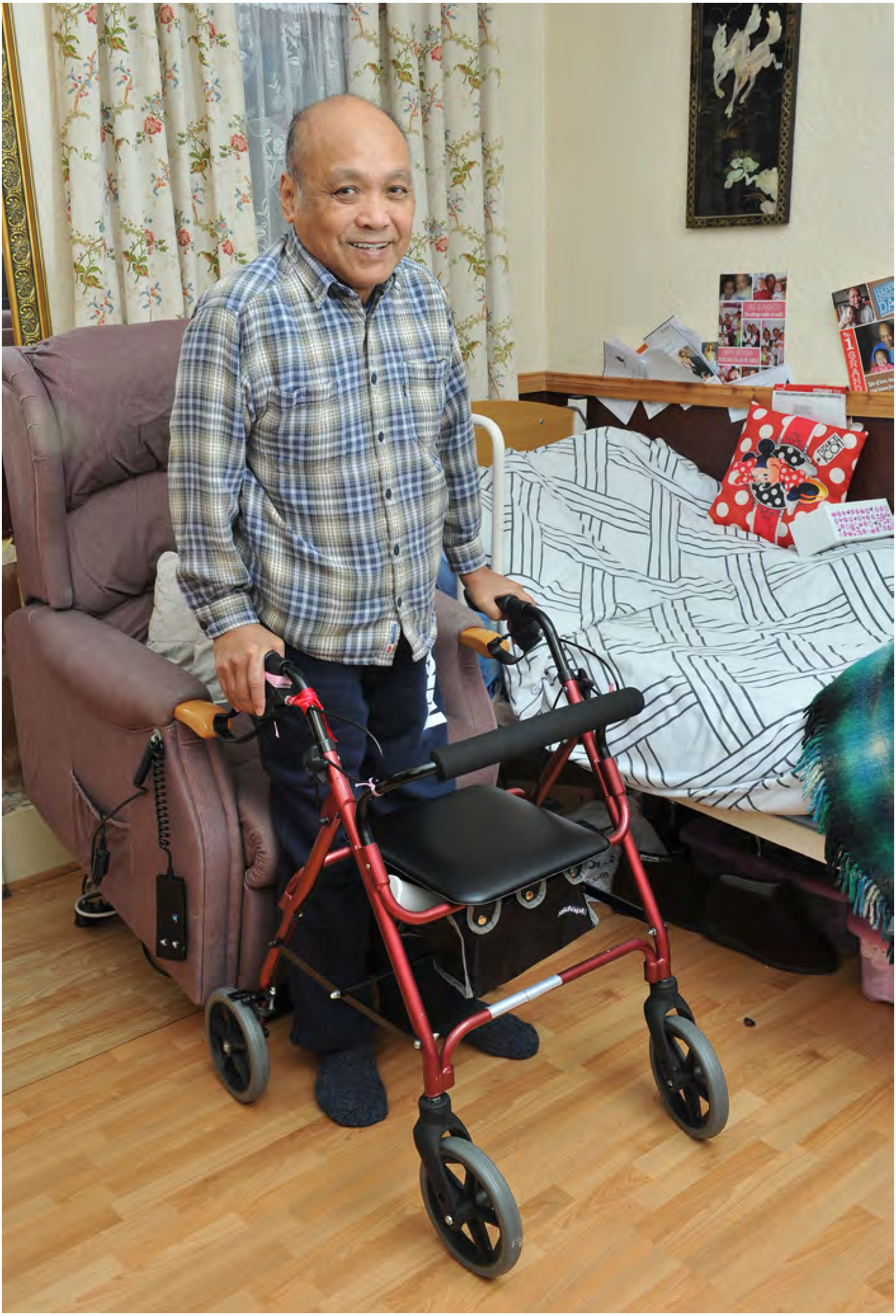
mnda
motor neurone disease
association

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

Summary Report
Ellie Munro, 2019



About MND and the MND Association

Few conditions are as devastating as motor neurone disease (MND). It is rapidly progressive in the majority of cases, and is always fatal. Patients will, in varying sequences and combinations, lose the ability to speak, swallow and use their limbs; the most common cause of death is respiratory failure. Most commonly the individual will remain mentally alert as they become trapped within a failing body, although some develop dementia or cognitive change. There are about 5,000 people living with MND in the UK. MND kills a third of people within a year and more than half of people within two years of diagnosis. There is no cure.

