

# ACT TO ADAPT

Access to home adaptations for  
people with motor neurone disease

**Securing safe and  
accessible homes for people with MND  
– home adaptations and the  
Disabled Facilities Grant**

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## About MND and the MND Association

Few conditions are as devastating as motor neurone disease (MND). It is a fatal, rapidly progressing disease of the brain and central nervous system, which attacks the nerves that control movement so that muscles no longer work. There is no cure for MND.

While symptoms vary, over the course of their illness most people with MND will be trapped in a failing body, unable to move, talk, swallow, and ultimately breathe. Speech is usually affected, and many people will lose the ability to speak entirely. Some people with MND may also experience changes in thinking and behaviour, and 10-15% will experience a rare form of dementia.

MND kills a third of people within a year and more than half within two years of diagnosis, typically as a result of respiratory failure. A small proportion of people experience slower progression and live with MND for longer, but survival for more than ten years is highly unusual.

A person's lifetime risk of developing MND is up to 1 in 300. It can affect any adult, but is more common in older people: it is most commonly diagnosed between the ages of 50 and 65. There are about 5,000 people living with MND in the UK.

The MND Association is the only national organisation supporting people affected by MND in England, Wales and Northern Ireland, with approximately 90 volunteer-led branches and 3,000 volunteers. The MND Association's vision is of a world free from MND. Until that time we will do everything we can to enable everyone with MND to receive the best care, achieve the highest quality of life possible and to die with dignity.



## Living with MND: why accessible housing matters

Accessible housing is of the utmost importance to people living with motor neurone disease (MND). Everyone has the right to live in a safe and suitable home. For people living with MND, this means an accessible home that enables them to maintain their independence, dignity and quality of life as the disease progresses.

A safe, warm, accessible home is a fundamental right, and it is also central to ensuring good health and wellbeing. Being trapped in inaccessible housing is linked to a range of negative impacts on physical and mental health, resulting from factors such as isolation and loneliness, lack of physical activity, disengagement from family and community, and unsafe environments contributing to accidents such as falls. For disabled people and people with health conditions, homes need to be built around their needs.

Unfortunately, thousands of people living with a disability reside in housing that does not meet their accessibility needs. According to Habinteg, there are around 1.8 million people with an accessible housing need in the UK; 300,000 disabled adults see these needs unmet. Only 7% of homes in England offer minimum accessibility features.<sup>1</sup>

Consequently, many people with MND seek to adapt their homes to meet their accessibility requirements. Our previous report, *MND Costs*, found that housing adaptations are one of the biggest one-off costs for people with MND. Adaptations range from smaller

aids such as grab rails or ramps, to more complex and expensive changes such as wet rooms, stairlifts or through-floor lifts, or extending the property. Costs vary accordingly. 43% of respondents to the *MND Costs* survey had received help to pay for these.<sup>2</sup>

Schemes like the Disabled Facilities Grant (DFG) can provide vital support to people who need to adapt their homes but cannot afford to do so. However, problems in policy and delivery can make the scheme difficult to access. A lack of information about what help is available for home adaptations, what to expect from the process and who to talk to can add to difficulties for people with MND, their families and carers when managing their often rapidly changing lives.

It is particularly important that support is available quickly for people with MND, and that it takes into account the person's developing mobility needs. It also needs to consider the emotional toll associated with making substantial changes to a person's home, or in some cases leaving that home behind.

This report sets out the challenges people with MND currently face in getting support to live independently and safely in their own homes. It highlights the challenges and stumbling blocks in complex local authority systems. It also celebrates some examples of good practice, and opportunities to build safe and accessible housing into the heart of services.



## A call to action

This report comes at a time when a major government-sponsored review of DFGs in England has been completed, and in the run-up to the scheduled end of the Better Care Fund (BCF), under which funding for English councils to support home adaptations sits, in 2020. The DFG is 30 years old this year. It is time to take action to make sure everyone has access to a safe and accessible home. Everyone has a right to live and die in their own home if they wish. By improving the systems that already exist, we can make this possible for everyone.

### Action needed from National Governments:

#### Funding

- National governments must maintain a clear commitment to ongoing central funding for DFGs when current allocations end. This must continue to rise to reflect demand and demographic change.
- National governments in England and Wales should review the funding distribution formula for DFGs, taking into account level of disability, levels of income, housing tenure and regional variations in building costs.
- National governments in England, Wales and Northern Ireland should raise the cap on the maximum grant level for mandatory DFGs to at least take into account inflation-based increases and rising building costs.
- National governments in England and Wales should recognise the real costs of delivering integrated DFG and home adaptations support, and consider revenue grants in addition to capital in order to adequately fund administration, expertise and systems improvements.
- National governments in England, Wales and Northern Ireland should review the means test to address key identified problems including:
  - The low savings threshold
  - Account not taken of real outgoings, including housing costs and the extra costs of disability
  - Levels not keeping pace with housing costs, benefit rates or inflation
  - Lack of alignment with social care means testing.

#### Timing

- National governments in England, Wales and Northern Ireland should include target waiting times for urgent and non-urgent works in transparent and measurable standards for home adaptations, and monitor performance against these targets.
- To improve the availability of accessible homes, the UK Government and national governments in Wales and Northern Ireland should implement the Equality and Human Rights Commission's recommendation to require all new housing to be built to accessible and adaptable standard by default, and a minimum of 10% to wheelchair accessible standard.

- To reduce delays arising from negotiations with landlords, national governments should actively publicise disabled tenants' right to a reasonable home adaptation, and include this information in its guidance on the rights and responsibilities of landlords and tenants in the private sector.

#### Information and Integration

- National government in England should review progress made towards integration of health, social care and housing under the Better Care Fund, identifying good practice and distance left to travel. This must include a specific focus on DFGs as part of integrated health, care, and wellbeing support
- National governments in England and Wales should allocate funding to help local partnerships continue to integrate services, develop data sharing systems and introduce effective multi-disciplinary case management for home adaptations, as part of a wider package of support.
- As part of introducing and developing national standards for home adaptations, national governments in England, Wales and Northern Ireland must introduce appropriate outcomes measurement based on recommended good practice for DFGs.

### Action needed from Local Government:

#### Funding

- All authorities with responsibility for DFGs should, as a minimum, put in place a transparent, fast-track, non-means tested process for adaptations under £5,000 by 2021.
- Every local authority with housing responsibility in England and Wales should develop a policy using its powers under the RRO 2002 to introduce discretionary support, following examples of good practice and evidence regarding return on investment, including:
  - Passporting for people with a terminal illness
  - Removing the means test for stairlifts
  - 'Lean' or no means tests for low-cost high impact adaptations
  - Increasing the cap on maximum grant level based on local costs
  - Allowing discretion and flexibility so that support is not unnecessarily delayed because of residual income such as sick pay.

#### Timing

- Local authorities and the Northern Ireland Housing Executive (NIHE) must review their compliance with target timescales and ensure they meet these in 100% of cases.
- Every local authority with responsibility for housing must make use of its powers under the RRO 2002 to introduce discretionary support for home adaptations, including fast-tracking systems.
- Local authorities should introduce fast-tracking systems for cases where the person has a terminal illness.

- Local authorities should look at their systems for approving works, including whether approved provider lists and schedules of rates for straightforward work can remove unnecessary steps.
- Local authorities should monitor and report annually on the end-to-end processing times for DFGs, from occupational therapy assessment to completion of work. They should establish the number of steps involved in the process and seek to minimise these where the number is excessive.
- Every local authority should establish an accessible housing register so they are better able to identify suitable properties, and provide accurate waiting times to people who need a new home.
- In lieu of mandatory national standards, every local authority should require all new housing developments to be built to accessible and adaptable standard by default, and a minimum of 10% to wheelchair accessible standard.
- Local authorities should introduce systems that provide a single point of contact for disabled people, with 'good conversations' at the start of the process and guidance along appropriate pathways.
- Local authorities should invest in Independent Living Centres, 'pop up' guidance or other information and advice methods to help people understand the options for adapting their home.
- Local authorities should improve their online information about DFGs, including publishing their assessment criteria, processes and other support options in accessible formats.
- Local authorities should build on good practice examples to continue to integrate services, develop data sharing systems and introduce effective multi-disciplinary case management for home adaptations, as part of a wider package of support.

### Information and Integration

- All local authorities should record the primary disability or health condition of DFG applicants in order to enable better evaluation and monitoring of how well they meet the needs of their local population.
- Local authorities and partners in health and housing should use NHS numbers to track, monitor and report on DFG caseloads.
- Local authorities should work to identify and share good practice in the provision of advice, information and support to people with progressive conditions, including focus on addressing the emotional impact.



## Methodology

This report brings together data from an engagement project including face-to-face sessions and surveys of people with MND and professionals, freedom of information request (FOI) responses and a review of policy and literature on home adaptations.

The **engagement project** comprised of:

- 15 engagement sessions at events around England and Wales for MND Association staff, volunteers, health and social care professionals and wider members
- three online surveys between March and July 2018 for:
  - people with MND and their families and carers
  - external professionals, including local councillors, and health, social care and housing professionals
  - MND Association staff providing support to people living with MND
- nine telephone interviews with survey respondents
- meetings with housing experts.

Engagement sessions reached an estimated 150 – 200 people, while the three surveys had 688 responses. Full or partial responses to the first survey, for people with MND, their families and carers, included the following groups:

- Family member or carer of a person who has MND: 31% (141 respondents)
- Person with MND: 30% (140)
- Bereaved family member or carer of a person who had MND: 29% (136)

- Volunteer for MND Association: 7% (30)
- Other: 3% (16).

Of these, 82% owned their own home, 10% lived in social housing, and 8% were in the private rented sector. 119 external professionals responded to the second survey, with the majority in occupational therapy roles, but others working in clinical, community or managerial roles. 19 MND Association staff responded to the third survey.

The **freedom of information requests** (FOIs) were sent by the MND Association in 2018 to all local authorities with responsibility for housing in England and Wales (this includes borough, district and unitary councils in England and all unitary councils in Wales) and the Northern Ireland Housing Executive (NIHE), which is responsible for DFGs in Northern Ireland.

There were 269 complete or partial returns from English local authorities with responsibility for housing, in response to MND Association's FOIs. This represents a response rate of 83%. 18 out of 22 councils responded from Wales, or 81%. 56 English councils and four Welsh councils returned data specifically on the number of people with MND who had applied for DFGs.

The **policy and literature review** considered the legislative framework for home adaptations and the role of housing in integrated health and care. It used existing research from a range of home adaptations experts and disability charities.

A full bibliography, with links to resources, is available at the end of this report.

## Why accessible housing matters for people with MND

Everyone has a right to decent housing. It is central to ensuring people can live independent lives.

Governments in England,<sup>3</sup> Wales<sup>4</sup> and Northern Ireland<sup>5</sup> have created Decent Homes Standards, stating that private-rented and social housing must be warm, free from hazards, up-to-date and in a reasonable state of repair. In addition, optional technical housing standards in England set out guidance for building new homes that are accessible now, and adaptable in the future.<sup>6</sup> However, with only 7% of homes in England offering minimum accessibility features, thousands of disabled adults remain trapped in inaccessible housing.<sup>7</sup>

Poor accessibility increases the risk of stress and isolation, restricts social participation, negatively affects quality of life and can increase the level of care family and friends need to provide, along with increasing the risk of physical injury and increasing costs for additional agencies.<sup>8</sup> There is clear evidence that improved housing conditions also deliver improved quality of life. A 2001 study found that 'adaptations restored confidence, dignity and self-respect, promoted independence and reduced stress', transforming lives, improving health and keeping people out of institutional care.<sup>9</sup> The Equality and Human Rights Commission (EHRC) found that unsuitable accommodation could cause a serious deterioration in mental wellbeing for disabled people, whereas successful housing interventions could 'transform people's lives for the better'.<sup>10</sup> The World Health Organization discusses health and housing with reference to Sustainable Development Goals for good health and wellbeing (SDG3), and sustainable cities (SDG11), to which the UK is signed up.

A lack of accessible housing carries costs to society as well as the individual. While there is currently limited evidence on cost savings to health and social care, safe and accessible homes can help to avoid or delay the need for more serious, and more costly, care. For instance, delayed discharges from hospital, which can be exacerbated by unsafe or inaccessible homes, in total cost the NHS £820 million a year.<sup>11</sup> While the primary reason for delayed transfers of care is the absence of a care package, waiting for equipment and adaptations accounted for 51,328 lost bed days in 2017/18.<sup>12</sup> Fractures as a result of falls among older people cost the NHS and social care around £4.4 billion a year, and can often lead to a move into residential care. Equipment and adaptations to make the home safer can help reduce these incidences.<sup>13</sup> The Building Research Establishment (BRE) estimate that work to fix Category 1 hazards (which includes excess cold and falls) would pay for itself in between 4.5 and 6.5 years.<sup>14</sup> Care and Repair Cymru, who deliver minor adaptations in Wales, estimated in 2011 that for every £1 spent a cost saving of £7.50 is made for health and social care.<sup>15</sup>

As this analysis demonstrates, providing quick and effective housing support is a vital part of making sure people can maintain their dignity, independence and the choice to stay in their own home when living with a terminal illness.

