

2021

# Accessible Housing Campaign Report



Duchenne  
UK

by  
Pathfinders  
Neuromuscular  
Alliance

Funded by  
Duchenne UK

## Table of Contents

Foreword .....	2
Executive Summary .....	4
Our recommendations.....	5
Findings from the survey and focus groups.....	8
Quantitative study - Accessible Housing Survey .....	8
Qualitative Study – Interviews and Focus Groups.....	12
Conclusions from qualitative and quantitative research.....	14
Case studies.....	17
Ryan O’Leary.....	17
Mitch Coles .....	19
Mark Chapman .....	21
Information for Adults with DMD - Housing Options.....	23
Social/Council Housing .....	23
Supported Living .....	23
Private Renting.....	23
Shared Ownership .....	24
Buying a home.....	24
Links to advice resources on Pathfinders.....	25
Schemes and Programmes for finding homes .....	26
HOLD .....	26
Mysafefhome .....	26
Habinteg .....	27
Golden Lane Housing .....	28
Branch Properties Accessibility Specialists.....	29
Potential campaign and project partners.....	30
Commonweal Housing .....	30
Abode Impact .....	30
Habinteg .....	30
HoME coalition.....	31
Potential new projects for neuromuscular charities .....	33
Information and awareness raising for the community and providers (e.g. estate agents) .....	33
Creation of independent living test flats.....	33
Setting up a dedicated housing association.....	34
Working with existing housing association to ring-fence properties for people with DMD.....	34

## Foreword



### Jon Rey-Hastie, CEO of Pathfinders

As an adult with DMD (Duchenne Muscular Dystrophy) who is now living independently, I have first-hand experience of navigating the process of finding an accessible home.

I went to university when I was 18 and stayed there to do a Masters and PhD. I was lucky enough to be provided university accommodation for the entire 8 years of my studies. However, due to the inaccessibility of student houses, I never got to experience moving into a house with my friends.

When I turned 30, I was able to negotiate a care package to provide 24-hour care from Personal Assistants (PAs). Previously my parents were always providing some level of care. It was a bitter fight with social services and the NHS to have a care package agreed, requiring me to go to the media to share my story.

After securing a care package, my brother bought a home and rented it out to me as my landlord. Finally, I was able to move out and live independently. I was very privileged that my brother was in the financial position to do this.

When I met my husband and we got married, I needed to move to a different area where we could both find work. Cue a two-year process of negotiating between 2 NHS authorities to facilitate the transfer of my care package, researching to identify my options, securing a mortgage, finding an accessible home and recruiting new PAs for my care team. It was a stressful, complex and confusing process for me as a 37-year-old man with a Doctorate who had been managing PAs for years.

We eventually found a shared ownership home and moved into it and the result has been amazing. I am delighted with what we achieved.

This report shows that my experience is not isolated. Some people living with DMD have managed to find housing and live independently, and as the report shows, this has been done in different ways. But with so many barriers, most have not been able to progress with their aspirations.

I believe it's unfair and ultimately unsustainable for adults with DMD to be expected to live with, and be cared for by their ageing parents indefinitely, when they have aspirations to live independently. Not all want to live on their own, but independence is possible wherever you live. It is my hope that by shining a spotlight on the barriers, we can push

for more action to increase the supply of accessible homes and support people to live independently within them.

I also hope that the case studies, information resources and organisation information we have gathered as part of this campaign make it somewhat easier for adults with DMD to find a housing solution that meets their needs.

I can't promise immediate action. But as CEO of Pathfinders, I can promise that we will passionately campaign to improve the options for adults with DMD and other conditions to live independently in their own home.