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.

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.

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.[1]

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.[2]

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.

Improved housing conditions deliver improved quality of life. The Equality and Human Rights Commission 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'.[3] The World Health Organization states that poor accessibility increases the risk of isolation, restricts social participation, negatively affects quality of life and can increase the level of care family and friends need to provide.[4]

A lack of accessible housing carries costs to society as well as individuals. Waiting for equipment and adaptations accounted for 51,328 lost hospital bed days in 2017/18.[5] Fractures as a result of falls among older people cost the NHS and social care around £4.4 billion a year.[6] Care and Repair Cymru, which delivers 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.[7]

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.

What is the Disabled Facilities Grant?

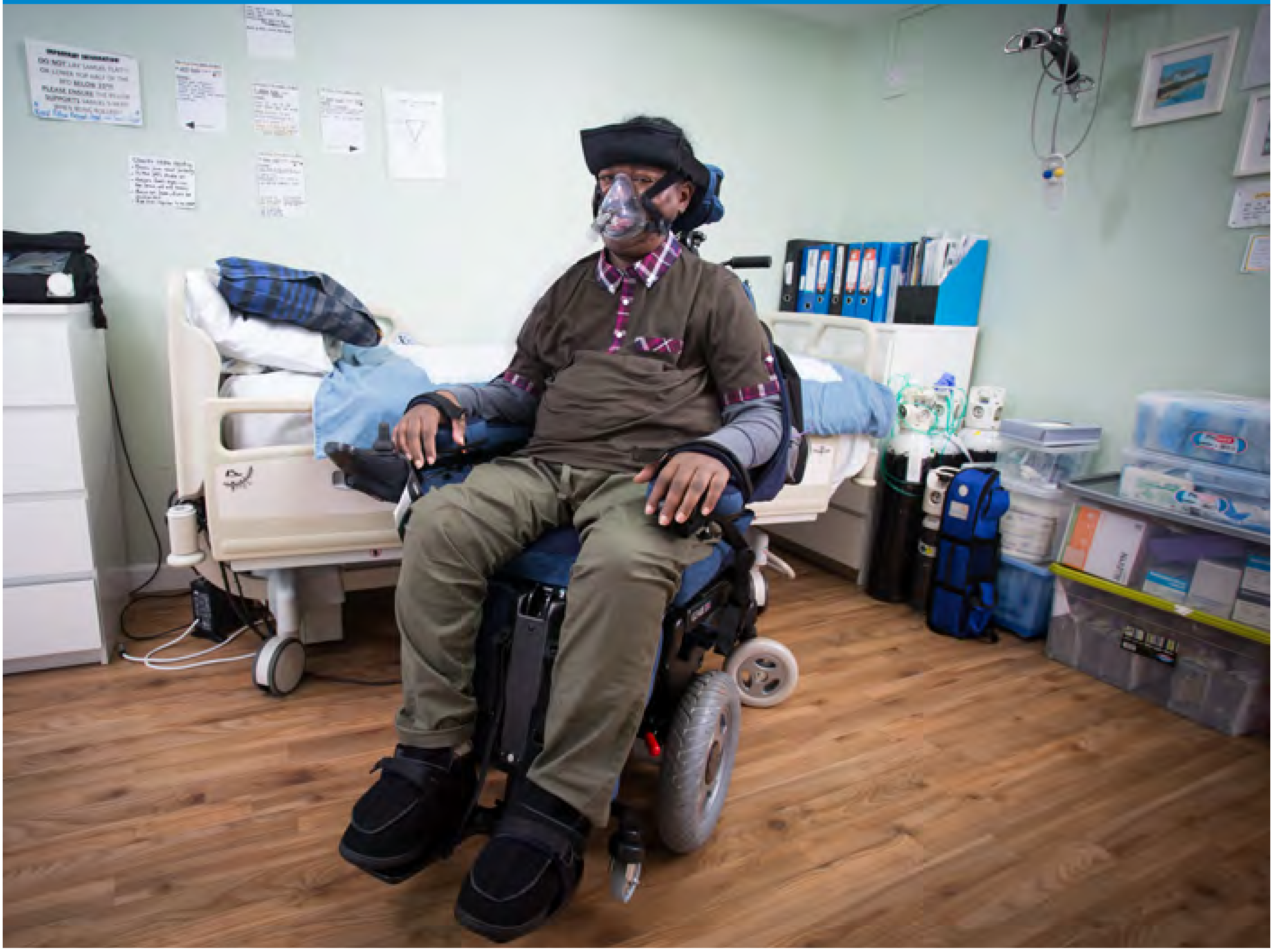
The Disabled Facilities Grant (DFG) is a means tested grant which can help towards the cost of adapting a home in England, Wales and Northern Ireland. It can provide funding for installing a stairlift or through-floor lift, creating a level access shower room, widening doorways, providing ramps and hoists or creating a ground floor extension. DFGs were introduced through the 1989 Local Government and Housing Act, and is currently governed by the Housing Grants, Construction and Regeneration Act 1996.