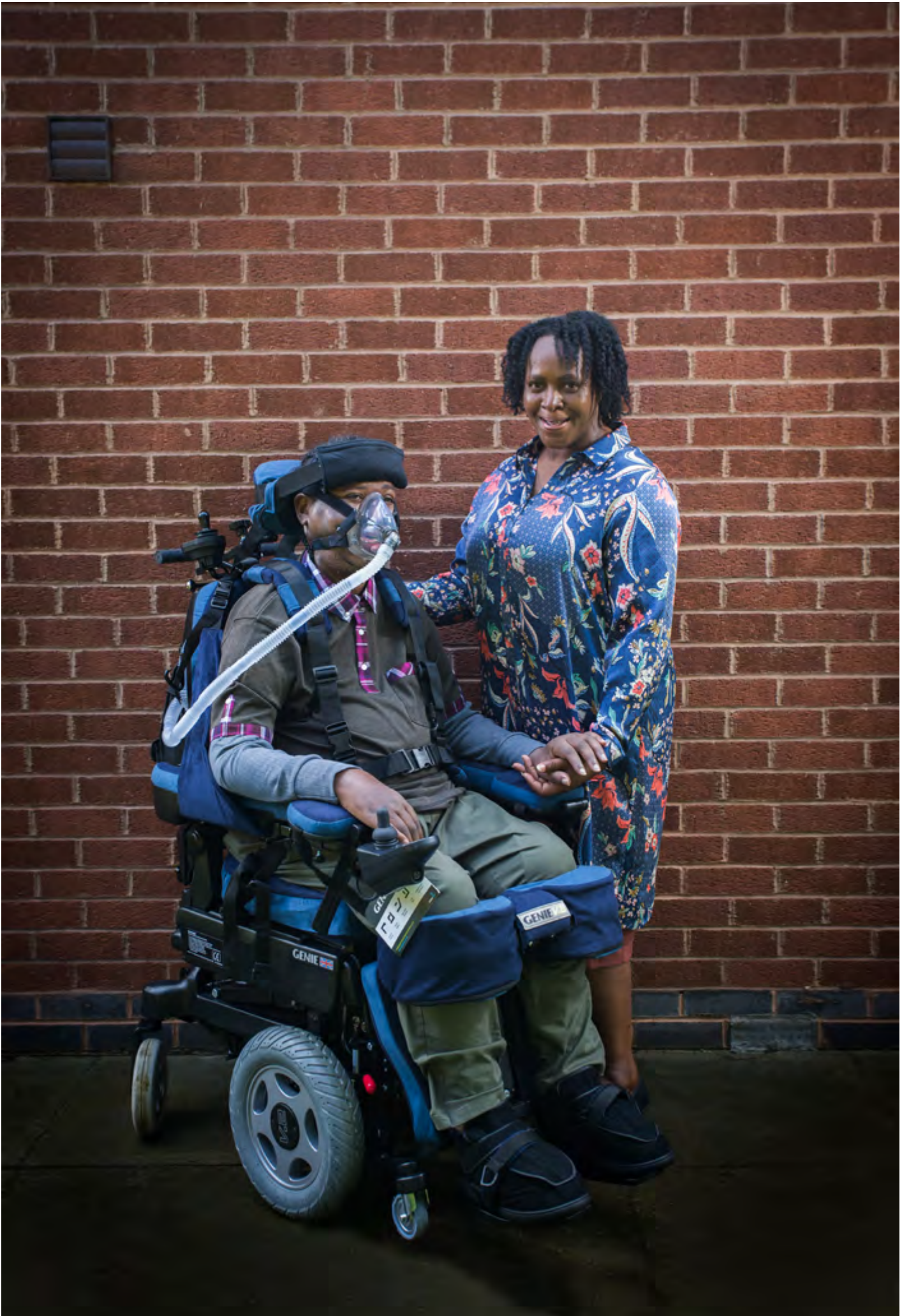
This report focusses on the delivery of home adaptations, because we believe this could be better for people with MND. There are, however, chronic issues with supply of accessible and adaptable private and social housing which while this report does not cover, are closely related. While some places in England, such as the Greater London Authority, Liverpool City Council and Northumberland County Council, have committed to building a certain proportion of new developments to meet accessible and adaptable housing standards, only 24% of planning authorities outside of London have committed to building a proportion of accessible homes, and only 18% of all authorities have committed to building a certain proportion to wheelchair-accessible standards.<sup>16</sup> These figures are improving, and authorities are becoming more aware of the benefits of building to these standards. However, as Habinteg states, 'More work needs to be done in embedding and influencing higher accessibility housing provision within local plans'.<sup>17</sup>

The main source of support for major home adaptations in England, Wales and Northern Ireland is the Disabled Facilities Grants (DFG) scheme. However, minor adaptations, defined under the Care Act as those costing less than £1,000 to purchase and fit, sit outside the DFG process. They are the responsibility of social services authorities in England and Wales, which are required to fund minor adaptations for the purposes of assisting with nursing at home or aiding daily living. In Northern Ireland, minor adaptations are the responsibility of Health and Social Care Trusts. Minor adaptations are not subject to a means test and do not need to be managed through the DFG process. In Wales, where minor adaptations have been brought under the umbrella of the Enable programme, they are categorised by type of adaptation rather than cost, but in practice cover the same type of lower-cost items such as grab rails, stair rails and small ramps. The majority of minor adaptations require a referral by an occupational therapist, although some authorities such as the NIHE waive this requirement for the lowest-cost adaptations.

Major adaptations are delivered through the DFG, a more complex process which is the primary focus of this report. The DFG operates differently in the three nations, but provides vital financial support in all nations for people who would otherwise struggle to pay to adapt their homes. At its best, this scheme can help people with MND make suitable adaptations to their homes, when they need them, to help them continue to move around their property and maintain their independence. However, practice varies drastically around the country.

DFG policy can be a complex area, but systems exist to help local authorities provide flexible support to the people who need it most. Recent policy has also encouraged councils to look at home adaptations as part of a wider, integrated health and social care system, with the needs of the person at its heart. There remain problems with both policy and implementation. However, there are also many examples of good practice for councils to follow. The next section gives an overview of the policy framework, and the problems and opportunities it presents.





## The current policy environment for home adaptations

The Disabled Facilities Grant (DFG) is a means tested capital grant which can help towards the cost of adapting a home. It can provide funding for adaptations such as installing a stairlift or through-floor lift, creating a level access shower room, widening doorways, providing ramps and hoists or creating a ground floor extension.

A person will qualify for a DFG if they can demonstrate that the work is 'necessary and appropriate' to meet their needs, including moving around and getting in and out of their property, and that the work is 'reasonable and practicable'. Under these circumstances, a local authority has a mandatory duty to offer a DFG, providing financial eligibility criteria are met.<sup>18</sup>

Eligibility is 'tenure neutral', so a person does not have to own the home they live in. They will usually need permission from their landlord to make any changes, however, if they live in private rented accommodation or housing association homes. Some local authorities will have agreements with housing associations whereby they may make a contribution to or otherwise fund the works. Council-owned social housing is the exception; it is funded through a different route in England, using resources from the Housing Revenue Account.

The DFG is a means tested grant, so the level a person receives will depend on their income and savings. If they are in receipt of certain benefits, however, they will automatically qualify for support, without further means testing. 'Passporting' benefits include:

- Income Support
- Income-based Employment and Support Allowance
- Income-based Jobseeker's Allowance
- Guarantee Pension Credit (not Savings Pension Credit alone)
- Housing Benefit
- Working Tax Credit and/or Child Tax Credit provided that the annual income for the purposes of assessing entitlement to the tax credit is less than £15,050
- Universal Credit (which is gradually replacing working-aged benefits and tax credits).

Contribution-based ESA and JSA are **not** passporting benefits.

In 70 to 75% of DFG cases the means test is not carried out, for the most part because of these passporting benefits.<sup>19</sup>

If the person is not in receipt of any of these benefits, there will be a further 'test of resources'. The Building Research Establishment (BRE) highlights four stages to the means test:

- **Assess how much the household needs to live on.** This is referred to as 'allowable income' and is calculated using basic amounts of income support/pension credit and a flat rate allowance for housing costs.
- **Compare this with their actual income to see if they have any 'surplus' income they could use to pay off a loan.** A 'tariff' income is added on for any savings over £6,000.
- **For those not in receipt of means tested benefits, calculate how big a loan they could afford to pay off using their 'surplus' income.** The calculations assume a loan period of 10 years for owner-occupiers and 5 years for tenants.

- **Compare the size of the loan they could afford with the cost of the work needed to see whether they qualify for a grant.** If the loan amount is less than the cost of works, the amount of grant is calculated as the total cost of works minus the calculated loan amount.<sup>20</sup>

The value of the property, if they own it, is not taken into account, and Disability Living Allowance, Personal Independence Payments and Attendance Allowance are disregarded, but the person's real outgoings are also not calculated.<sup>21</sup> Household income is assessed under the test of resources, rather than individual income.

According to legislation, the maximum amount of grant that can be awarded is currently £30,000 in England, £36,000 in Wales and £25,000 in Northern Ireland, but local authorities are free to top this up at their discretion. The average grant in England in 2015, according to Care and Repair England, was £6,500.<sup>22</sup>

There are some restrictions on the type of work a DFG can usually pay for. Work that could be covered includes:

- Making it easier to get into and out of the dwelling by, for example, widening doors and installing ramps;
- Ensuring the safety of the disabled person and other occupants by, for example, providing a specially adapted room in which it would be safe to leave a disabled person unattended, or improved lighting to ensure better visibility;
- Making access to the living room easier;
- Providing or improving access to the bedroom and kitchen, toilet, washbasin and bath (and/or shower) facilities; for example, by installing a stairlift or providing a downstairs bathroom;
- Improving or providing a heating system in the home suitable to the needs of the disabled person;
- Adapting heating or lighting controls to make them easier to use;
- Improving access and movement around the home to enable the disabled person to care for another person who lives in the property, such as a spouse, child or another person for whom the disabled person cares;
- Facilitating access to and from a garden for a disabled occupant or making access to a garden safe for a disabled occupant.<sup>23</sup>

Level access showers are the most common DFG-funded adaptation, accounting for 55% of DFGs. Stairlifts represent a quarter of grants, ramps are 10%, and more expensive extensions represent 3% of approved applications.<sup>24</sup>

The MND Association works across England, Wales and Northern Ireland. The DFG and wider home adaptations systems are similar in these three nations, but with some important differences in policy and delivery.

### DFGs in England

DFGs were introduced through the 1989 Local Government and Housing Act, and are currently governed by the Housing Grants, Construction and Regeneration Act 1996.<sup>25</sup>

In 2014, after 25 years of operation, the overall fund was moved into a pooled budget called the Better Care Fund, administered by the Department of Health and Social Care (where previously it had been the responsibility of the Department of Housing, Communities and Local Government (DHCLG)). This budget is part of the government's integration agenda, and so includes other pooled funding for social care and clinical commissioning groups (CCGs), and requires them to produce integrated spending plans.<sup>26</sup> Reducing delayed transfers of care from hospitals, and lost hospital bed days, is a central focus.<sup>27</sup> The ambition is that local health and social care systems should be integrated by 2020, and there is a mechanism for 'graduating' from BCF.<sup>28</sup> It is unclear what happens to DFG funding at this point. Safe and accessible homes are built into other policy areas too. The Royal College of Occupational Therapists (RCOT) has also produced a guide to DFGs in the context of the Care Act 2014, for instance.<sup>29</sup> It notes that home adaptations can be a crucial part of promoting the wellbeing of an individual, a principle that runs throughout the Act. The Wellbeing Principle includes components such as personal dignity, control over day-to-day life, and, of most direct relevance, the suitability of living accommodation. Safe and accessible homes can help meet the Care Act duty to prevent, delay or reduce care needs for adults in England. The Act also makes provisions for minor adaptations, defined as those costing less than £1,000, completed separately from the DFG system.

Foundations, the national body for Home Improvement Agencies, sees the inclusion of DFGs in the wider fund as a positive step; 'for the first time it means housing has to be involved in local discussions about the health and social care commissioning.' Despite early concerns, the total amount available for DFGs in England has steadily risen since its move to the BCF, with a percentage increase of 79% from £220 million to £394 million in 2016/17,<sup>30</sup> and rising further to £431 million<sup>31</sup> and £468 million<sup>32</sup> in 2017/18 and 2018/19 respectively. 2017/18 also included an additional £42 million boost from the 2017 Autumn Budget.<sup>33</sup> In 2019/20 the total DFG allocation through the BCF rose again, to £505 million.<sup>34</sup>

To further drive integration, a National Memorandum of Understanding, *Improving Health and Care through the Home*, was signed in 2018 by the Ministry of Housing, Communities and Local Government (MHCLG), the Department of Health and Social Care, NHS England, RCOT and a range of voluntary organisations, setting out a shared commitment to joint action across government, health, social care and housing sectors in England.<sup>35</sup>

Government commissioned a major independent review of the DFG and home adaptations in 2018, which was led by the University of the West of England (UWE). It provides a comprehensive assessment of the processes involved in accessing home adaptations with and without financial support, and across different housing tenures. It also offers a range of recommendations on how to improve the system. These will be referenced at different points throughout this report.

## How are DFGs administered in England?

DFGs are managed by councils with housing responsibilities - either unitary authorities (including London boroughs) or lower tier authorities such as district councils and metropolitan authorities.

Social services departments in unitary authorities and county councils are highly likely to be involved, however, particularly through occupational therapists, who will conduct needs assessments for disabled people.

In 2002, the government introduced a Regulatory Reform Order, giving local authorities greater flexibility to use DFG funding for preventative schemes. This is a powerful tool; it means that some councils may offer several different programmes that work to deliver adaptations faster and with less bureaucracy. These schemes are sometimes referred to as 'discretionary' DFGs, whereas the main DFG is 'mandatory'. Discretionary DFGs can be used for a wider range of work than mandatory DFGs. Foundations showcases some examples on its website; these and other case studies will be discussed later in the report.<sup>36</sup>

A local council will not necessarily administer DFGs themselves. Home Improvement Agencies deliver around half of all DFGs in England, according to Foundations, and councils may outsource services to other voluntary and private sector providers.<sup>37</sup> Other councils have set up semi-independent organisations to help make DFGs and other home adaptation support work effectively.

## DFGs in Wales

In Wales the DFG system is broadly the same as in England. The main difference in regulations is that the maximum permitted grant is £36,000. Local authority and housing association tenants can apply for DFGs, although social landlords may fund adaptations from their own resources (or those of the Welsh Government) without going through the full DFG process. Local authorities still have responsibility for administering grants. Again, organisations like Care and Repair Cymru might be responsible for running schemes in local authority areas. Local authorities in Wales have the same powers as English councils to provide discretionary support, through the Regulatory Reform Order (RRO) 2002.<sup>38</sup>

DFGs exist within a wider policy and strategy framework in Wales. The Welsh Government has published a new framework on independent living which will review the spending and allocation of funding for home adaptations and continue to support people to live independently.<sup>39</sup> The new strategy defines independent living in the following terms: 'all disabled people having the same freedom, dignity, choice and control as other citizens at home, work, in education and in the community.' It roots policy and strategy in the United Nations Convention on the Rights of Persons with Disabilities, and sets out to address the barriers disabled people face as a result of attitudes, systems and access. It also cites the Equality Act 2010 and the duty to make reasonable adjustments, and the Well-being of Future Generations Act 2015, which requires public bodies to work together collaboratively and sustainably to address short and long term needs. The Government's Strategic Equality Plan, adopted in 2016, includes disabled people's right to independent living, including housing, in its first objective.<sup>40</sup> Funding was made available in 2018 to encourage joined-up working between social care and health boards, including to help older people maintain their independence.<sup>41</sup> Finally, while the Government's target of building 20,000 new affordable homes by 2021 does not include any consideration of accessibility or adaptability for market properties, the Development Quality Requirements will mean

that 13,500 homes built by Registered Social Landlords, funded by government, are built to Lifetime Homes Standard (LHS).<sup>42</sup> This means they meet certain accessibility requirements, and will be easier to adapt in the future (although LHS homes are still not accessible for wheelchair users). Even so, EHRC found that in some cases disabled people in Wales were waiting in excess of five years for a suitable property. Shelter Cymru has developed a campaign for a Living Home Standard,<sup>43</sup> which includes consideration of whether homes are suitable for the age and disability-related needs of everyone in the household.

Wales has reviewed its support for home adaptations and other aids for independent living over recent years. A 2013 Communities, Equality and Local Government Committee Inquiry found a convoluted system, with a confusing number of entry points.<sup>44</sup> Likewise, a 2015 review conducted by Shelter Cymru found that the home adaptations service was fragmented and complex, with sometimes long delays in DFG delivery times.<sup>45</sup> A 2018 report by the Wales Audit Office called the system 'hugely complicated, reactive and inequitable.'<sup>46</sup> It makes the point that opportunities to use funds more effectively, such as through pooling arrangements and integrated approaches, are generally not taken, and there is too little oversight and monitoring of impact.