Jon Rey-Hastie

## Executive Summary

At a meeting of Pathfinders' Duchenne adults working group in early 2021, one of the priority issues that adults with Duchenne Muscular Dystrophy (DMD) felt needed to be addressed were the challenges involved in finding accessible housing and living independently. Following this meeting, and further discussions between Duchenne UK and Pathfinders, Duchenne UK agreed to fund a 6-month research study and scoping exercise to inform future work on housing accessibility for adults with DMD. The study was led by Dr Jon Rey-Hastie, CEO of Pathfinders, in partnership with Dr Janet Hoskin at the University of East London.

In June 2021, Pathfinders undertook a survey of 29 adults with DMD, 10 parents and one partner of adults with DMD. This was followed by a series of interviews and focus groups in September 2021 with adults with DMD and their parents.

The survey identified that 31 adults with DMD wished to live independently in their own accommodation, yet only 13 were doing so at the time of the survey. The top 3 barriers to doing this were identified as a lack of accessible housing overall, a lack of information regarding how to find accessible housing, and a lack of sufficient care and support for adults with DMD to live independently.

The lack of accessible housing identified by our respondents supports recent research data from the English Housing Survey which shows that 91% of homes do not provide the four main features that would make it even 'visitable' by a disabled person. Housing association Habinteg estimates that over 400,000 wheelchair users are living in homes which are neither adapted nor accessible.

The lack of information regarding accessible housing reported by our respondents related to both information about accessibility of individual properties, as well as information about the process of securing a home. Information was considered lacking in both the private and social housing market. Finding properties typically required independent research by respondents, and visiting or bidding on unsuitable properties that could have been quickly ruled out had access information been available.

The difficulties in securing an adequate care and support package for adults with DMD were a significant hurdle to achieving independent living. In many cases, parents were expected to provide a large proportion of care for their adult children with DMD who lived with them, having already done so for their child's entire life. This could in some cases be at the expense of the health of the parents who were acting as unpaid carers. Respondents told us how a health or other crisis which caused the breakdown of care was the only thing that led to improvement in the support available to facilitate independent living.

Pathfinders also undertook research into current provision of support available for adults with DMD to access housing. There are some excellent services for disabled people, such as mysafehome and the HOLD scheme that have been used by some adults with DMD to secure an accessible home. Habinteg, the disability housing association, is also pursuing a range of initiatives and campaigns to improve both the availability of and information regarding accessible homes. However, these services have both location, capacity and funding limits.

Both within this report and on its website, Pathfinders has provided information on different housing options available to better support adults with DMD who wish to live independently. We also set out proposals for projects that could support the community such as creating training flats for adults with DMD to prepare for independent living, and proposals to boost supply of accessible housing. These proposals are aspirational at this stage. Using this report, Pathfinders intends to campaign to improve the prospects of adults with DMD and other muscle-weakening conditions to secure accessible housing and independent living. We have developed the following recommendations which underpin our campaign:

## Our recommendations

- **Information about finding accessible housing on the private housing market needs to be readily available and accessible for disabled people.**
  - **We call on estate agents to provide basic accessibility information on all advertised properties.** This should be available online by default.
  - **We recommend that Local Authority housing teams should be equipped to provide basic signposting resources for people enquiring about accessible housing on the private housing market.**
- **Information about finding social housing needs to be readily available and accessible for disabled people.**
  - **We call on Local Authorities to share contact details of housing officers with a clear route of contact across multiple methods of accessible communication.** These officers should have detailed knowledge of the process for disabled people to access housing and declare accessibility needs, and a clear understanding of where to signpost applicants for more support and information.
  - **We call on all Local Authorities to provide an accessible housing register in line with best practice, to ensure advertised properties have clear accessibility information which can be matched to the access needs of housing applicants.** Some Local Authorities (e.g. Tower Hamlets) currently do this themselves, and Homefinder UK (in partnership with Habinteg) offer a nationwide scheme which social landlords can join.
  - **We recommend Local Authorities provide training to housing officers on the application process for disabled people and how to identify and**