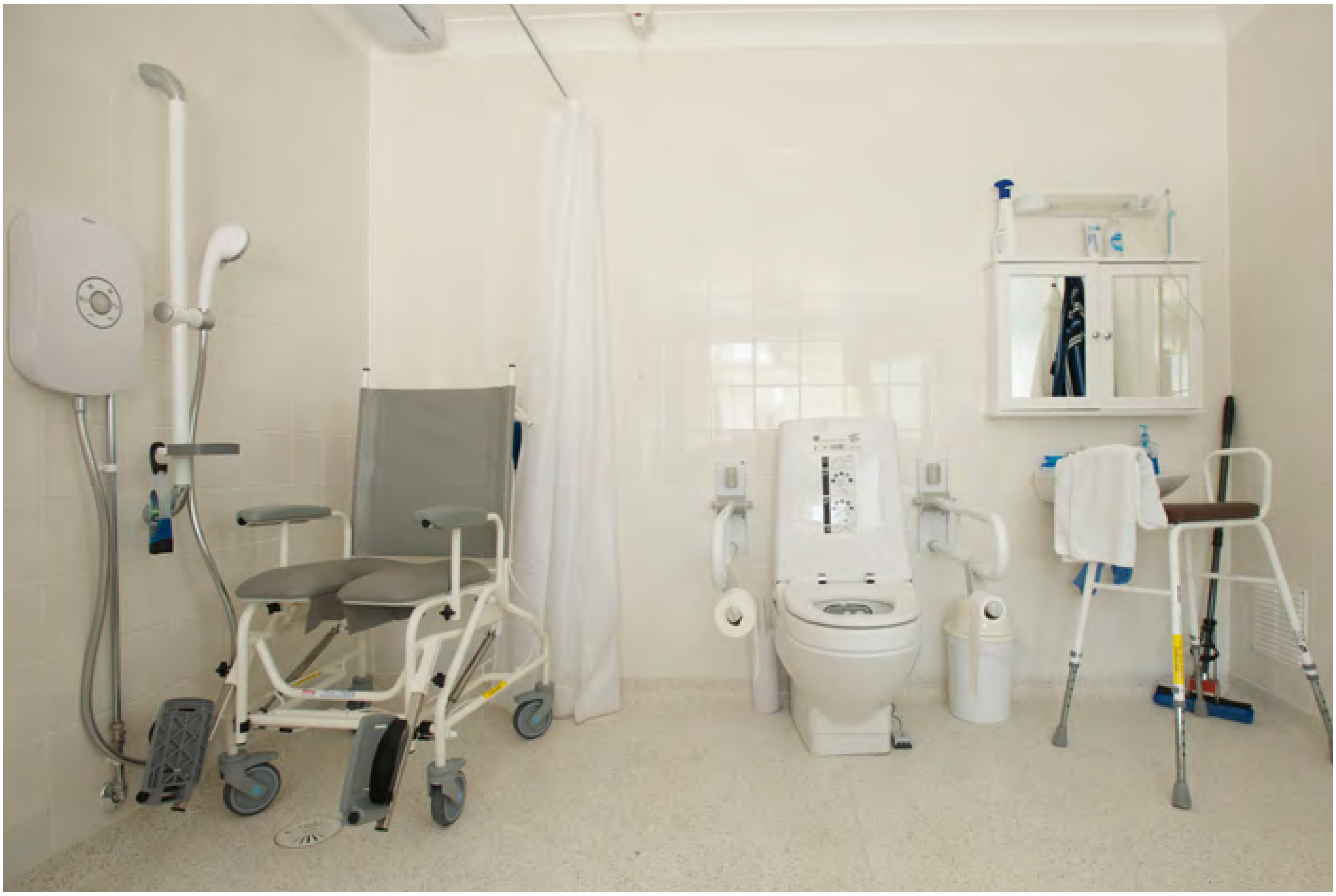
A person will qualify for a DFG if they can demonstrate that the work is 'necessary and appropriate' to meet their needs, including moving around and getting in and out of their property, and that the work is 'reasonable and practicable'. There is also a 'test of resources', which is based on household income and savings. Certain benefits, such as Employment and Support Allowance and Universal Credit, mean that a person will be passported through the means test.