As acknowledged by the 2018 report, the Welsh Government has taken some steps to review and improve the home adaptations system. In 2016 it launched an umbrella scheme called ENABLE, designed to simplify, speed up and better monitor the system. This organises grants according to type of aid or adaptation – small, medium or large – regardless of housing tenure. The ENABLE programme also incorporates additional funding for Physical Adaptation Grants for social housing tenants, and Rapid Response Adaptations (managed by the 11 Care & Repair Agencies that cover Wales) for smaller items that enable a person to stay in or return to their home after a hospital admission.<sup>47</sup> In 2018 the Welsh Government also launched a consultation on draft service standards for home adaptations, with an aim of improving consistency of delivery by service providers, including local authorities, third-party deliverers, registered social landlords and occupational therapists. The new service standards were published in April 2019.<sup>48</sup> They include seven standards covering

quality of equipment and service, and sets out expected time frames for the different stages of the process. This has the potential to establish a robust, transparent and measurable framework for delivering adaptations.

## DFGs in Northern Ireland

The Northern Ireland Housing Executive (NIHE) is responsible for delivering DFGs in Northern Ireland. Assessments will be made by occupational therapists within Health and Social Care Trusts. The maximum grant available is £25,000, which is paid on completion of all work. There is a separate process for people living in Housing Executive properties and Housing Association homes, and priority is given to people with a limited life expectancy.<sup>49</sup>

The Department for Communities and the Department of Health published an Inter-Departmental Review and Action Plan for housing adaptations services in 2016, following on from earlier reviews in 2013 and 2002.<sup>50</sup> The report references a range of building initiatives and regulations for building accessible and adaptable homes in private and social sector housing. Recommendations include improving electronic communications and data sharing between NIHE, Health and Social Care Trusts and other statutory partners; ensuring better representation of disabled people in housing policy decision making structures; reviewing interagency case management arrangements; and appointing a dedicated specialist occupational therapist, with support for training in environmental design, in every Health and Social Care Trust. There were plans to develop an Accessible Housing Register for social housing, which is expected to be completed in 2019/20.

The 2013 review resulted in the production of an Adaptations Design Communications Toolkit, which includes details of minor adaptations that can be provided without the need for assessment, design standards and formats, and communications guidance for occupational therapy.<sup>51</sup>

There is limited detail from government or independent sources about the effectiveness and operation of home adaptations policy in Northern Ireland. Further research is necessary to determine whether people with MND are able to access the support they need to stay in their own homes in Northern Ireland.

## Home adaptations: Issues and challenges for people living with MND

There are a number of barriers disabled people face when trying to adapt their home. We wanted to know the experiences of our members, supporters and professionals working in the field. Through surveys we asked them to choose three options for the ‘three biggest challenges’ for accessible housing, to help us better understand these barriers.

Of 387 respondents to our survey for people with MND, their families and carers, 96% chose the **cost of adaptations** as a major barrier to adapting their home. A further 39% selected a lack of financial help for adaptations or house moves, and 23% indicated the cost of moving home. Engagement event findings highlighted the cost of repairs as well as adaptations and housing alternatives, the availability of council resources, means testing, grant restrictions and costs of returning homes to their prior condition after the person with MND dies.

A quarter of respondents selected the **length of time** taken to make adaptations. 21% chose a lack of availability of accessible homes, which drives up waiting times, and a small percentage (16 people, or 4%) chose the length of time they needed to wait for a new accessible home. A fifth told us the length of time it takes to hear whether they were eligible for grants such as the DFG was a problem, 12% waiting to hear whether the grant application had been successful and a smaller number, 25 people (about 7%), indicated the length of time taken to obtain planning permission. Free text responses and information collected at engagement events also indicated that time taken to get assessments, approvals, acquire quotes, complete work or secure alternative housing were major issues for people with MND, their families and carers.

23% of respondents chose **lack of support** from local services, and a further 22% chose **lack of information** about how to adapt their homes. 11% referred to the complex application process for adaptation grants, and a small number (22 people or 6%) selected a lack of information about moving to an accessible home. People at

engagement events also felt that there was either a lack of or poor quality support, poor communication by professionals, conflicting advice or a lack of knowledge about MND among professionals.

When broken down by housing type, cost and time still came out strongly for all respondents, although the social housing cohort cited lack of support from local services (44.4%) and lack of available housing (41.7%) more frequently in comparison to the results from all respondents. Engagement events highlighted the issue of securing private sector landlord permission to make adaptations.

We also asked professionals what they felt were the biggest barriers people living with and affected by MND faced when securing accessible housing. Respondents could select multiple options. Of 92 respondents, 87% selected the emotional burden of having to organise adaptations or move home. MND Association staff strongly agreed with this, and it was a theme at engagement events as well. 83% of external professionals indicated that a lack of available accessible homes was a barrier, and three quarters chose the length of time waiting for an accessible home. 71% indicated the length of time taken for adaptations to be built, 59% chose the length of time taken to get a housing needs assessment, 58% the length of time taken to obtain planning permission and over half the length of time to hear back about eligibility (54%) or successful application (51%). 77% said that the cost of moving home was a barrier, and 65% indicated the cost of adaptations. Professionals also indicated that restrictions on types of adaptations possible was an issue (73%), and this was also raised at engagement events.

The table below highlights common themes from survey responses and engagement events. These issues shape the rest of the report, drawing further on data from surveys and engagement events, council FOI returns and previous research on challenges in policy and practice. The challenges, possible solutions and examples of existing good practice are discussed in the next sections.

**Table 1:** top challenges for people with MND in adapting their homes – responses from people affected by MND, health and social care professionals, MND Association staff and from engagement events.

People affected by MND	Health and social care professionals	MND Association staff
<ol style="list-style-type: none"> <li>1. Cost of adaptations</li> <li>2. Lack of financial help/costs</li> <li>3. Length of time</li> </ol>	<ol style="list-style-type: none"> <li>1. Emotional burden of moves or adaptations</li> <li>2. Lack of availability of accessible homes</li> <li>3. Costs</li> </ol>	<ol style="list-style-type: none"> <li>1. Emotional burden</li> <li>2. Lack of availability of accessible homes</li> <li>3. Cost of moving home</li> <li>4. Time</li> </ol>

### Engagement events and free-text responses

- (a) Time: slow speed of process
- (b) Knowledge and support
- (c) Funding and cost
- (d) Council resources and budgets
- (e) Psychological barriers and mental wellbeing
- (f) Housing availability
- (g) Specific challenges for different types of housing status
- (h) Building and design

## Costs and financial support for home adaptations

As stated, *MND Costs* research found that housing adaptations are one of the biggest one-off costs for people with MND, in some cases reaching into the 10s or even 100s of thousands of pounds. One survey respondent reported spending £110,000 on adapting the family home for a person living with a slow-progressing form of MND. Elsewhere, Muscular Dystrophy UK research found that many families who did qualify for a DFG had to supplement their grant because the cost of work far exceeded the grant limit. For many of these families, the charity states, 'this meant incurring huge personal debt, suffering long term financial hardship or relying on the generosity of wider family members to see them through'. Over a third of survey respondents had encountered financial difficulties when adapting their home.<sup>52</sup>

Overall, 57% of DFGs cost less than £5,000. 35% were under £15,000 and only 8% were over £15,000. The average value of a DFG rose from just over £7,000 in 2009/10 to nearly £9,000 in 2016/17, reflecting increases in building costs. There is considerable regional variation, however; in London, only a third of work is under £5,000, whereas in most other areas between a half and two thirds are under £5,000. The average cost of the two most common adaptations is £5,000 for showers, and between £2,400 and £4,500 for stairlifts.<sup>53</sup> The total funding level for the year 2016/17 was £394 million, a 79% increase on the previous year's total of £220 million.<sup>54</sup>

As Habinteg argues, rising central government budgets are certainly good news, but there is a risk these are offset by increasingly squeezed local authority funding.<sup>55</sup> This will have a knock-on effect on councils' ability to top up DFG funding for those who require more than the limit, or in areas where demand outstrips supply. Indeed, Muscular Dystrophy UK found that 'well over a third' of local authorities responding to their Freedom of Information (FOI) requests awarded no discretionary payments for DFGs, and many did not offer discretionary payments at all.<sup>56</sup> Foundations found that some authorities contribute significantly more additional funding than others; 'some areas appear to have sufficient funding, while others suffer from backlogs and delays.'<sup>57</sup> The recent UWE review of the DFG and other adaptations found that English local authority top-up funding dropped to a very low level in 2016/17.<sup>58</sup> This, they suggest, runs contrary to central government's intention that councils would continue to add their

own resources, and that the number of grants would thus increase significantly. They also point out that the cost of work has risen over the years, and that cases are increasingly complex. Service costs, such as staff and administration, are also not taken into account in funding allocations. Some councils have had to either introduce charges or top-slice budgets to cover these.

People with MND and health and social care professionals told us that costs of adaptations and a lack of financial support were significant barriers to securing an accessible home. Issues were also raised by FOI returns from local councils. The following section explores these findings in more detail.

## People with MND and professionals: high costs mean inaccessible homes

Of 387 respondents, 96% chose the cost of adaptations as a major barrier to adapting their home. A further 39% selected a lack of financial help for adaptations or house moves, and 23% indicated the cost of moving home was a significant barrier. People with MND, their families and carers can spend significant amounts of money making their homes accessible. Through surveys and engagement events they told us that the cost of adaptations or of relocating, as well as equipment repair, and removal after bereavement, represented a considerable burden on top of managing an often rapidly progressing illness. People at engagement events and in survey responses also told us about problems with VAT charges in relation to DFGs. This is a problem Foundations has identified as well, and they recommend reviewing these rules to make sure they are consistent and fair.<sup>59</sup>

People felt that the means test for DFGs was unfair, particularly in terms of both the low savings limit and the fact that it does not take into account real outgoings, which can be substantial for someone with MND. *MND Costs* found that the extra regular and enhanced costs of managing the disease equated to £9,645 per year, not including one-off costs for equipment and adaptations.<sup>60</sup> A lack of flexibility, or realistic consideration of the loss of income working aged people with MND will often face when they are no longer able to work, can also result in both delays and financial hardship. Problems are also caused by the fact that the test of resources is based on household, rather than individual, income.

## Experience in Northern Ireland: Ciara's story

Ciara's husband Joe was diagnosed with MND in November 2014 and they had a very negative experience with trying to get suitable housing adaptations. Ciara recalls that their occupational therapist was good and went to their house before Joe was discharged from hospital to take her through what would be required. In order to meet Joe's needs they needed a downstairs bedroom and bathroom built. However, following the OT's recommendations they found that they did not qualify for financial help and the system was not responsive to their needs.

In Ciara's words: "After a very late diagnosis Joe returned home from hospital and slept in our kitchen on a hospital bed. All of his equipment, commode, wheelchair etc was jammed into our kitchen. Our home was in turmoil and we had to hold it together for the sake of our two boys."

"We applied for financial aid to have this building done. We were turned down for any assistance as we both worked. We were told to reapply when our circumstances changed. As far as we were concerned they had already changed dramatically and we didn't have time to wait! Joe's work colleagues, family and friends began raising money to have our house



adapted. The building started early February and was completed before Easter 2015."

"As it turned out, it really was too late for Joe. Seven months after diagnosis Joe died. The whole process was shocking to me. I couldn't believe that we were basically told we would have to do it ourselves. On top of the horrendous news of Joe's diagnosis we did not need this stress."

*The savings limit for financial assistance is unfair to those that have saved during their working life.*

**MND Association member**

*More flexibility about eligibility for grants (I was denied any assistance as I had just two months sick pay before losing all my income and couldn't wait as my husband couldn't access the bathroom at all, so had to self-fund).*

**MND Association member**

*I feel the local authority I work for respond quickly to individuals with MND, however, I have found many are not eligible for grant funding as their spouse may be working or the means testing prevents them applying as the grant does not take account of outgoings.*

**Health and social care professional**

*Even if they are eligible for a DFG, the cost that the person is expected to pay towards adaptations is so high that many people can't afford it.*

## Experience in the North West: Darren's story

Darren was diagnosed with MND in August 2018, and the disease is now affecting his mobility and ability to move around his home. He currently uses a manual wheelchair and is on a waiting list for a powered chair. He is still able to go upstairs with the assistance of a grab rail and wants to be able to go upstairs for as long as he can. He is able to use the bathroom, with the help of a balance board, but is finding it more difficult, so he has sought help to get further adaptations to his home.

Through discussions with his occupational therapist, it was decided that the best option would be to convert the garage into a bedroom and wet room to cater for his future needs as his MND progresses. This would take the pressure off navigating the stairs and using the main bathroom in the future.

The cost of the garage conversion, ramp installation and external paving is estimated at £40,000. However, the family has had no financial assistance from their local authority towards the costs of their adaptations, as the council's means test concluded that they were ineligible for support. Darren felt that the means test looked only at income but took no account of relevant outgoings resulting from his condition.

Darren was told that he wasn't eligible for the DFG by phone in February 2019 but didn't get any subsequent written notification. This has made it difficult for him when trying to get support from charities as they required written confirmation that he had been declined support from the local authority. This generated extra stress when trying to get some support.

Drawing on support from his family, his critical illness insurance pay-out, his pension, and saving his Personal Independence Payment, Darren has been able to take forward his necessary

adaptations, which are now in the planning stages. However, he regrets the impact of the cost on himself and his family.

*"I still want to lead a life and do what I can to create memories etc. However, all that costs money and the adaptations also have a big cost. The prospect frightens me. We will have spent so much of my pension and insurance pay-out into making my own home liveable and functional, which comes at a massive premium. After we've had the works done, we will be struggling to afford anything above normal daily life. The DFG would have helped a lot if they'd been more amenable, even if it meant we still had to pay a certain contribution."*





Costs and contributions can prevent the right work getting done at the right time. This is related to the need for better information and timely assessments that take future needs into account.

*(One) issue I have had for two patients is that they have received their assessment, accepted need for adaptation, had the financial assessment and then decided they are unable to contribute the amount of money required to support the adaptation. They have been re-assessed once their financial situation altered and when not required to contribute to the cost have proceeded with the adaptation. However this often feels too late.*

**Health and social care professional**

Engagement events and survey results also showed that the caps on DFG grants - £30,000 in England, £36,000 in Wales and £25,000 in Northern Ireland - could be problematic, where major work is needed. While just 5% of projects are in excess of £30,000, finding the extra funding can create additional delays for the most severely disabled people. Moving to another property is often not an option, as already accessible housing is often not available. The grant limit in England has been the same since 2008, and does not reflect either inflation increases or regional variations in building costs. UWE calculates that had it raised in line with inflation, the upper limit would be £38,000 today. It also notes that working to a strict cap risks working on the basis of cost minimisation, rather than in a person-centred way. Some local authorities have recognised problems with the cap and have either raised the maximum grant allowed, or provide top-up grants or loans to cover extra costs up to a certain limit. Chorley Council, for instance, has raised its limit to £40,000 and Cheshire East to £50,000, while West Sussex has top-up funding up to a maximum of £30,000, Portsmouth £15,000, and Somerset, Worcester City, Oxford City and Rochdale £10,000.

