is the individual themselves, or the local authority, or a combination of both parties.

1. **Needs assessments** determine if an adult has a care and support need. Local authorities must carry out assessments regardless of the level of needs an adult has. Assessments should be holistic and person-centred, and they represent a critical intervention in their own right.<sup>79</sup> They include an assessment of:
  - the impact of an adult’s needs for care and support;
  - the outcomes an adult wishes to achieve in day-to-day life;
  - whether, and if so, to what extent, the provision of care and support would contribute to the achievement of outcomes.<sup>80</sup>

Needs assessments must include any people that the adult requests to be part of the process, including carers. Assessments can be done face-to-face, as part of a joint assessment by relevant agencies, or as part of a combined assessment alongside a carer.

Assessments should be appropriate and proportionate accounting for:

- A person’s wishes, preferences and desired outcomes;
- The severity and overall extent of a person’s needs;
- The potential fluctuation of a person’s needs.<sup>81</sup>

**1a. To determine eligibility** for care and support, a local authority is required to assess whether:

- An adult has a physical or mental impairment;
- Their impairment is preventing them from being able to achieve two or more specific outcomes;
- Being unable to achieve these outcomes has a significant impact on their well-being.<sup>82</sup>

A person is considered unable to achieve a specified outcome if:

- It cannot be achieved without assistance;
- Achieving an outcome without assistance endangers, or is likely to endanger, the health and safety of the adult, or others;
- An outcome can be achieved without assistance but takes significantly longer than would normally be expected.<sup>83</sup>

**2. Financial assessments** are used to determine when a local authority has the right to charge individuals for using care and support services. Some people are entitled to free care, while others are means-tested to determine the level of support they can receive.<sup>84</sup>



- The ‘upper capital limit’ determines whether a person is entitled to some or whole financial support for care and support. The ‘upper capital limit’ for care given in a residential care home setting is £23,250. Anyone with assets and capital below this level can seek means-tested support. Local authorities may also provide financial assistance to people above this level at the local authority’s discretion. Most people with assets and capital above this threshold, will not be entitled to any financial support.<sup>85</sup>
- The ‘lower capital limit’ in a care home setting is £14,250. People with income below this level do not have to contribute anything to the cost of their care and support. Local authorities may also provide financial assistance to people above this level at the local authority’s discretion. People with assets and capital between the upper (£23,250) and lower (£14,250) capital limit will be subject to a means-test to determine what financial support they might be eligible for.
- For care and support arranged outside of a care home setting, local authorities can choose to contribute towards the cost

of care, even when a person has capital and assets of more than £14,250.<sup>86</sup> Local authorities can also choose to charge for services at home alongside other non-residential services. However, this must be done in accordance with guidance issued by the Department of Health and Social Care.<sup>87</sup>

There are certain kinds of care and support which must be arranged for free, regardless of a person’s financial assessment. These include:

- Community Equipment (aids of any value and minor adaptations costing £1000 or less). These aids must be provided free of charge whether provided to reduce or prevent/delay needs;
- Intermediate care, including reablement care, which must be provided free of charge for up to 6 weeks;
- Care and support provided to people with Creutzfeldt-Jakob Disease;
- Aftercare services and support provided under section 117 of the Mental Health Act (1983);
- Any service or part of a service which the NHS contribution is under a duty to provide including continuing healthcare and the NHS contribution to registered nursing care.<sup>88</sup>

## ANNEX 6 – INFORMATION AND ADVICE SERVICES

Information and advice services are one of the most important statutory duties set out by the Care Act for local authorities. These services are important as they help people make well-informed choices about care and support and understand how it is funded.

The Care Act states ‘a local authority must establish and maintain a service for providing people in its area with information and advice relating to care and support for adults and support for carers’.

Local authorities should provide good information across a number of areas including:

- How local authorities work;
- Choice of care and support services in local authorities including information on providers;
- How to access available care and support services;
- How to access independent financial advice relating to care and support;
- How to raise concerns regarding safety and well-being of adults.<sup>89,90</sup>

## ANNEX 7 – DISABLED FACILITIES GRANTS

Under the Housing Grants, Constructions, Regeneration Act, to qualify for a Disabled Facilities Grant an applicant must meet the following eligibility criteria:

- Be aged 18 or over at the date of application;
- Be either the owner or the tenant (including licensee) of a dwelling and be able to provide an owner’s certificate or a tenant’s certificate (owners may apply on behalf of the tenant);
- Satisfy a means test as prescribed by the Housing Renewal Grants Regulations 1996, if the applicant is a person with a disability;
- The adaptations must be for the benefit of a person who is ‘disabled’ as defined in Section 100 of the Housing Grants, Construction, Regeneration Act 1996;
- Under the Housing Grants, Construction Regeneration Act 1996, a person is considered disabled if:
  - Their sight, hearing or speech is impaired;
  - They have a mental disorder or impairment of any kind;
  - they have been physically substantially disabled by illness, injury or impairment present since birth, or otherwise.<sup>91</sup>

There are four stages of the current means-test system, set out in the Housing Renewal Grants Regulations means test.