The maximum value of grant in England is £30,000. In Wales it is £36,000, and in Northern Ireland it is £25,000. DFGs are administered by local authorities with housing responsibilities in England (district, borough and unitary councils), local councils in Wales, and by the Northern Ireland Housing Executive. Depending on where you live, the service might be provided by an external organisation such as a Home Improvement Agency (HIA) or a branch of Care and Repair England or Wales.

Local authorities in England and Wales have powers to introduce extra or alternative support for home adaptations. This is often called a 'discretionary DFG', and might include raising the level of maximum grant, removing means testing for certain items or introducing fast-tracking systems.

You can find out more about DFGs through the MND Association's information sheet.





The current policy environment for home adaptations

DFGs were introduced through the 1989 Local Government and Housing Act, and are currently governed by the Housing Grants, Construction and Regeneration Act 1996.[8] In 2014, the overall fund in England was moved into a pooled budget called the Better Care Fund, administered by the Department of Health and Social Care. This budget is part of the government's health and social care integration agenda.[9] The ambition is that local health and social care systems, including housing, should be integrated by 2020.

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.' The total amount available for DFGs in England has steadily risen since its move to the BCF, with a central government investment of £468 million in 2018/19.[10]

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, the Royal College of Occupational Therapists (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.[11]

Government commissioned a major independent review of the DFG and home adaptations in 2018, potentially indicating a commitment to addressing some of the issues with DFG operation.

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.[12] 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.' Government has created a scheme called ENABLE which seeks to bring different housing grants under one umbrella. 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. They include seven standards covering quality of equipment and service, and expected time frames. This has the potential to establish a robust, transparent and measurable framework for delivering adaptations.[13]

In Northern Ireland, the Department for Social Development and the Department of Health, Social Services and Public Safety published an Inter-Departmental Review and Action Plan for housing adaptations services in 2016.[14] 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.[15]

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 and engagement events 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.