Some people were unhappy about charges levied against properties in return for DFGs, or requirements to pay back costs above £5,000, up to a limit of £10,000, if the property is sold within a number of years. This is not an uncommon policy in England; almost three quarters of authorities reported placing land charges in 2016/17, although UWE reports that this money is sometimes simply reabsorbed into general funding, rather than reinvested into the DFG pot. Local authorities are required to consider whether reclaiming this money will cause a person or family financial

hardship. It is important that they follow this procedure, and communicate it appropriately, particularly when the property is sold following a bereavement, given the range of costs that will be incurred. Six in 10 bereaved family members surveyed as part of MND Costs said that MND had taken a financial toll to a great extent or some extent.

*I object very strongly to a charge being set against my property since it was not my fault that I was diagnosed with MND.*

**MND Association member**

There was some feeling that adaptations might be driven by cost, rather than appropriateness. Health and social care professionals also commonly referenced cuts and funding pressures on local authority teams. Building costs have also increased, putting extra pressure on budgets.

*The price of through-floor lifts has literally gone through the roof.*

**Health and social care professional**

*Money is being pumped into DFG's but, due to austerity, there are nowhere near enough OTs within Adult Social Care to complete the required assessments in a timely manner and that is also the case with the grants officers. People have to wait months before being seen to even get the ball rolling and it is often the case that they do not qualify for DFG funding anyway.*

**Health and social care professional**

To address some of these concerns, the UWE independent review recommends removing the means test for stairlifts, given their clear return on investment, and the ability of local authorities to refurbish and recycle units; and considering removing the means test for palliative care cases, given the cost savings involved in helping a person to remain in their own home at end of life.<sup>61</sup> Given the high proportion of grants worth under £5,000, Foundations argues that there is a strong case for cutting bureaucracy on this basis.<sup>62</sup> Some local authorities have already tried this and other approaches to reduce financial barriers; some good practice case studies are detailed as follows:

**Eastbourne Borough Council and Lewes District Council** have developed a new joint policy for DFGs, including extra support. It has increased the maximum DFG limit to £50,000, and removed the means test for works costing below £8,000. There is no means test for people leaving hospital or receiving palliative care. There are additional match-funding arrangements with East Sussex County Council for works in excess of £50,000. Relocation expenses of up to £10,000 are available where moving is a preferable option. There is a non-means tested Hospital Discharge Grant of up to £3,500 for interventions including cleaning, decluttering and repairs, and there is a Hardship DFG for people who are assessed as having a contribution but are unable to meet it or secure a loan.

(Disabled Facilities Grants Policy, Eastbourne and Lewes Councils, 2019)

The **Middlesbrough Staying Put** service, now based in the Adult Social Care team, has existed for nearly 30 years. It is designed to be a single point of access, working alongside the occupational therapy team, to manage home adaptations. A hospital-based team also works with ward patients to find housing interventions to support discharge. Staying Put operates a Handyperson Service – Middlesbrough Mobile Adapt and Mend Service (MMAMS) - which is staffed by disabled people. The service has also been noted for the extent to which it seeks and monitors service user feedback.

Middlesbrough has made use of its powers under the Regulatory Reform Order (RRO) 2002 to provide discretionary funding. A Small Measures grant of up to £6,000 is designed to address health, rather than disability, needs, such as improving warmth. Social Care Funding for adaptations operates where either the works exceed the £30,000 mandatory DFG maximum grant, or where a high means tested personal contribution means the works will likely not progress. In addition the Council is developing a Dementia Grant of up to £3,000. There is also assistance available for relocation costs where this is a more practical option, and can support service users to access charitable funding sources where they do not qualify for in-house support.

(Home Adaptations for Disabled People, Home Adaptations Consortium, 2013; Good Practice Case Study, Home Adaptations Consortium, 2015; Middlesbrough – local authority in-house home improvement agency, Centre for Ageing Better, 2018)

**Sunderland City Council** has an arms-length Home Improvement Agency as part of Sunderland Care and Support, a local authority trading company set up in 2013. The Council has made use of its powers under the Regulatory Reform Order (RRO) 2002 to introduce discretionary loans and grants for home adaptations, alongside the mandatory DFG.

Grants are available without a means test up to the value of £8,000, where the applicant is receiving palliative care. Works costing less than £8,000 in other cases are subject to a 'lean' means test, rather than the full mandatory DFG test of resources; this means that anyone with savings of less than £20,000 will be passported through. Relocation grants are available for tenants up to the value of £1,000 where this is a more cost-effective option. Loans are available for qualifying work above the £30,000 limit, and for relocation where this is a more practical option. Work is completed by firms on a list of approved providers, subject to meeting regulations and quality of work tests.

Sunderland Care and Support also provides a Handyperson service, equipment loans, telecare and other support.

(Housing Financial Assistance Policy, Sunderland City Council, 2017 – 2020; Home Adaptations Consortium Good Practice Case Study, 2015)

## What does local authority data tell us about DFG funding?

National government funding for DFGs in England was distributed to unitary, borough and district councils according to a national formula.

### Levels of spending

FOI data showed that councils spent an average of 82% of their DFG funding allocation, but with wide variations between areas. Two councils spent less than 1% on grants, but this is explained by their small populations. The table below shows the number of councils spending different levels of budget.

**Table 2:** proportion of DFG budgets spent by English local councils

Level of spend	Number of councils
110% or more	12
100 – 109%	68
90 – 99%	38
80 – 89%	32
70 – 79%	45
60 – 69%	31
50 – 59%	17
40 – 49%	16
30 – 39%	8
0 – 1%	2

Councils most commonly report spending at least 100% of their budget, but these councils only represent 30% of all respondents. It is hard to tell from these results, however, whether this reflects a sensible allocation of resources, or that council budgets are being exhausted. Some councils also report budgets higher than their 2016/17 allocations due to rolling over previous years' funds; this may disguise extra spend to some extent, given annual fluctuations in demand. It is also not clear whether those which have spent a lower proportion of budgets have done so because of lack of demand, or lack of awareness of DFGs.

14 out of 22 councils in Wales used at least 90% of their DFG budget; Gwynedd had the lowest spend at 54%. No councils spent more than 100% of their budget.

### Funding allocations

One way to shed some further light on the issue is to look at the proportion of disabled people and people with life-limiting illnesses in each authority, and to compare grant data with each local authorities' Index of Multiple Deprivation (IMD) ranking.<sup>63</sup> Census data from 2011 provides an indicator of the number of disabled people who feel their day-to-day activities are limited a lot, and to a lesser extent, as well as total population figures for that year. This includes people of all ages.

Comparing this data with the value of grants shows that, to some extent, the higher the proportion of the population reporting a severely limiting disability, the higher the value of grant. There is no

correlation between more severe disability and percentage spend, however. 47 local authorities had a proportion of 10% or higher of a population who identified as more severely disabled. 16 of these spent 100% of their DFG budget, and one council spent over 100% of their budget. On the whole, the lower the IMD rank (i.e. the higher the level of deprivation), the higher the level of grant allocation councils receive. Blackpool is a notable anomaly; it ranks 95th in terms of total level of grant (£1,146,297), but second in terms of proportion of people reporting a severe disability (13.55% of the total population) and fourth in the IMD rankings. The council with the largest grant is Leeds (£7,000,000), but this council is IMD ranked at 100 out of 326, and has a comparatively lower proportion of the population reporting a more severe disability (7.87%).

However, these results should be treated with some caution. IMD ranking is an average ranking across a number of different indicators, and measured at a smaller geography than local authority level; as such, the figures may disguise greater variations in deprivation levels within council boundaries. The census figures do not distinguish between different types of disability, so will include those who may not have extensive physical needs. They rely on self-identification; a person may not consider their day-to-day activities limited to a great extent, even if they do require adaptations. These figures also do not reflect other population characteristics that are likely to be relevant to DFG funding – in particular, the age of local populations – or other factors relating to housing costs or proportions of council housing stock (which is funded differently to other housing types).

The funding allocation process for local authorities is not transparent; it has been difficult to locate a clear explanation of the allocation formula from government sites for this report. BRE highlighted the complexity of the system in 2011; it is 'allocated to each local authority using a complex mixture of distribution formula, local indicators of disabled facilities grant need and bid submission to the Government Offices.'<sup>64</sup> Data used includes the English Housing Survey, which measures the condition of housing in regions, the number of people claiming Disability Living Allowance (and presumably PIP) or Attendance Allowance, comparisons with previous years' figures and other data submitted in historic local authority bids. Underspend or overspend by some local authorities, however, does not necessarily reflect a lesser or greater need for funding, as many factors are at play. Local health, social care and housing authorities need to have data monitoring systems in place to track current and predict future need.

UWE's independent report took a further look at DFG budget allocations. It proposed producing an allocations formula based on an IMD deprivation measure, and Personal Independence Payment (PIP) or Attendance Allowance (AA) recipients. It recognised that this would underestimate need, as these benefits are underclaimed, but that this data was more up-to-date than Census data used above. It also took into account the percentage of 'frail elderly' in each area – the percentage of people aged over 65 who are 90 years old or above, and the amount of local authority-owned social housing stock (residents of which would not be eligible for DFGs) in each area. The results showed significant swings in allocations as a result of these proxy measures, particularly in relation to housing stock, although the researchers recommended further work to establish whether these were really the correct measures,



or whether other factors such as income data should be taken into account. It points out that given some of the swings involved, changes should be introduced incrementally.

### Closed cases

If work is deemed necessary and practical, the council has a duty to deliver a DFG, subject to means testing. However, cases may be closed for a range of reasons, including affordability. Councils describe preliminary assessment systems, or systems whereby referrals do not get to application stage if they are likely to be ineligible on the test of resources.

Common reasons for closing cases are recorded in the table below. It is, unfortunately, not possible to quantify the frequency of case closure according to reason, as only some councils have provided numbers against reasons. However, an attempt has been made to record how many councils gave each reason.

**Table 3:** Reasons given by English local authorities for closing cases

Reason for closing cases	Number of councils citing reason
0, N/A or data not held	187
Means test failed/contribution too high	73
Applicant died	41
Applicant moved (moved house, moved into residential care or left area)	39
Application withdrawn (by applicant, OT or not stated)	30
Incomplete information (including refusing to complete the means test, and not responding to enquiries)	28
Work done by other means (including work already complete, completed by registered social landlord, privately funded or funded by other means)	25
Works or person not eligible [reason not stated]	22
Work deemed not necessary, appropriate, reasonable or practicable	17
Landlord refused permission (private and social)	15
Adaptation not wanted (eg different adaptation wanted)	13
Property unsuitable for adaptation	12
Time limit expired	5

In Wales, common reasons are broadly the same. Ten councils did not provide information, while eight reported applicants failing the means test. Welsh councils do not mention unadaptable properties, but this may still be an issue for some applicants.

Financial eligibility for DFGs is clearly a concern, and is likely to account for some instances of applicants not supplying financial information, finding other means of funding, or withdrawing applications for unstated reasons (although these will be mixed). The number of instances of people failing the means test is also likely to be higher, given the substantial number of councils that

pre-screen enquiries for financial eligibility. It would be interesting to know, although difficult to quantify, the value of cases closed for this reason, as there is some evidence, discussed earlier, that minor grants to prevent falls can deliver significant cost savings.

The returns from this FOI, and some exploration of excluded cases by UWE, suggest that this issue could be interrogated further to better understand the impact of the current means test on creating accessible homes.

### What's the future for DFG funding?

BRE estimated in 2011 that £1.9 billion (at 2005 rates) would be needed to provide adaptations to all those theoretically eligible – far outstripping the amount available.<sup>65</sup> The allocation system, determining the total amount given to each local authority, was found to be highly complex and lacking in transparency, with too great a risk of fluctuation without considering relative local need. Analysis here and in other reports suggest that there are some areas that would see their allocations change significantly if different assumptions were used, but that more research is needed to understand which measures are the most appropriate. Government needs to consider the real costs of delivering DFGs, rising building and housing costs and collecting the kind of data that can help predict need if it wants to see councils meet targets for increased grants awarded.

There are good examples of local councils in England that have used discretionary powers to remove means tests, increase grants limits or provide additional grant support for aids, adaptations and equipment. There are also examples of councils that make specific provisions for people at the end of life. We encourage more councils to use these powers, given both the cost and the quality of life benefits that even lower-cost adaptations can deliver.

There are two additional policy issues that government will need to address; one is the scheduled end of the Better Care Fund in 2020, and the other is the relationship between DFGs and any changes proposed in the forthcoming Social Care Green Paper, which was originally due to be published in 2017 but has been repeatedly delayed.

It is not yet clear what, if anything, will replace the Better Care Fund as a mechanism for delivering funding, and encouraging integrated health, care and support services. While we certainly do not expect DFG funding to end, there may need to be new arrangements made. This may provide an opportunity to review both the allocation formula and data monitoring systems. It will be important to share examples of successful service integration as a result of pooled funding, and to encourage councils to continue this work.

The Social Care Green Paper is likely to consider new mechanisms for funding social care, and may also revisit the idea of a cap on the cost of care. As the UWE report points out, there is an option for the DFG means test to be re-aligned with the means test for social care, or to include eligibility for social care funding as a passporting 'benefit'.<sup>66</sup> This would simplify the system for professionals and disabled people, although it would have different effects on the eligibility of different age groups. However, this will depend on what changes are proposed in the green paper. The UWE review also suggests including costs of adaptations as contributions to the

cap on lifetime personal funds spent on meeting a person's care needs, which was previously proposed at £70,000. Given the role of adaptations in preventing or delaying additional social care needs, this might act as an incentive to ensure people have prompt access to adaptations that mean they can remain in their own homes. This will likewise depend on if the idea is retained and how the cap is designed in the green paper.

## Recommendations

### Action for National Governments

- National Governments must maintain a clear commitment to ongoing central funding for DFGs when current allocations end. This must continue to rise to reflect demand and demographic change.
- National governments in England and Wales should review the funding distribution formula for DFGs, taking into account level of disability, levels of income, housing tenure and regional variations in building costs.
- National governments in England, Wales and Northern Ireland should raise the cap on the maximum grant level for mandatory DFGs to at least take into account inflation-based increases and rising building costs.
- National government in England should recognise the real costs of delivering integrated DFG and home adaptations support, and consider revenue grants in addition to capital in order to adequately fund administration, expertise and systems improvements.
- National governments in England, Wales and Northern Ireland should review the means test to address key identified problems including:
  - The low savings threshold
  - Account not taken of real outgoings, including housing costs and the extra costs of disability
  - Levels not keeping pace with housing costs, benefit rates or inflation
  - Lack of alignment with social care means testing.