## ANNEX 8 – METHODS

This report uses a mixed methods approach. We began with a review of literature of reports produced by other charities, government and academics on the function, provision and delivery of aids and adaptations in the home. We then commissioned two pieces of research into home aids and adaptations and their impact on the quality of life for people with musculoskeletal conditions.

1. People are assessed for how much they need to live on. This ‘allowable income’ is calculated on a set of standard allowances for living costs, using basic levels of pension support/pension credit and a flat rate allowance for housing costs.
2. This ‘allowable income’ is then compared with a person’s actual income to see if they have any ‘surplus income’ that could be used to pay off a loan for an adaptation. A ‘tariff income’ is added for any savings above £6000. If a household is in receipt of any means-tested benefit, it is automatically ‘passport through’ and awarded a 100% grant even if they have a small surplus income according to this calculation.
3. For those not in receipt of a means-tested benefit, how much of a loan they could afford is calculated using their ‘surplus income’. These calculations assume a loan period of 10 years for owner-occupied properties and five years for tenants at a standard rate of interest and incorporates ‘tapers’.
4. The loan size is compared to what a person could afford with the cost of the work needed to see whether they qualify for a grant. If the loan applicants can afford does not cover the cost of the works, the amount of the grant is calculated as the total cost of the works minus the affordable loan amount.<sup>92</sup>

psoriatic arthritis, undiagnosed joint pain, osteoporosis and patellofemoral pain syndrome. Each participant self-assessed as having at least moderate difficulty with two or more outcomes. Approximately one third had one or more major adaptations, a third had an aid or minor adaptation and a third had none. Six 'expert interviews' were also conducted between February and April 2016. These included: Two local authority occupational therapists; one occupational therapy consultant helping to implement the Care Act in local authorities in London; one aid and adaptations lead in a local authority; one adaptations lead in a housing association; one team manager in a home improvement agency. The qualitative research also included a synthesis of fifteen ethnographies from a previous project done by Revealing Reality for Versus Arthritis in 2015. These ethnographies included a half-day ethnography and seven-day diaries completed by five males and ten females, aged between 36-73 across the UK. Again, participants had a range of musculoskeletal conditions including osteoarthritis, osteoporosis, rheumatoid arthritis, back pain and ankylosing spondylitis, ranging from mild to very severe.

2. The second piece of research was quantitative and carried out by ICM Unlimited between August and September 2016. 1059 participants with musculoskeletal conditions undertook a 20-minute online survey on their use and views of aids and adaptations and the impact they had on their day to day life. An additional 154 of these participants undertook a 10-minute online version of the Musculoskeletal Health Questionnaire (MSK-HQ). The MSK-HQ asks respondents to assess their musculoskeletal health over the last 2 weeks against 14 different factors including sleeping and needing help from others. Each respondent gets a score out of 4 for each question, with the maximum score available being 56. A high score denotes better general musculoskeletal

health. 30% of participants had inflammatory conditions, roughly 50% had conditions of musculoskeletal pain, and around 20% had osteoporosis and fragility fractures. Statistical analysis was performed by ICM Unlimited using SPSS or a similar statistical package. Additional analysis was carried out by Versus Arthritis in order to determine the number of participants with eligible care needs using SPSS Statistics 24. Participants were asked 'Thinking of the following activities (i.e. managing toilet needs, being appropriately clothed, maintaining a habitable home environment) please select the option which is most appropriate to you'. A participant was defined as being "unable" to do an activity of daily living if they responded with 'Can do with assistance but with significant pain, stress, or anxiety', 'Can do without assistances but doing so endangers or is likely to endanger the health and safety of themselves or others', 'Can do with help or supervision from another person', or 'Can't do at all'. Conversely, a participant was defined as being 'able' to do an activity of daily living if they responded with 'Can do independently' or 'Can do with aid'.

A participant was classified as having an eligible care need if they were unable to do two or more of the fourteen outcomes of daily living they were questioned about. 538/1059 (50%) participants had eligible care needs. Further descriptive analysis was performed to identify the relationships between eligible care needs and variables of interest including demographic characteristics, the use and impact of aids and adaptations, disease severity, and local authorities. We then synthesized the findings of this research in the context of relevant policy documents including the Care Act 2014, the Housing Grants, Construction, Regeneration Act 1996 and supporting guidance and regulations. This report is comprised of the main findings and recommendations from this research.

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## NOTES

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