> *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.*
>
> **MND Association staff**

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. People living in social housing chose lack of available housing (41.7%) more frequently. 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. Engagement events highlighted the issue of securing private sector landlord permission to make adaptations.

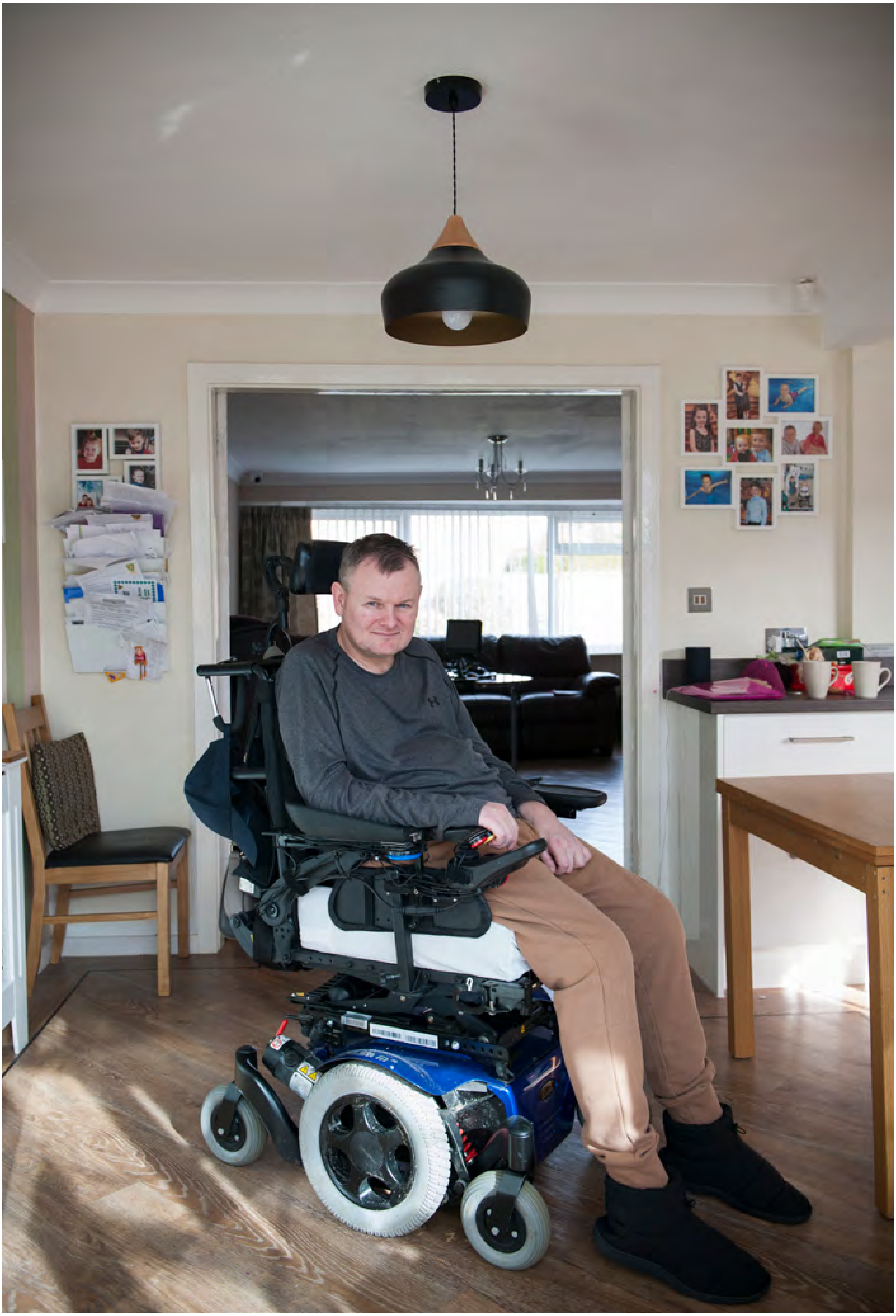
> *Haven't got time with this disease to wait for grants or council adaptations. We moved to a bungalow but the patient had died before door answering system completed, and they turned up morning he died to adapt doorways for wheelchair.*
>
> **MND Association member**

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. People living in social housing cited lack of support from local services (44.4%) more strongly than respondents as a whole.