### Action for Local Government

- All authorities with responsibility for DFGs should, as a minimum, put in place a transparent, fast-track, non-means tested process for adaptations under £5,000 by 2021
- Every local authority with housing responsibility in England and Wales should develop a policy using its powers under the RRO 2002 to introduce discretionary support, following examples of good practice and evidence regarding return on investment, including:
  - Passporting for people with a terminal illness
  - Removing the means test for stairlifts
  - 'Lean' or no means tests for low-cost high impact adaptations
  - Increasing the cap on maximum grant level based on local costs
  - Allowing discretion and flexibility so that support is not unnecessarily delayed because of residual income such as sick pay.

## Timescales and delays: the impact on people with MND

Section 34 of the 1996 Act states that DFG applicants should be notified of their eligibility as soon as is reasonably practicable, and not later than six months after the date of application. In some circumstances payment can be delayed for up to 12 months.<sup>67</sup> Section 37 says that work should be completed within a year, although again there is some discretion for local authorities.<sup>68</sup> The Home Adaptations Consortium recommends local performance indicators that set target timescales for 95% of adaptations to be carried out in 55 working days for urgent cases and 150 working days for non-urgent cases.<sup>69</sup>

In 2015 Leonard Cheshire found that 62% of councils had failed to fund adaptations within the one year deadline, and 44% of councils recorded waits of over two years.<sup>70</sup> The Local Government Ombudsman's 2016 report on common complaints about the DFG process also highlighted problems with timescales, in terms of making referrals in the early stages, ensuring occupational therapy assessments happen in a timely manner, and delays in completing work.<sup>71</sup>

Budget issues can exacerbate waiting times in some areas. Care and Repair England questions both the sufficiency and the quality of local provision, stating that it is 'highly variable'; 'In some areas budgets are under spent; in others they are vastly oversubscribed with reported delays in excess of two years for a DFG.'<sup>72</sup> Foundations echoes this; 'timescales vary between authorities and from year to year. Some are clearly able to deliver straightforward showers and stairlifts within a very short timeframe, while others take months.'<sup>73</sup>

UWE points out that real waiting times are hard to quantify, because the process crosses over different services, and sometimes different authorities, meaning there may be multiple waiting lists to contend with. Councils and housing teams may not know how long a person has waited for an occupational therapy assessment or a referral, or whether they have waited for an initial assessment for minor adaptations and equipment before being passed over to the DFG route. This complicated process also means that the person who needs adaptations has to navigate a confusing system of handovers and changing personnel. As the UWE report says, 'the 2014 Care Act said that service users should have a single point of contact throughout the customer pathway, but this seems very difficult to apply when service provision crosses departmental and administrative boundaries.'<sup>74</sup> Some councils have, however, recognised the complexity of the system and the delays it can cause, and have taken steps to remedy it.

The average waiting times in 2016/17 were nearly 10 weeks between application and approval (with a range of between one day and over a year), and over 17 weeks between approval and certified date of completion (with a range of three weeks to one year). The considerable range of timescales suggests that there is likely to be considerable variation in people's experience of the service. There is also regional variation, in part as a result of shortages in contractors; in London, for instance, it takes an average of nearly six months from approval to completion, compared to around four months in other areas.<sup>75</sup>

People with MND and professionals raised issues to do with timescales and waiting times at different stages of the home adaptations process as common problems. This included time to complete work, but also time waiting for assessments, for planning permission and time spent waiting for a new home if they needed to move to a more accessible property. These issues are particularly pertinent with a disease like MND, where progression is often rapid, so a fast and effective service is crucially important.

### People with MND and professionals: long waiting times reduce quality of life

Common issues raised by people affected by MND and professionals at engagement events relating to waiting times and their impact included:

- Time taken waiting for occupational therapy and financial assessments
- Time from assessment to adaptations approval and grant processing
- Time taken for planning permission
- The need for each adaptation job to seek multiple quotes from builders
- Time taken for adaptations to be built/aids received
- Time taken to get alternative suitable housing
- Timing of request in financial year; this might be delayed due to lack of local funds
- Inflexibility of process overall leading to unnecessary delays.

The Home Environment Assessment and Response Team (HEART) works through North and South county offices covering together the six district councils in Warwickshire. After a review of fragmented services across district councils showed it was a 220-step process where 35% of people dropped out along the way, an integrated service was piloted then expanded across the county. Officers from housing, social care, strategic commissioning, integrated care and public health are part of the HEART team and management board. Housing assessment officers are trained in skills of caseworkers, occupational therapy assistants and grant officers to provide a single point of contact and a simplified system for service users. As of 2018, the customer journey had reduced to 22 steps and the drop-out rate to 3%.

(Foundations Case Study #7, 2017; Disabled Facilities Grant (DFG) and Other Adaptations – External Review, Mackintosh et al., 2018)

## Timing and the nature of MND

This list speaks to the range of steps necessary to take as part of the DFG process, and the range of points at which delays can occur. The impact of long process times, multiple handovers and the delays that can happen as a result are obvious for people with a rapidly progressing and terminal illness like MND:

*Haven't got time with this disease to wait for grants or council adaptations. We moved to a bungalow but the patient had died before door answering system completed, and they turned up morning he died to adapt doorways for wheelchair.*

**MND Association member**

*Some of the most significant challenges are associated with how long things take. People with MND generally have a need for adaptations or a move to a more accessible home to be achievable in a timely way as their disease progresses. Yet they often spend time waiting - for assessment, for applications to be processed, for information to be communicated, for building work to begin.*

**Health and social care professional**

*The process for applying for a DFG is a long, complicated process. The timescales are too long for people living with a terminal disease.*

**MND Association staff**





## Experience in the Midlands:

### Josie's story

Josie lives with her husband, who was diagnosed with MND in 2017, and their two children. Her husband's mobility has significantly deteriorated to the extent that he has had several falls and injuries and seen a reduction in his independence.

In October 2018 they began looking into getting home adaptations and had a good experience with their OT, who recommended a through-floor lift and a wet room conversion. However, since then they have faced difficulties in trying to finance the adaptations and get the works progressed.

They did not qualify for financial assistance through a DFG, but as Josie says, *"There was no consideration for the fact that we still had a mortgage and two teenage kids at home. In my view there should be different criteria for terminal cases as whilst our income might suggest that we could borrow the money for the work, in reality no financial institution would consider us for finance."* They reluctantly agreed to put a charge on their property, with the money loaned to them to be paid back out of any future sale of their home.

One of the biggest frustrations for Josie and her family has been the lack of progress on getting the works approved and started. Although they were told they were a priority case, between November 2018 and May 2019 they had been waiting with limited progress despite numerous calls and emails to the council which were often ignored. It was only if Josie indicated she would be raising the issue with her local councillor or making a complaint that any action ever happened. As Josie says, *"You only seem to get action when you complain."*



In the meantime, they struggled to make-do. Whilst they thought they had given plenty of time to have adaptations done in anticipation of her husband's future needs, the process took so long that the adaptations became desperately needed.

After further delay, the works eventually began in July 2019 and were finally completed at the end of August 2019. When reflecting on the process, Josie says *"There's been so much additional stress put upon us by the whole process at a time when we are already dealing with one of the most stressful situations we've ever known."*

Adaptations also need to be planned and made in a way that takes into account the progressive nature of the disease. The home needs to adapt to the changes in mobility the person will face. Survey responses from people with MND suggest this does not always happen.

*MND progresses so quickly that some adaptations are no longer appropriate once installed.*

*At the moment I can climb the stairs to the bathroom - with stair rails to pull myself up - but for how much longer ?*

*For us time was so important. The ramp and wheelchair came too late and because of length of time for grant for wet room we had to make do with a poor version of a wet room that flooded every time we used it.*

*The speed of adaptation. MND is a disease where you are always chasing your tail. One day you are ok ... the next you have lost a personal faculty. Property adaptations for MND affected should be impressively proactive. More in expectation than reaction.*

#### **MND Association members**

#### **Time of year**

The Home Adaptations Consortium makes it clear that the timing of application should not make a difference to its processing or outcome.

*Potential service users should not be disadvantaged because of the time of year at which they first enquire about the service. Although it is likely that authorities will have spent their DFG budget towards the end of a financial year, they should not refuse or defer a service. The DFG is mandatory and the local housing authority is obliged to work within the timescales laid down in the Housing Grants Construction and Regeneration Act 1996.*

This issue was only raised once at an engagement event, so hopefully the example is an anomaly, but local authorities need to ensure they act in a timely manner regardless of the time of year.

#### **Time to organise complex work**

Some housing authority requirements for multiple quotes for even low-cost work can both cause delays and unnecessary stress for individuals. Even with more expensive adaptations, these problems can be minimised with scheduled rates and approved providers, although there should be some flexibility in this approach too.

Likewise, planning permission for more substantial adaptations can add to the time taken to complete work. People need to be supported through these processes as much as possible to achieve the best and swiftest outcomes.

*I need ceiling track hoists and a new lift inside my property and also outside. The hoists will be installed in August but although I already have a lift outside, I need planning permission for the new one. I have to wait eight weeks for planning permission and I can't have the indoor lift replaced until they receive planning permission because they'll get a deal buying two lifts together.*

*Drawing up plans and planning permission took a year. Finding a builder another six months. Work took a year.*

#### **MND Association members**

Lead-in time for adaptations will clearly be increased where a person is in private rented tenure and needs to secure a landlord's permission for works, on top of other issues. Health and social care professionals with whom we spoke for this report indicated that this was a serious issue that could prevent work being completed. The person would then face the additional delay of trying to find an accessible home.

Under the Equality Act 2010, landlords may not refuse consent unreasonably, but in practice it is often difficult for tenants to challenge a refusal of consent. Short-term tenancies compound the issue, as a DFG application usually requires an accompanying certificate that states an intention to remain living in the property for five years. This is only a notice of intent, not a firm commitment, but in practice it may discourage people in shorter tenancies from seeking a DFG. The EHRC found in 2018 that tenants in the private rented sector frequently found it more difficult to obtain adaptations than owner-occupiers or social housing tenants.<sup>76</sup> In 2019, the EHRC supported a successful court case brought by a disabled tenant against a landlord who was found to have acted unlawfully by refusing permission for reasonable adaptations.<sup>77</sup>

Disabled tenants' right to a reasonable home adaptation is not widely understood, and is not mentioned in the Government's guidance on the rights and responsibilities of landlords and tenants in the private sector.<sup>78</sup>

#### **Time taken to find a new home**

While not an issue addressed to any great extent by this report, the time taken to find alternative property was also raised by professionals. In some cases it will not be practical to make adaptations to a home, because the home is not adaptable. Housing teams should be aware of what accessible homes are available in the area, and provide support to people to move, if this is the most appropriate option. This also means that more new stock needs to be accessible and adaptable; a chronic shortage of accessible homes is a key barrier to independent living for all disabled people.

*There needs to be more adapted housing available and local authorities need to understand how fast MND can progress and that people don't have time to wait months and months for decisions, grants and adaptations.*

**MND Association staff**

The difficulty of finding a new accessible home is compounded by a lack of information provision regarding the availability of accessible homes. Research published by the EHRC in 2018 found that across the UK only 22% of local authorities have an accessible housing register. In Wales however, where the Welsh Government has actively encouraged the development of accessible housing registers, 52% of local authorities have one in place.<sup>79</sup>

In addition, the lack of mandatory accessibility targets for new housing developments restricts the supply of available accessible housing to people considering moving home. The Equality and Human Rights Commission found in 2018 that “building regulations in England and Wales. . . have produced houses that are generally inaccessible”, so that only 7% of homes in England offer minimal accessibility features. It called on the UK Government to require new housing to be built by default to minimum accessibility standards (requirement M4(2) of Schedule 1 to the Building Regulations 2010), with a minimum of 10% of new-build houses built to higher wheelchair-accessible standards (M4(3) design standard).<sup>80</sup>

**Cardiff Accessible Homes** is an independent project set up in 2003 and supported by Cardiff County Council alongside local housing associations, to help people who need to move to an accessible property. It maintains a list of accessible homes, a list of people who need to move, and matches people to properties.

(Your Guide to Cardiff Accessible Homes, 2019)

**What does local authority data tell us about timescales?**

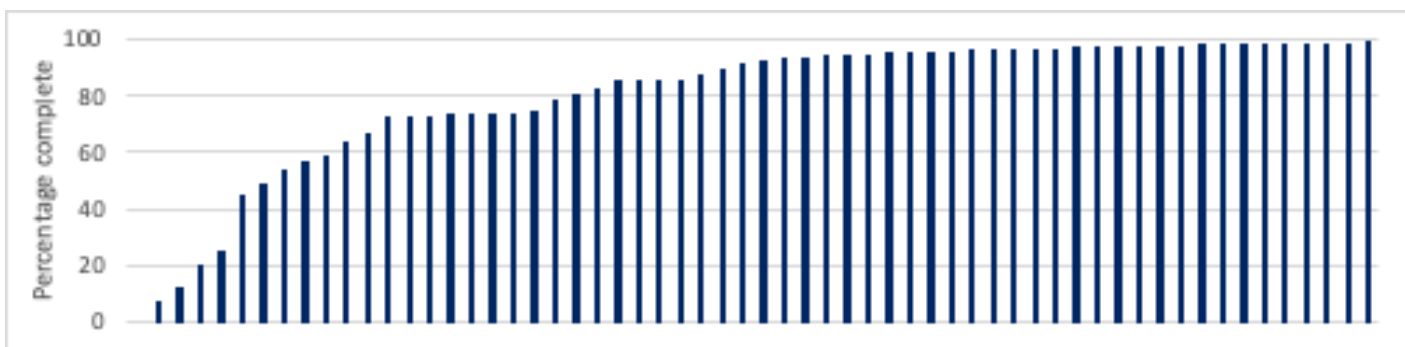
**Waiting times in England**

For the most part local authorities in England report meeting the statutory six month deadline for assessing DFG applications in 2016/17, according to FOI returns. 197 councils, or 74% of respondents, say that 100% of applications were processed within this time period. A further 32 councils (12%) reported completing the process within the time frame for between 90% and 99% of cases. One council noted that, while its approval time rate was at 79% in 2016/17, ‘this has now been improved to 100% with most grants approved within five working days’. A number of councils have introduced new systems to reduce waiting times, and these are discussed later on.

Of the remainder, seven councils reported processing applications within the timeframe in less than half of all cases. One council stated that they did not process any applications within six months; this council reported receiving in excess of 2000 applications in 2016/17, by far the most of any council, and reports a rate of 50% for completing payments within a year of approval, so it is conceivable that its backlog is severe. One council noted that the projects falling outside of the timeframe were ‘generally larger projects such as extensions which required longer feasibility periods’.

The following chart shows the range reported of percentage of applications processed within six months, for all councils that provided an answer of less than 100%. It shows that while for the most part, only small numbers of applications exceed the target, there are some areas where this is a real concern.