**classify properties according to access needs.**

- **Government and Local Authorities must commit to increase the provision of accessible housing**
  - **We join Habinteg in calling for National Government and local planning authorities to establish policies to supply a proportion of homes meeting wheelchair user dwellings standard.**
  - **We call on all Local Authorities to include a commitment to building accessible housing in their local plans.**
  
- **Local Authority housing services should be joined up with social care and health support.**
  - **We recommend that when an applicant with social care and health needs joins the housing register, this should trigger a joint meeting between housing, social care and/or continuing healthcare to ensure support is ready when the applicant finds a property.**
  - **We call on Local Authorities to ensure housing and independent living are discussed at Transition Reviews for Education Health and Care Plans from the age of 14 years, and at annual social care or continuing health care review meetings.** This needs to encompass the needs of the whole family as well as the needs of the person with DMD. Housing professionals should be involved or at the very least alerted to these plans.
  
- **Local Authorities' health and social care teams need greater awareness of the needs of people with DMD and need to provide additional support for their care.**
  - **We recommend that DMD charities provide training resources to professionals and families on DMD in adulthood.**

This should raise awareness of better life expectancy and quality of life for adults with DMD so that they can be aspirational about their living arrangements in the future.
  - **We call on Local Authorities to identify parents of adults with DMD who have provided care for over 20 years and ensure regular carer assessments are carried out.**

There should be no expectation that family members should be unpaid carers for the entire life of their children where they do not wish to do so.
  - **We call on Government to urgently review workforce issues in the care sector including low pay and a lack of applicants for care roles.**

Any changes in pay rates must be supported by increased funding for people who directly employ personal assistants. Without regard to increasing individual care packages, increasing pay for carers would simply reduce hours of support available for people employing them.
  
- **Training should be made available to support people with muscle-weakening conditions to live independently**

- **We call on Government to provide funding for training on employing personal assistants, led by disabled people's user led organisations.** Training should cover the recruitment and management of Personal Assistants, available at a national level and underpinned by a network of professionals who can offer support.
- **We recommend that DMD charities develop information resources to support people with muscle-weakening conditions to become more independent.**