> *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**

We also asked professionals what they felt were the biggest barriers people living with and affected by MND faced when securing accessible housing. 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.

Many of these problems are exacerbated when services don't work together. We want to see local authorities, health and housing teams building on good practice to integrate services, create shared data systems and case management that provides people with MND with a swift, effective and seamless service.



How are local authorities performing in delivering home adaptations?

In 2018 we sent local authorities a freedom of information request (FOI) to find out how they were spending their home adaptations budgets, how quickly they were delivering home adaptations and what some of the reasons might be for people not being able to access DFGs. There were 269 complete or partial returns from English local authorities with responsibility for housing, or 83%. 18 out of 22 councils responded from Wales, or 81%.

Funding

FOI data showed that English councils spent an average of 82% of their grants, but with wide variations between areas. Councils most commonly reported spending at least 100% of their budget, but these councils only represent 30% of all respondents. 10% of councils spent more than 100% of their budget – 28 in total. All but eight out of 22 councils in Wales used at least 90% of their DFG budget. No councils spent more than 100% of their budget.

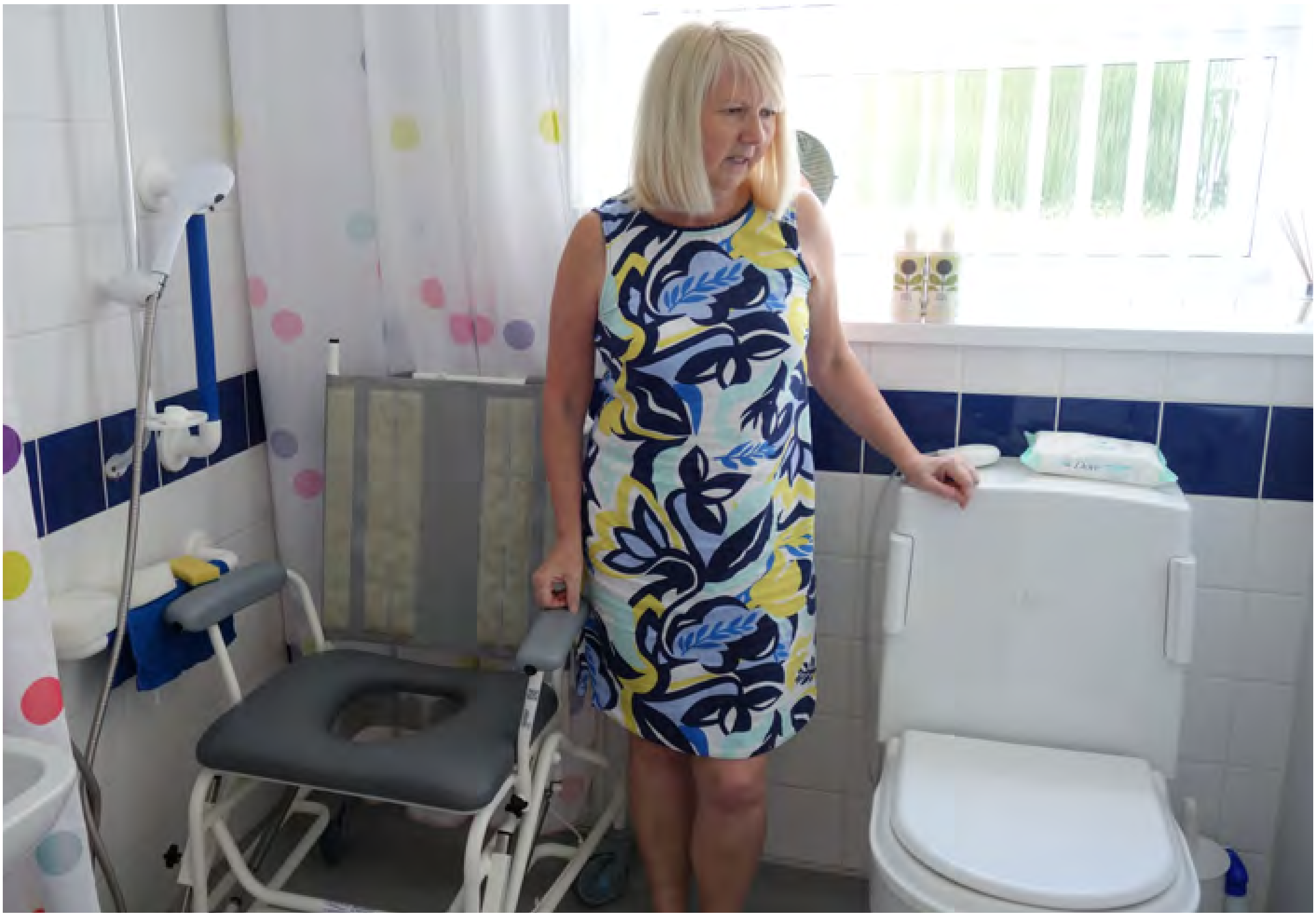
Different spending levels do not necessarily mean that councils get too much or too little funding. The allocation process is complex, and it is hard to determine current or future need based on current available data. The DFG Independent Review recommended reviewing and changing the allocation method to take better account of levels of disability, and type of housing in each area.