**Chart 1:** percentage of DFG applications processed within six months in each council reporting less than 100%



Moving on to work completed, 156 councils, or 58% of respondents, reported that 100% of approved DFGs were paid within one year. Councils are able to extend this deadline at their discretion, and a number refer to longer timelines to enable private contractors to be involved or for more complicated projects. Others refer to complications such as long hospital stays, missing information or other issues. Nevertheless, this seems like a disappointingly low proportion of councils completing works within a year.

Of the remaining authorities, 74 (28%) completed 90% of payments within one year. Seven councils reported that they funded projects within one year in 50% or less of all cases.

### **Fast-tracking**

Fast-tracking systems can help 'simple' and urgent cases, including people with a terminal illness, to be processed quickly and efficiently. This can be particularly valuable for people living with a rapidly progressive condition such as MND, for whom the statutory timescales are often much too long.

184 responding councils (68%) report that they have some degree of fast-tracking or prioritisation system, although these vary in type and formality. 20 councils did not have a fast-track system in place in 2016/17, but do now.

Many councils operate a system based on recommendations from managers and occupational therapists, some of which seem quite informal. In some cases urgent applications are flagged by senior managers or occupational therapists and processed quickly, while in others recommendations are made to a panel, which then in turn makes a decision. Some classify certain adaptations as urgent based on the applicant's situation – for example, whether they are living with a terminal illness, in receipt of palliative care or in need of a hospital discharge. Other councils operate schemes based on type of equipment such as stairlifts, modular ramps, ceiling-track hoists, level-access showers and other small works that do not require a surveyor. A small number of councils state that they do not use a priority system because they do not have a waiting list, and thus do not need one.

A selection of councils provide details of more formal, established schemes. Examples of these are given in the following table.



**Table 4:** examples of fast-tracking systems

Council	Details of scheme
Sevenoaks District Council	Provides 'Accelerated Facility Grants' for works costing less than £7,500, open to all.
Chichester District Council	Discretionary DFG policy, and ongoing DFG transformation project to improve service delivery times.
King's Lynn & West Norfolk Borough Council	Discretionary Adapt Grant for adaptation assistance.
Central Bedfordshire Council	Provides Prevention Assistance using discretionary capital to provide works that might otherwise be provided via a DFG in a fast-track way where there is imminent risk of admission to hospital or care home, or to prevent delayed discharge from such an institution.
Luton Borough Council	Discretionary Minor Adaptations Grant for adaptations costing between £1,000 and £5,000 for people in receipt of income-related benefits (alongside an approved contractor list for fast-tracking other urgent cases).
Dorset combined authorities	'Local' DFG described as 'removing some of the processes that have historically slowed down approving applications'. Simplified application form, increased maximum grant and no means test for works costing less than £5,000.
City of York Council	Discretionary DFG – non-means tested DFG where the total value of works is up to £5,000 for adults.
Sunderland City Council	Discretionary non-means tested grants up to £6,000 for palliative care cases or to facilitate hospital discharge.
Brighton and Hove City Council	No means test for work up to the value of £5,000, with a fast-tracked application process via a third party.

Dacorum Borough Council, Colchester Borough Council, Maidstone Borough Council and Havant District Council were all in the process of reviewing or introducing schemes at the time of the FOI returns. Many councils reported low numbers being processed through fast-track schemes, likely in part because these schemes were relatively new in lots of authorities. St Helen's Borough Council, however, processed 413 applications through its fast-track scheme, 69% of all applications.

**West Sussex** have appointed a county-level Adaptations Co-ordinator for DFGs, co-funded by local district and borough councils from their DFG allocations. They are working together, along with co-terminus Clinical Commissioning Groups, to improve the DFG process, cut down on bureaucracy and make more innovative use of discretionary funds. During a pilot phase, co-locating teams, occupational therapists (OTs) and grant officers undertaking joint visits, simplified paperwork and IT systems and waiving means testing was found to improve end-to-end process times by at least 83 days, and provide a better service user experience. In 2017 it also introduced extended warranties for equipment, reduced the number of quotes necessary for simple works to one, and simplified the referrals process for straightforward adaptations.

In addition the councils removed personal contributions for works under £5,000, provided better support, taking into account outgoings, in assessing the affordability of contributions, made provisions for top-up funding up to a maximum of £30,000 where works exceed the £30,000 DFG limit, and created a relocation grant up to £10,000 where moving home is a more practical option. There is a means tested 'tech' grant, DFG fees grant and a safe and warm homes grant, and a non-means tested hospital discharge grant of up to £3,000. The councils and CCGs are also running a pilot providing minor home adaptations grants of up to £1,000 and deep clean funding of up to £1,500 through top-sliced DFG funding, without the need for formal application.

(Discretionary Disabled Facilities Grants, Horsham District Council, 2017; Disabled Facilities Grants – Phase 3 Integration of Service Delivery, Chichester District Council, 2017; Pilot of Minor Adaptations and Deep Clean Services for eligible West Sussex residents with disabilities, West Sussex County Council, 2018; Disabled Facilities Grants – Appointment of County Adaptations Manager, Chichester District Council, 2018.)

**Cheshire East Council** has worked to reduce adaptation timescales initially by four months, and then further by the introduction of a framework agreement for level access showers with a target for installation within six weeks. It has a priority pathway for urgent cases such as end of life care, hospital discharge and risk of injury.

In addition, Cheshire East has detailed information on its website about support offered and steps involved in applying for and receiving a DFG. The Council also made use of its powers under the Regulatory Reform Order (RRO) 2002 to extend its home adaptations support. It has increased the level of maximum grant to £50,000; introduced Independent Living Loans offering up to £15,000 interest free to fund means tested contributions to DFGs, top up DFG costs beyond the maximum grant or carry out works where a person provides care for a person who does not normally live with them; and a means tested grant of up to £2,000 to help with relocation costs where this is a preferable option.

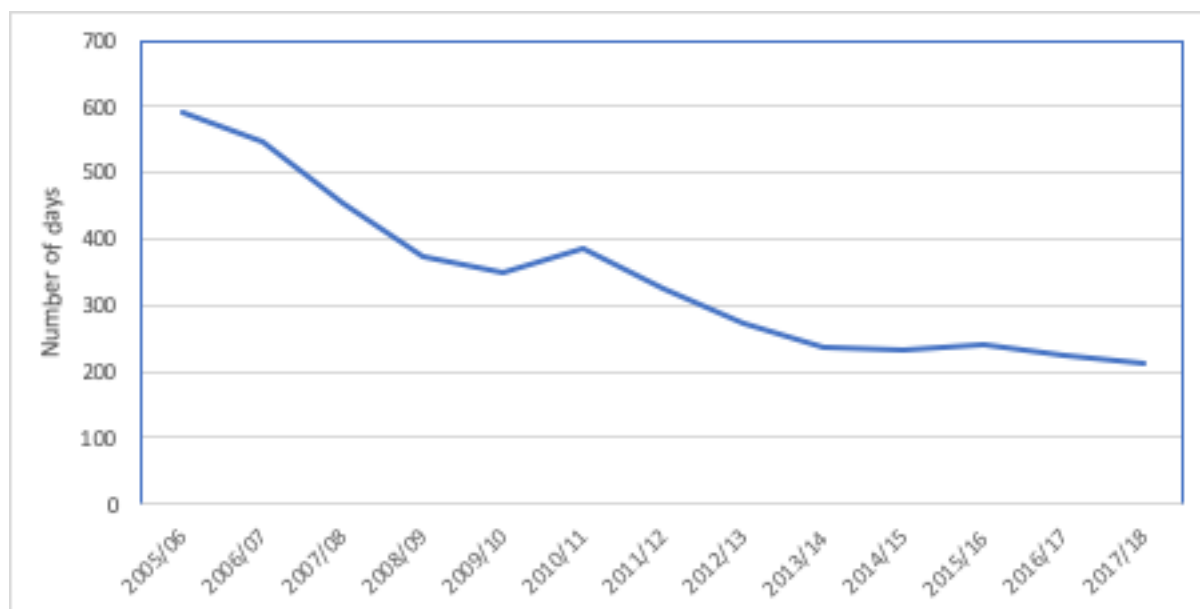
(Home Repairs and Adaptations for Vulnerable People: Financial Assistance Policy, Cheshire East Council, 2017; Disabled Facilities Grant (DFG) and Other Adaptations – External Review, Mackintosh et al., 2018.)

### Waiting times in Wales

All but one responding councils in Wales provided data on completion times, and for the most part they are able to process applications and make payments within the timelines in 100% of cases. Five councils fail to process applications within six months 100% of the time. Of these, only two fall below 95%; one at 92% and the other at 72%. Six councils fail to make payments within one year in all cases, and three of these in less than 95% of cases. All but two councils have some form of fast-track process. More flexible forms of grants under the ENABLE system may provide additional fast-track schemes for smaller, urgent work across all councils.

Wales has established local performance indicators for DFG delivery times. The average across Wales was 213 days, around 30 weeks, in 2017/18 (the most recent year available), with a range from 122 days in Powys to 297 days in Merthyr Tydfil.<sup>81</sup> The chart below shows a steady reduction in DFG completion times between 2005/06 and 2017/18.

**Chart 2:** Average number of calendar days taken to deliver a DFG in Wales, 2005/06 – 2017/18



### Waiting times in Northern Ireland

The Northern Ireland Housing Executive provided data on average time between initial referral and project completion for the delivery of minor adaptations to NIHE homes. The average period was 32 weeks in 2016/17, 23.5 weeks in 2017/18, and 14 weeks in 2018/19, suggesting a significant reduction in time taken. However this data applies only to NIHE homes. There is no formal fast-track process in place for adaptations in Northern Ireland.

## How can DFG timescales be improved?

Overall, the pattern from the available data is of variability. While the vast majority of councils in England meet the 6th month target for processing applications, there is still a quarter that do not. 37% of councils in England do not make payments within one year, although the reasons for this are, in some cases, legitimate. The existence of a range of fast-tracking or prioritisation systems in different councils is encouraging, but again there is significant variability, and some have systems that are far advanced compared to others. While some councils state that they do not require a fast-tracking system, some of these simplified schemes both speed up processing and reduce the burden of applying for and securing a grant in the first place.

As has been shown, councils have the ability to introduce more flexible systems through the Regulatory Reform Order (RRO) 2002, and many have made good use of this power. However, only half of councils in England had created an RRO policy by 2016/17. All councils should make use of these, building on good practice examples, in order to make more effective and timely use of DFG funding. [Foundations](#) has produced a guide to help with this process, and the case studies here and in other reports provide examples of changes that can be made.<sup>82</sup>

As will be discussed in the next section, there needs to be better data monitoring in order to fully understand the end-to-end wait times for someone applying for a DFG across the range of different systems they will encounter. Applicants can be tracked via NHS numbers, which would also help local bodies to understand their wider interactions with different health, social care and housing services. Case studies show that through better integration of these services the number of 'steps' in a DFG process can be drastically reduced, cutting down the waiting time and improving the otherwise confusing service.

People need to be supported through the full range of processes relating to home adaptations, including planning applications, understanding what adaptations they need at the right time, and finding a new home if this proves necessary. This is not an easy process, given both its complexity and the emotional impact of having to make substantial changes to the home in response to the impact of MND. Different options, however, such as modular or flat-pack extensions or units, may provide quicker and simpler solutions that allow a person to stay in their own home.<sup>1</sup> 'Smart' home technology also has the potential to provide quick solutions to some problems.

## Recommendations

### Action for National Governments

- National governments in England, Wales and Northern Ireland should include target waiting times for urgent and non-urgent works in transparent and measurable standards for home adaptations.
- To improve the availability of accessible homes, the UK Government and national governments in Wales and Northern Ireland should implement the Equality and Human Rights Commission's recommendation to require all new housing to be built to accessible and adaptable standard by default, and a minimum of 10% to wheelchair accessible standard.
- To reduce delays arising from negotiations with landlords, national governments should actively publicise disabled tenants' right to a reasonable home adaptation, and include this information in its guidance on the rights and responsibilities of landlords and tenants in the private sector.

### Action for Local Government

- Local authorities and NIHE must review their compliance with target timescales and ensure they meet these in 100% of cases.
- Every local authority must make use of its powers under the RRO 2002 to introduce discretionary support for home adaptations, including fast-tracking systems.
- Local authorities should introduce fast-tracking systems for cases where the person has a terminal illness.
- Local authorities should look at their systems for approving works, including whether approved provider lists and schedules of rates for straightforward work can remove unnecessary steps.
- Local authorities should monitor and report annually on the end-to-end processing times for DFGs, from occupational therapy assessment to completion of work. They should establish the number of steps involved in the process and seek to minimise these where the number is excessive.
- Every local authority should establish an accessible housing register so they are better able to quickly identify suitable properties, and provide accurate waiting times to people who need a new home.
- In lieu of mandatory national standards, every local authority should require all new housing developments to be built to accessible and adaptable standard by default, and a minimum of 10% to wheelchair accessible standard.

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1 Totally Modular, for instance, provides modular disabled access extensions.

## Information and integration: making sure people with MND get the right support at the right time

People with MND told us they don't always feel they get the right information and support to adapt their homes. Systems need to be set up with the people who need them in mind; they should be simple, swift and seamless. Some local housing teams and partnerships are working to achieve this, and there is a growing body of good practice that others can follow. Local authorities have a duty to provide accurate information to people under the Care Act 2014. This must include home adaptations, and information must help people with MND understand their options, the process and the need early on.

Integrated systems can be easier to navigate for people who need care and support. Foundations notes that in England, bringing DFGs into the Better Care Fund (BCF) provided a crucial opportunity to improve delivery.<sup>83</sup> It suggested that local authorities should explore options for joining up health, social care and housing services, reducing bureaucracy and coordinating approaches across multiple districts. This is a view that Care and Repair England shares; it sees the increasing funds and the budget's relocation into the BCF as an opportunity to develop integrated practice, with safe and accessible housing central to a person's health and social care needs.<sup>84</sup> The Local Government Ombudsman, however, highlights a number of cases of poor integrated working between social services and housing, referrals not being made between teams, or where relevant services are not consulted about a person's holistic needs.<sup>85</sup> As the BCF approaches its scheduled end, reviews need to examine how, or whether, housing, and particularly accessible housing, has been integrated into people's experience of health and social care, and what distance is left to travel.

One element of integration of services is ensuring people can be appropriately tracked through systems, to make sure they get the best support at every stage. As Care and Repair England and Foundations both highlight, one condition of the BCF 2016/17 was 'better data sharing', using a person's NHS number as a consistent identifier across services. As Care and Repair England states, 'To enable more integrated and effective provision of home adaptations (and DFG specifically) using the NHS Number as a common identifier in DFG cases will have clear advantages, not only for service users but also for tracking impact and outcomes of interventions eg. potential to link to hospital and care home admission records.'<sup>86</sup> Better data sharing systems across health, social care and housing could enable local authorities to properly plan for and monitor DFG demand.