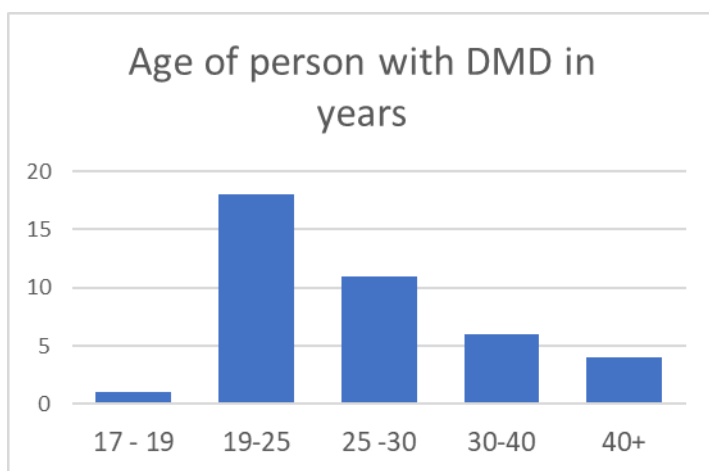


## Findings from the survey and focus groups

### Quantitative study - Accessible Housing Survey

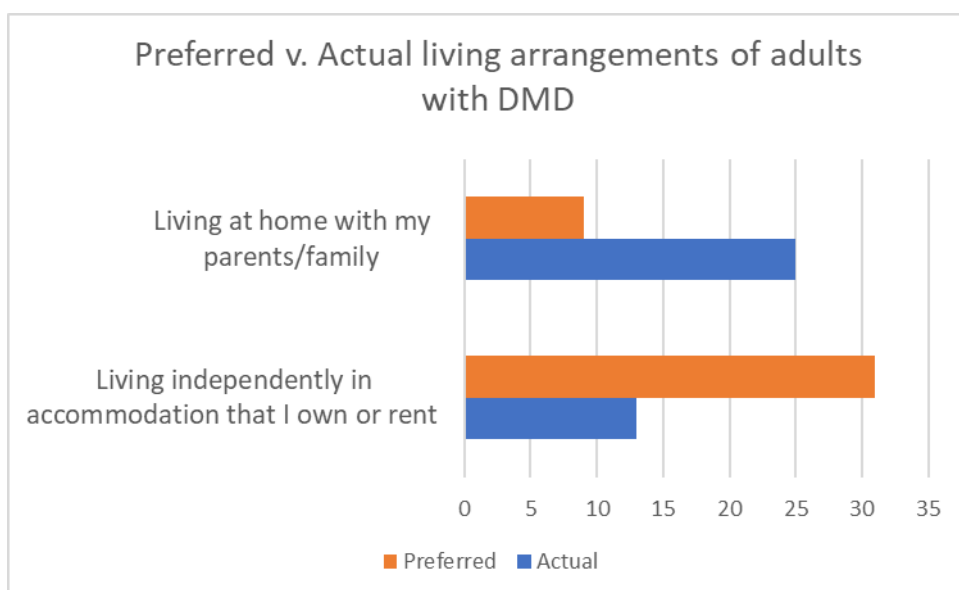
Our quantitative data comes from an online survey of 40 people, comprised of 29 adults with DMD, 10 parents and one partner of an adult with DMD. Participants were recruited via social media by charities and organisations working with people with DMD, as well as direct messaging and emails by the researchers.

The age profile of respondents was as follows (parents responded on behalf of their young person with DMD):

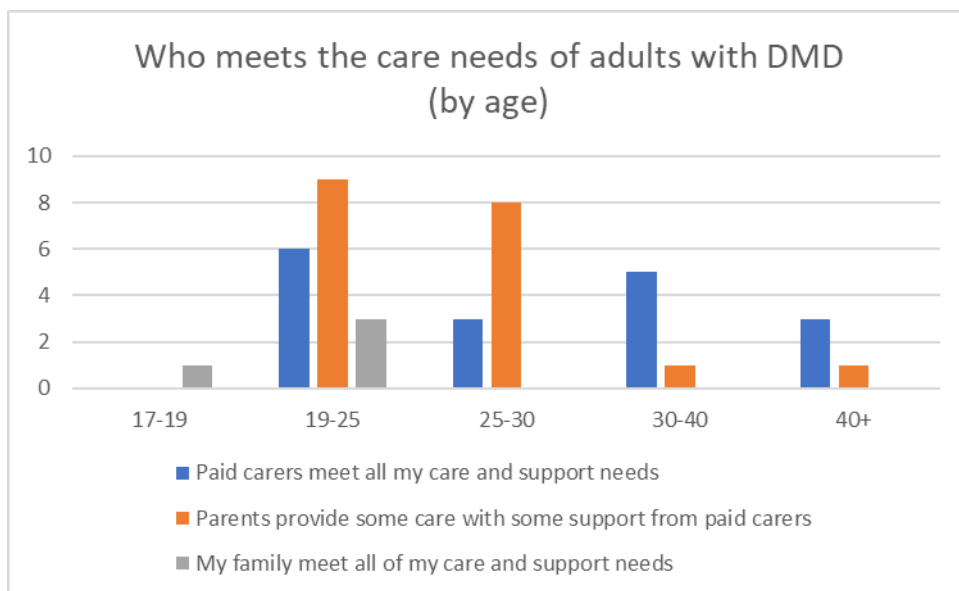


Total respondents: n=40

We asked respondents about their current living situation (or the young people they supported), compared to what they wanted. As shown below, the majority of respondents (31) wanted to live independently in their own accommodation, but only 13 were currently doing so. This shows a significant unmet need in regard to independent living for adults with DMD.