Councils most commonly told us that failing the financial eligibility test was the most common reason for closing DFG cases. However, we know that councils can create policies for 'discretionary' DFGs that offer non-means tested support. Lots have used these powers to remove the means test for lower cost adaptations. Eastbourne Borough and Lewes District Councils, in partnership, have removed the means test for works costing below £8,000 and for all works for people receiving palliative care, while Brighton, York and Dorset have all removed the means test for works under £5,000.

Other councils, such as Chorley and West Sussex, have created 'top up' grants for works costing more than the £30,000 limit in England, or raised the limit itself.

Timing

While most councils complete applications and payments within the specified time limits, there is still significant variation. 74% of respondents in England told us 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. Of the remainder, seven councils reported processing applications within the timeframe in less than half of all cases. 156 councils, or 58% of respondents, reported that 100% of approved DFGs were paid within one 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. In Wales, all but five out of 18 councils told us they are able to process applications within six months 100% of the time. Of the five, 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.



The variation across the country is concerning, and professionals and people with MND tell us the wait is still often too long. There are, however, some very positive examples of fast-tracking schemes for urgent and low-cost cases. Sevenoaks, Chichester, Luton and King's Lynn and West Norfolk all told us they have formal schemes for speeding up adaptations, for instance. Wales has also 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.[16]

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. 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 rapidly developing needs.

While some councils, such as Salford and Leicestershire, have done considerable work integrating home adaptations teams as part of wider health and social care systems, it is clear there is some distance left to travel. Integrated teams can make sure people have access to professionals with the right expertise, who can help guide the process efficiently and effectively. This includes making sure people with MND have the right information early on to understand and navigate often complex systems.

A call to action

This report comes at a time when the results of a major government-sponsored review of home adaptations systems has been completed, and in the run-up to the scheduled end of the Better Care Fund, under which funding for home adaptations sits, in 2020. The DFG is 30 years old in 2019. It is time to take action to make sure everyone has access to a safe and accessible home.

The MND Association is calling for action to make sure housing matters for people living with MND. 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 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.

Information and Integration

- 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.

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