Habinteg sounds a note of caution when framing the benefits of safe and accessible housing in terms of health economics, however. While the transfer of responsibility to the BCF has been broadly welcomed, and seems to have brought some benefits, there is a risk that this 'may encourage adaptations to be seen as more about 'health', in a narrow sense, as opposed to independent living and rights to choose'. Habinteg argues that 'adaptations are important not simply because they may cut the risk of accident, acute admissions or 'bed blocking', but because they help remove barriers which other people do not face.'<sup>87</sup> An effective and efficient home adaptations service should form an integral part of a person's care; it can make it possible for someone with MND to live and die with dignity, in a place of their choice.

Integrated systems need to take into account the fact that people will face housing challenges at different points in their lives. As the UWE report points out, younger disabled people (defined as aged under 55) were more likely (32%) to state their accommodation was unsuitable than those over 75 (12%). At the moment these are the groups often excluded from the DFG because of the failure to account for housing costs in the means test. They may also be less able to access supported accommodation, if they do have to leave their homes, as this sometimes only provides for people aged over 65. Information, advice and support needs to be available to and appropriate for working-aged disabled people, and those who need to self-fund, in order to reduce the stress involved in having to navigate complicated systems alone.

In February 2018, the Ministry of Housing, Communities and Local Government (MHCLG), the Department of Health and Social Care, NHS England, the Royal College of Occupational Therapists (RCOT) and a range of voluntary organisations signed a joint National Memorandum of Understanding, setting out a shared commitment to joint action across government, health, social care and housing sectors in England. Rooted in the Health and Social Care Act 2012 and the Care Act 2014, it establishes seven indicators of success:

1. Better strategic planning
2. Better understanding of the preventative role of housing
3. Greater collaborative care
4. Better use of resources
5. Improved signposting
6. More shared learning
7. Wider sector engagement.<sup>88</sup>

In addition, the NHS Confederation set out nine principles for a [new care settlement](#) in February 2019, in advance of the Social Care Green Paper. The first of these is that care must be integrated:

*Care and support should be integrated around the needs of those using the service along with those of their families and carers. The NHS, social care, housing and voluntary sectors should work together seamlessly to maximise people's independence, health and wellbeing.<sup>89</sup>*

Together with other policy drivers, these provide a further framework and basis for a cross-sector approach to ensuring housing is embedded in integrated health and social care systems, with a role for organisations across different sectors to play.

### People living with MND: left without support

People with MND told us they sometimes struggled to access occupational therapy assessments, felt there was poor communication by professionals, and felt that some did not understand MND sufficiently to help them plan for future needs. The process of applying for a DFG, and of getting the work completed, was too complex, and for people who did not qualify for financial support, there was no other advice or support to help them adapt their homes.





### **Getting the right advice**

However adaptations are funded, it is vital people get the right advice at the right time.

*Lack of knowledge regarding 'future proofing' adaptations. I have seen people wait eight months for a stairlift, by this point the patient is hoist transferred and therefore cannot use a stairlift. With correct advice they would have considered moving property or adapted for single storey living.*

### **Health and social care professional**

*We had no help at all; there were no plans available; no equipment advised; no "this is your best option for flooring" it was us and just thinking hard about it all with no support from anyone. Considering the outlay I think we should have been entitled to someone saying you need to think about this door opening this way; why not include environment controls now, think about the hoist and joist placement; we had to do everything ourselves and I can't forgive the system for this lack of support. There should be resources you can be pointed towards with the basics included.*

### **MND Association member**

*Greater support to people who are classed as 'self-funding' - ie advice from OT/Councils in the same way people receiving DFGs would access.*

### **MND Association staff**

*We really struggled to work out how best to adapt our home. We asked the council for ideas via our OT but the surveyor really struggled to come up with ideas. It took us six months to work out what was best after consulting various tradesmen such as lift companies. Colin only lived two months after the work was completed and we had really struggled to get him upstairs using the stairlift prior to the wet room being completed.*

### **MND Association member**

## Experience in East Anglia:

### Martin's story

Martin was diagnosed with MND in November 2017. His home was unsuitable for adaptation so he started looking at other options and was advised to move into a Housing Association or Council bungalow in his area.

Martin was frustrated by the process of trying to find suitable housing: *"The system didn't focus on the individual and what their needs might be, let alone any understanding of a degenerative disease like MND... It was hard to know what the properties were like from a website as there wasn't enough detail about interiors such as flooring or door widths making it really difficult to know if they might work for me."*

Once Martin had found a suitable home, the situation only became more difficult due to the lack of available information and support. *"When I finally found a bungalow it needed work for my future needs, like a wet room and cooker at the right height. The properties from this housing association are rented out like a shell; without any flooring and with bare walls so I knew moving was not going to be quick, easy or cheap. Although there was no way I could*

*live there immediately, I had to start paying for the new bungalow straight away so had the extra cost of paying two rents. I tried to get advice by calling the council, but no one called me back and then I was told to go in person to the council offices where someone could help. They didn't and said I should telephone instead. Communication was a joke and really frustrating."*

The problems continued when Martin had difficulty with the adaptations he needed. *"Adaptations such as ramps and handrails at the front and rear of the property took ages to sort. My occupational therapist visited and said that the handrails at the back were not even suitable and needed changing."*

Martin says: *"There has been a catalogue of communication problems between all agencies involved which have made it much more complicated and drawn out than it should be... No one seems to know what anyone else is doing whether from the council, the housing agency or the contractors hired to do the adaptations."*

When reflecting on the process overall, he says: *"The whole thing has been frustrating, stressful and really tiring."*



People need high quality information right from the start. Research has indicated that almost half of DFG recipients heard about the scheme through word-of-mouth. Not only is the DFG process itself difficult to navigate, but it is hard to get the right information about it in the first place. Often only a very limited amount of information is available online, and rarely are application forms available. A person often needs to know what to search for in the first place to find the right information, which leaves getting the right support too often to a matter of chance. Local authorities should review how they promote DFGs, ensure sufficient and relevant information, including about process, timescales and eligibility, is available.

*Added stress, confusion and upset to an already very difficult situation. If it had been left to my mum who was sole carer for my dad and already at the point of exhaustion.. then she wouldn't have known where to even start with looking to apply for anything. Luckily I had access to the internet (sounds ridiculous but not everyone does/ is able) so could find info to start us being able to get things moving.*

**MND Association member**

Voluntary organisations, including the MND Association, can also help to make sure people get the advice they need. The MND Association has an information sheet for people with MND, and can provide advice and support through its MND Connect helpline and local branches. Other organisations such as Disability Rights UK provide information about requirements and eligibility. Organisations should be proactive in promoting DFGs to disabled people, and promoting safe and accessible homes as a central wellbeing requirement.

**Oxford City Council's Home Improvement Agency** has been noted for its local DFG promotions campaign, targeting both the public and other professionals. This included appointing a coordinator to run an awareness raising programme, rebrands, press work and promotional events, information leaflets and booklets, meetings with local groups and key staff in other public services. The HIA positioned itself as a 'problem solver' for NHS hospital discharge teams trying to reduce delayed transfers of care. It employed an Occupational Therapist directly, who assumed responsibility for the majority of referrals including those related to hospital discharge and terminal illness. The programme has resulted in increased referrals for both DFGs and the handyperson service.

In addition, the Council incorporated feedback generated from existing and potential service users during the campaign into its revised housing assistance policy. It made use of its powers under the Regulatory Reform Order (RRO) 2002 to provide discretionary funding support. This includes a non-means tested Adapted Homes Grant of up to £8,000, a relocation grant of up to £15,000 for those eligible for DFG but for whom moving is a more practical option, means tested discretionary grants of up to £10,000 to fund DFG works in excess of £30,000, or other works not covered by DFG, and other small grants schemes.

(Oxford City Council – Local authority in-house home improvement agency, Centre for Ageing Better, 2018; Housing Assistance and Disabled Adaptations Policy, Oxford City Council, 2019.)



## The emotional aspect of adapting a home

Health and social care professionals told us there needs to be due consideration of the emotional element of coming to terms with an MND diagnosis, and being ready to make sometimes major changes to a home. Again, appropriate and timely information can help people get ready to make these decisions.

*Readiness to consider house move or adaptation - many of the challenges could be addressed soon after diagnosis but before health and function has declined significantly but people are often not ready to consider what will be needed to meet their longer term needs until it is necessitated by changes in their ability.*

*Can be difficult for people with MND to accept the changes they will need in the future and plan ahead in plenty of time.*

*There is also a huge emotional burden when you have to leave the family home.*

### Health and social care professionals

Professionals need to be mindful of the emotional burden of coming to terms with a diagnosis and the changes to a person's life it causes. Information and advice from different services should support people appropriately and sensitively to make the right decisions.

Equally, however, innovations in equipment design can reduce the impact of these changes on the 'feel' of the home. A small number of people told us adaptations can make homes feel clinical. We also know that people affected by MND can feel overwhelmed by the number of professionals that can suddenly come into their lives after diagnosis, and the amount of equipment they suddenly need to get around. The UWE report argues that too much focus on unit cost over quality in service tendering means that equipment is still designed 'more for a hospital rather than a home'. Investment in developing higher quality solutions, as well as quicker and more flexible options mentioned earlier, could help improve disabled people's day-to-day quality of life in the long run. Today, Independent Living Centres can help disabled people understand their choices, try out equipment and get used to the kind of adaptations they might need, and greater use of investment in 'smart' home technology can help provide solutions that allow people with MND to maintain control and independence.

Without the right support and information, people can feel helpless and trapped in their homes. People told us about the sense of isolation they felt when they didn't get the help they needed from council services, and about the confusion complicated systems can cause. This stress has the potential to exacerbate other issues with health and wellbeing. Following good practice in information, signposting, advice and integration of services can mitigate this risk.<sup>2</sup>

**The Dorset Accessible Homes Service** was launched in April 2015 and brings together services across the six district councils within Dorset County Council. An external company runs this service.

The service is housed in two 'mi-life' centres, and also runs a mobile demonstration unit and pop-up events. This means disabled people can look at different options for aids, adaptations and equipment, and start thinking about how they can fit into their own home. It can provide advice and information, assessments, a handyperson service, support to consider housing options and subscription-based telecare support.

The County Council made use of the Regulatory Reform Order (RRO) 2002 to reformulate how home adaptation support is provided. It created two grants; the Dorset Accessible Homes Grant for major adaptations and a Safe and Secure Grant for urgent essential repairs and adaptations. Under the DAHG, there is no means test for work costing less than £5,000. The upper limit on grants is £45,000. The grant can also assist with the costs of moving to a more appropriate home if the work necessary is not feasible. Safe and Secure grants are means tested (based on passporting benefits) and available for people aged 50 or over to carry out works to reduce accidents, enable independent living or allow hospital discharge, up to a maximum of £2,000.

(Private Sector Housing Assistance Policy, Dorset County Council, c.2016; Foundations DFG Case Study #4, 2016; Dorset Accessible Homes Service, 2019.)

2 The example is from Dorset Combined Authorities. It should be noted that Dorset County Council ceased to exist in April 2019, and was replaced by two unitary councils covering a) Christchurch, and the existing unitary authorities of Bournemouth and Poole and b) the districts of Weymouth and Portland, West Dorset, North Dorset, Purbeck, and East Dorset. It is not clear how the new arrangement will affect provision.

## **Builders, specifications and practical know-how**

People with MND told us they sometimes struggled to know what kind of works to undertake, and to find builders and contractors with the right skills and understanding to complete that work. Support for self-funders is just as important as for those who qualify for DFGs. Health and social care professionals note that everyone with care needs is entitled to an occupational therapy assessment under Care Act 2014 duties, but that further technical support may not always be available.

*(The challenge of) finding a quality builder that pays attention to detail, that prepares properly to reduce dust etc, that doesn't take shortcuts, that doesn't lie about specific work done when it hasn't been done properly, that uses competent people, and does not rush the work.*

### **MND Association member**

*Self-funders are not precluded from assessments, unfortunately our local authority does not have sufficient technical officers to advise them on planning of adaptations, which can lead to costly mistakes. I personally feel this is not equitable, we used to be able to offer the service but due to cost savings staff are not being replaced.*

### **Health and social care professional**

As previously mentioned, Independent Living Centres can help disabled people understand the range of work and other solutions that may be possible. Approved provider lists and design specifications can also help people make informed decisions. The Northern Ireland *Adaptation Design Communications Tool Kit* mentioned earlier is cited by UWE as an example of what can be achieved through cross-sector collaboration, involving disabled people, occupational therapists and housing specialists to create a well-used and evidence-based guide to standard designs.

**Chorley Home Improvement Agency** created an online schedule of rates for all their shower adaptations. There is a standard specification that has been pre-priced by a list of approved contractors. The HIA select the appropriate items, and the online system adds up the rates submitted by each builder to provide instant quotations. Contractors are selected based on price and past performance. This process saves three or four weeks compared to a traditional paper-based approach. It also means that if a contractor is unavailable for some reason, the HIA has alternative quotes already prepared. The online system also allows for fixed price materials from a framework and a series of alternative options to allow for client choice.

In 2017, Chorley piloted a scheme through the Integrated Community Wellbeing Service whereby Lancashire Care Foundation Trust occupational therapist (OT) could refer people with DFG needs direct to the in-house Chorley HIA, rather than via Lancashire County Council (LCC), in order to speed up the process for service users. They also took on cases from the LCC waiting list, using Foundation Trust OTs to progress assessments.

By making use of powers under the Regulatory Reform Order (RRO) 2002, Chorley Council has also removed the means test for cases where the occupational therapy referral is for one item only, and specifically for level access showers, stairlifts, through-floor lifts, ceiling track hoists and wash-dry toilets. It has raised the maximum grant limit to £40,000.

(Chorley Liaison Home Adaptation Services, Chorley Council, 2017; Private Sector Housing Assistance Policy 2017-2018 (Consultation Draft), Chorley Council; Disabled Facilities Grant (DFG) and Other Adaptations – External Review, Mackintosh et al., 2018)

## Safe and accessible homes as a central part of health and wellbeing

A number of health and social care professionals we spoke to stressed the importance of integrating health, social care and housing to improve the ability of teams to 'see the whole picture'. Not only does this allow for better care planning, but it removes some of the stress and confusion for the person trying to navigate the complex systems.

*Numerous professionals involved in the process of moving/ adaptations can be confusing for individuals with MND (Social Care OTs/ Project Managers/ Financial Assessors/ Subcontractors) and it can be unclear who the individual needs to contact.*

*Adaptations team not liaising with pwMND regularly so the process takes a long time. The person with MND often has so many other people involved and not always able to monitor with adaptations team to chase up.*

### Health and social care professionals

As stated, integration of health and social care, with housing at its heart, has been a major policy ambition for successive governments, and one that some councils have made considerable progress on, with integration of budgets (particularly those for DFGs and for the Integrated Community Equipment Service (ICES), created for minor adaptations) staff teams and service pathways. Integration and collaboration may also include collaboration across council boundaries, as in the Dorset case referenced earlier, or in Rutland, mentioned below.