We also asked respondents about who meets their care and support needs. There is a general trend that older respondents are more likely to have their care needs met by paid carers, as their needs increase due to DMD. Parents play a significant role in providing care for most respondents under 30. We know that having paid carers working with adults with DMD during the day and night increases the need for additional space in their homes.

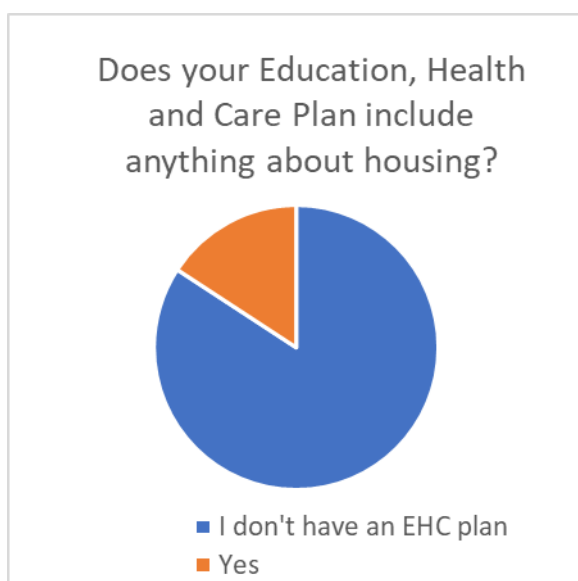
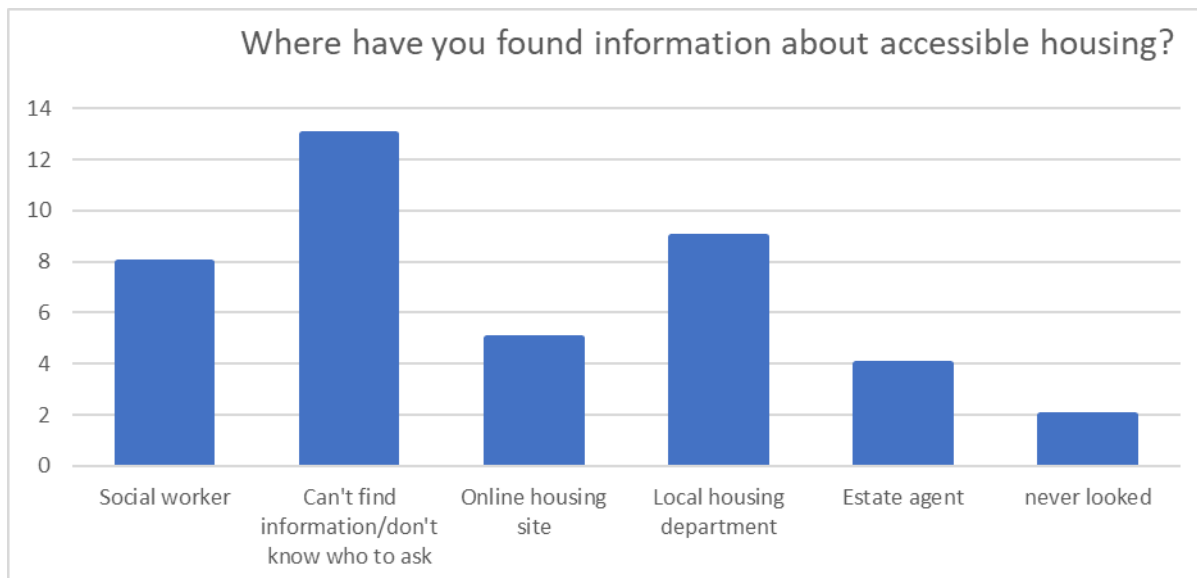


The 3 biggest obstacles for respondents finding suitable accessible housing were a lack of information about accessible properties, insufficient accessible properties and a lack of care and support to live independently.