Housing is already a central part of delivering health and social care in policy, but the extent to which this translates into practice varies around the country. Housing should be embedded strategically at a local level through Joint Strategic Needs Assessments (JSNAs) to enable a focus on collecting good data; in Joint Health and Wellbeing Strategies (JHWS) to translate this data into action; and into integrated teams with the right expertise and case management processes to make sure this works in practice. For the person in need of home adaptations, there should be a single point of contact, a coherent and well-explained plan for how to proceed, and follow-up to ensure that their housing needs are met, that they are satisfied with the service and that any changes to other health and care needs are recorded and actioned.

**Bristol City Council** engaged in a systems redesign process, with an aim to speed up the service, and put the service user at the heart of it. They introduced a 'triage' system that directed people down appropriate routes according to their needs, and created an integrated team of occupational therapists, caseworkers, surveyors and technicians to facilitate this. The Council also created a Rehousing Occupational Therapist role to provide advice and practical help in moving home, where this represents a more practical option. In the first nine months of operation this allowed 26 households to move and saved £477,000 in adaptation costs.

Bristol has made discretionary DFG funding available for topping up mandatory DFGs where works exceed £30,000, Hospital Discharge Grants for people with low levels of savings (under £23,250), and a £5,000 maximum Discretionary Adaptation Assistance grant, also subject to level of savings.

(From Home Adaptations to Accessible Homes: Putting people at the heart of redesigning the adaptation service in Bristol, Housing LIN, 2012; Disabled Facilities Grant (DFG) and Other Adaptations – External Review, Mackintosh et al., 2018; Private Housing Policy, Bristol City Council, February 2019)

**Portsmouth** has redesigned its system, delegating more authority to individual occupational therapists and reducing the need for joint visits with housing practitioners apart from in complex cases, with the result that waiting days between first contact with Adult Social Care and a housing team DFG referral are down from 125 to 5. The service has high standards for client feedback to ensure service improvement.

As well as these measures, more discretionary support has been introduced including Disabled Facilities Assistance, a loan of up to £15,000 to top up works in excess of the mandatory grant limit; grants to replace obsolete or broken equipment; Palliative Care Assistance providing the loan and installation of reconditioned stairlifts; and support for relocation costs up to £30,000.

According to the Centre for Ageing Better, there are also plans to increase the maximum mandatory DFG limit to £40,000, and to remove the means test for specific types of work such as stairlifts and over-bath showers.

(Portsmouth – In house home improvement agency, Centre for Ageing Better, 2018)



In 2016, two separate social and non-social housing adaptations services within **Salford** came together as part of a wider health and social care service redesign, and became the Accessible Accommodation Team. This, housed within Salford Royal NHS Foundation Trust (now within the Northern Care Alliance NHS Group) along with Salford Adult Social Care services, was co-located with the occupational therapy service, intermediate home support team, equipment and wheelchair services, charity Disabled Living, and a private retailer. This created pooled knowledge and a pooled organisation (but not pooled budgets), providing a single point of contact for disabled and older people. In addition to adaptations, the service includes a handyman scheme, a comprehensive information service for self-funders and affordable warmth and heating replacements. The AAT is ultimately overseen by an integrated advisory board and committees from Salford City Council, Salford Royal NHS Foundation Trust, Salford Clinical Commissioning Group and other stakeholders.

Steps have been taken to streamline the process for assessment and delivery of works, to address waiting times. In 2018 the service removed means testing for stairlifts and hoists (in addition to an existing equipment recycling policy), removed the General Consent condition (which requires home owner recipients to pay back an amount of grant received, up to £10,000, upon sale of the property) and reorganised budgets for bespoke equipment above £1,000.

(Salford – Salford Care Organisation part of the Northern Care Alliance NHS Group, Centre for Ageing Better, 2018; Amendments to Private Sector Housing Assistance Policy, Salford City Council, 2018)

**Rutland** is a small, unitary authority in the East Midlands, trialling a new approach in light of historic underspend of DFG budgets, with most residents failing the test of resources. It introduced a Health, wellbeing and Prevention policy priorities (HaP) grant to deliver rapid interventions, without a means test, of up to £10,000. Complex DFGs costing over £10,000 are delivered by Peterborough County Council, because Rutland has so few each year. A 12-month pilot started in October 2017. By the end of March 2018 49 cases had been opened and 24 completed. The average time from application to completion for a level access shower is 12.6 weeks, with stairlifts taking 2.7 weeks through a single supplier.

More people are coming forward because of the flexible, non-stigmatising approach. The offer is also more personalised than some other services, and efforts are made to get away from 'medicalised' equipment, adaptations and services. Service users can top up funding to upgrade the specification if they wish.

(Disabled Facilities Grant (DFG) and Other Adaptations – External Review, Mackintosh et al., 2018)

In the words of **Leicestershire County Council**, '**Lightbulb** is a Partnership Programme supported by the seven District Councils in Leicestershire and Leicestershire County Council. The Lightbulb Programme aims to bring together a range of practical housing support into a single point of access or referral. A holistic housing needs assessment (the Housing MOT) will ensure that any housing support needs are proactively identified and that the right solution is found.' Service re-design was in part driven by national reform and local outcomes, and in part by service users who told the council that they wanted a more joined-up and proactive approach. It was funded through the Department for Communities and Local Government (DCLG) Transformation Challenge Award. It is a partnership between Leicestershire County Council, district councils, the county's Clinical Commissioning Groups, Leicestershire Partnership Trust, and University Hospitals of Leicester. Integrated locality teams in each district offer services including minor adaptations and equipment, DFGs and other housing advice, with pooled budgets. A new role of Housing Support Co-ordinator brings together technical and casework skills, to provide a single point of contact for service users. There is a performance management system to help staff monitor progress and outcomes related to DFGs. As of February 2019, the project has been extended for another three years.

(Leicestershire Equipment, Adaptations and Assistive Technology Strategy 2016-2020; Housing LIN Case Study 135, 2017; Disabled Facilities Grant (DFG) and Other Adaptations – External Review, Mackintosh et al., 2018; Blaby District Council, 2019)



## **Professional Knowledge of MND**

Some people with MND, MND Association staff and health and social care professionals told us that services don't always understand the nature of MND.

*More information for social care professionals involved with individuals with MND about the rapid progression of the condition.*

*Health professionals involved need a thorough understanding of MND, experience in designing suitable adaptations, the drive to progress speedily, seek help from MND Association and specialists when needed.*

### **Health and social care professionals**

*They send people who do not understand MND.*

*Knowledge of condition by person giving advice and also a sensitivity for rest of occupants of home.*

### **MND Association members**

People living with MND and health and social care professionals also gave us examples of good practice and experiences.

*Council OT was very helpful - answered our emailed /telephoned questions etc. we did have a visit, but if she'd have had more time for more face to face / site support it would have been even better eg a detailed look at the plans, discussion of alternative options etc.*

### **MND Association member**

*In Hull, all MND cases are given High Priority for assessment of housing needs (or any needs) though there are inevitable delays in process of gaining adaptation or rehousing.*

*I work as a Community OT within the Swansea Area. Whenever recommended DFGs for MND clients I will always place them as a priority wherever possible. Obviously this is essential in relation to deterioration (sometimes rapid) in a client's function. Early awareness of a client's diagnosis is essential allowing the OT service to assess and provide DFG recommendations for clients who are eligible.*

*I can only speak for the locality in which I work where health professionals are based in specialist community neuro teams and the occupational therapists have close working relationships with their counterparts in social care. In West Sussex occupational therapy assessments, and advice on possible adaptations, are available to all people with MND regardless of eligibility for DFGs.*

### **Health and social care professionals**

The MND Association works to raise awareness of MND and its affect on people's lives through national and local campaigns. The [MND Charter](#) includes people with MND's right to timely and appropriate home adaptations, to help them maximise their quality of life. Adopting the MND Charter is one way that councils can promote better understanding of the needs of people with MND by different services and professionals.

An additional challenge was highlighted during engagement events where professionals from a range of organisations might not be aware of the DFG themselves, of how the complex process works, or of alternative forms of support. This is perhaps understandable, given the range of possible pathways a person could be routed down, and the difference between assessment processes for DFGs, social care, minor adaptations services, continuing healthcare or other interventions. Again, simplified better integrated teams and case management systems, and conversations early on after an MND diagnosis, recognising the needs that are likely to develop, can help avoid people missing out on the right support.

As well as understanding the nature of the disease and how this will create housing needs, it is important that services are strategically planned to meet the needs of people with progressive conditions like MND. This, again, requires accurate and integrated data collection, to properly understand both what current and future demand looks like, and how the experience of service users can be improved.

### **What does local authority data tell us about information and integration?**

56 English councils and four Welsh councils returned data on people with MND. The rest stated that they did not hold the data, or that it would cost too much to extract. Several indicated that this was only held at OT or Social Services level, implying that in two-tier authorities this data is not usually passed on. Two councils stated that while they do not collect condition-specific data, they may in some cases record that the person has a progressive neurological condition.

In England, 35 councils had no applicants living with MND and 14 had one applicant. Six had between two and five. One council had 10 applicants with MND, and one had four, cancelling all four 'due to client's contribution exceeding the cost of works'. In Wales, two councils had one application each from a person living with MND, while one had three and a further one had zero. No applications from people with MND in Wales were recorded as cancelled.

The lack of data on medical conditions and types of disability means it is impossible to know whether particular populations with different types of needs are being well-served by the DFG system. Someone with a progressive condition may need a different kind of aids and adaptations service to someone with a non-progressive disability or a fluctuating condition. In the case of MND, given the rapid nature of progression the service will need to be quick and adaptable to developing needs, and different solutions may be better than, for instance, major extension work that will take some

time to complete. For those with slower-progressing forms of the disease, the service must be mindful of future needs as well as current. Given councils often state that the data is kept by a service in the upper-tier authority, or in a different department, it also speaks to concerns regarding lack of integration between systems.

### **How can DFG information and integration be improved?**

Based on research by the MND Association and other organisations, there is still some distance left to travel in improving information and integration of services to make sure home adaptations systems work well around the people who need them.

Integrated teams can make sure people have access to professionals with the right expertise, who can help guide the process efficiently and effectively. Occupational therapists can, and often do, act as champions for people with MND and similar conditions. Some authorities have pooled funds and embedded OTs in housing teams, as well as adaptations case workers in hospital discharge teams and housing experts in social care teams, to better make use of their expertise and to provide a swifter more seamless assessment service. Sensitive conversations need to start early on after a diagnosis, with detailed information about what adaptations might help, how the process works, including assessment and eligibility, and what alternatives there may be. This means that health and social care professionals and housing officers need to be well informed about both the nature of MND, and the steps involved in getting support for home adaptations. UWE highlights the practice in Scotland of staging 'good conversations' at the start of the home adaptation process. These include supported self-assessment, alternative housing options, effective signposting and routing to appropriate services.<sup>90</sup>

There is a noticeable lack of information about the DFG process, or other accessible home options, on council websites across England and Wales. While basic facts and definitions of the grant are available, it is less common to find information about assessment processes, eligibility, waiting or processing times, discretionary or alternative support, or the experience of adapting a home. Again, Independent Living Centres can help guide people through these processes, but not every local authority has one of these, and initial online information would provide a useful introduction. [Central Bedfordshire](#) and the [City of York](#) are better examples.

There are numerous national policy drivers for integration of health, social care and housing services, recognising the difference that a system built around the person's life can provide with more appropriate, comprehensive and seamless support. Not only would this generate cost savings, but for people newly diagnosed with MND it would reduce the stress and anxiety involved in trying to navigate complex and often siloed services. However, it costs money and takes time to successfully achieve major systems redesign and to make sure the right professionals are in place; some local authorities have demonstrated the difference it can make, and provided blueprints for other councils, but more sharing of expertise and, crucially, more investment, is required to make sure good practice exists across the country.

## Recommendations

### Action for National Governments

- National government in England should review progress made towards integration of health, social care and housing under the Better Care Fund, identifying good practice and distance left to travel. This must include a specific focus on DFGs as part of integrated health, care, and wellbeing support.
- National governments in England and Wales should allocate funding to help local partnerships continue to integrate services, develop data sharing systems and introduce effective multi-disciplinary case management for home adaptations, as part of a wider package of support.
- As part of introducing and developing national standards for home adaptations, national governments in England, Wales and Northern Ireland must introduce appropriate outcomes measurement based on recommended good practice for DFGs.

### Action for Local Governments

- Local authorities should work to identify and share good practice in the provision of advice, information and support to people with progressive conditions, including focus on addressing the emotional impacts.

- Local authorities should introduce systems that provide a single point of contact for disabled people, with 'good conversations' at the start of the process and guidance along appropriate pathways.
- Local authorities should invest in Independent Living Centres, 'pop up' guidance or other information and advice methods to help people understand the options for adapting their home.
- Local authorities should improve their online information about DFGs, including publishing their assessment criteria, processes and other support options in accessible formats.
- Local authorities should build on good practice examples to continue to integrate services, develop data sharing systems and introduce effective multi-disciplinary case management for home adaptations, as part of a wider package of support.
- All local authorities should record the primary disability or health condition of DFG applicants in order to enable better evaluation and monitoring of how well they meet the needs of their local population.
- Local authorities and partners in health and housing should use NHS numbers to track, monitor and report on DFG caseloads.

## Conclusion

People living with MND need safe and accessible homes, to help them realise their right to independence and quality of life. Living with a terminal illness should not mean that these rights are sacrificed. People need to be supported to live and die in their own homes, if they choose to.

It is essential that people living with a progressive and terminal condition such as MND are supported to access home adaptations in a timely manner. They need rapid access to the adaptations that can enable them to live at home for longer, maintain their health and wellbeing for as long as possible, and remain engaged with their communities, families and friends.

DFGs, where they operate as part of a flexible and integrated package of health, care and wellbeing support, can help people with MND to achieve this. Support for home adaptations goes beyond financial support. Help to understand options, navigate systems and, if necessary, find a new home is vital too.

Unfortunately, support for home adaptations remains a postcode lottery. With patchy data, it is hard to pinpoint exactly where improvements can be made. With limited and hard-to-access

information, it can be difficult to even find out what support exists. Some local authorities have introduced innovative new approaches to ensuring systems work best for the people they are designed for, but others are trailing behind.

This report makes a range of recommendations that complement those made by UWE, Foundations, BRE, Habinteg, Shelter Cymru and many other organisations over the years. As the DFG turns 30, it is high time for changes to be made to make grants fairer, more transparent and more accessible. Developments in other areas of health and social care can help to frame this, and should in turn themselves take into account the role of home adaptations in living safely and independently.

People live with MND for different lengths of time. While for many it is a rapidly progressing disease, for some it presents longer term needs. Home adaptations support needs to be sensitive to the impact of MND on people's lives. It also needs to be built around those lives, to help people with MND, their families and carers live with dignity.



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