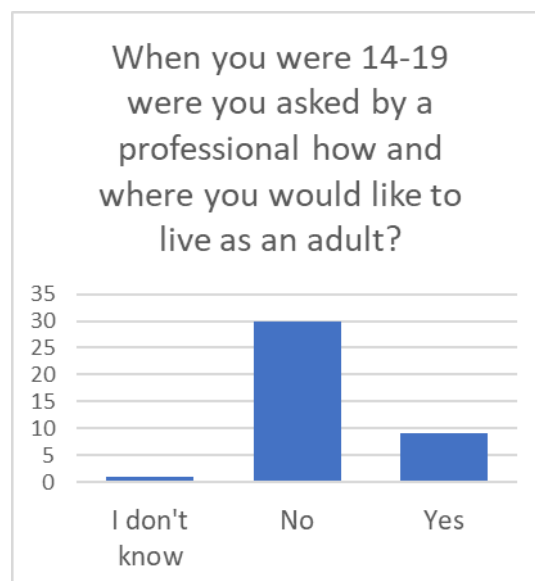


Regarding where people found information about accessible housing, again the majority were unable to find information. The most frequently mentioned sources were the local housing department and social worker. Conventional means of finding property

information such as estate agents and online sites such as Rightmove were rarely used. While some respondents had been asked about where they wanted to live, or in some cases had this included in their education, health and care plan, the majority of respondents received no such proactive support. It was also unclear whether being asked about housing options actually translates into any practical support.

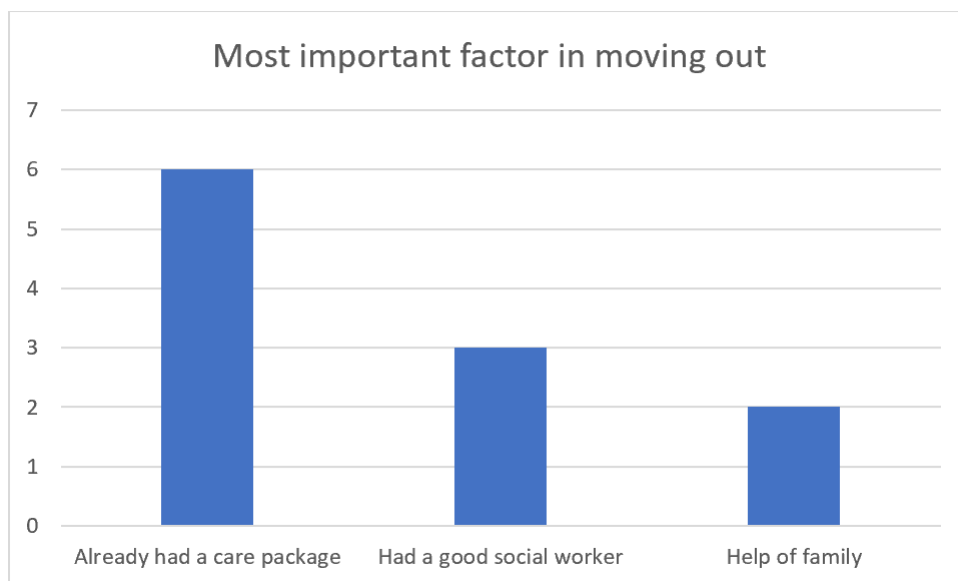


N=19 (only adults with DMD aged 17 to 25)

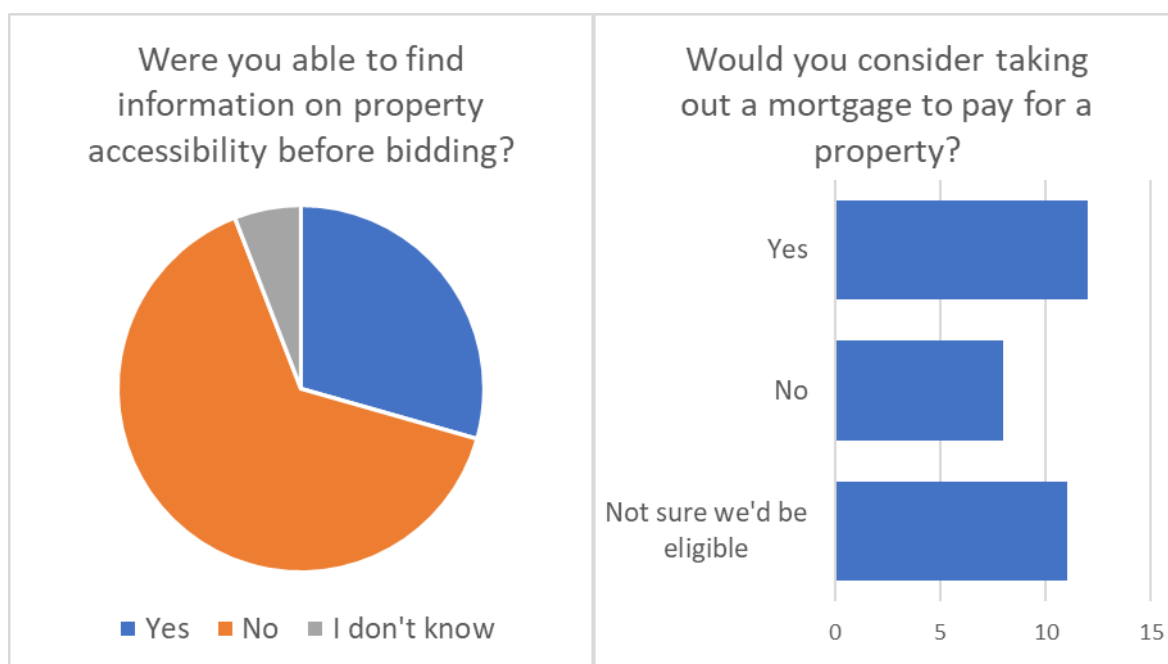


N=40 (all respondents)

For individuals who had successfully achieved their aspirations to live independently, we asked them to identify the most important factor in making this happen. As shown below, the importance of having a care package in place, a good social worker and supportive family were vital in making this happen.



Two other key findings from the survey worth further consideration related specifically to the lack of information on finding accessible housing. The first was that the majority of respondents on the housing register identified that they were unable to find information about housing accessibility on properties they were expected to bid on. The 2<sup>nd</sup> was that a large number of respondents were unsure if they were eligible for a mortgage to buy a property.



N = 17 (respondents on the housing register)

## Qualitative Study – Interviews and Focus Groups

Our qualitative data comes from focus groups and interviews with adults with DMD (n=11), their parents (n=3) and/or partners (n=1).

As Duchenne Muscular Dystrophy (DMD) is a physically deteriorating impairment, an adequate support package is necessary from social services or the NHS in order for people to live independently away from the family home. Therefore housing is inextricably linked to having a care package, and it is difficult to talk about one without the other. Some of the participants had achieved their goal of living independently away from the family home (n= 4); some had chosen to stay in the family home with an independent care package (n=2); while the remainder (n=5) had some elements of care but were looking to increase this in order to move out.

Keeping this in mind, the following six themes have emerged from our data:

### 1. Lack of Information

- This is the most common problem reported by those participants who have not yet managed to find accommodation, many finding it difficult to know where to start, how to navigate complicated social housing systems and who the *'right people'* are to talk to.
- There is confusion over how to use the council bidding system and those that do master it report that accommodation on the list is not appropriate for someone with access needs.
- There is a need to push and fight to obtain information, and participants (and their families) do not always have the capacity to do this.

### 2. Crisis to get care package

- It is difficult to get an adequate care package organised in order to live independently.
- Some participants who have achieved residential independence have only achieved so after medical emergency/ intervention (eg. tracheostomy which demands 24-hour care)
- Some had to put themselves at risk in order to get a care package eg. one participant reported having to go against medical advice and leave hospital without a bed in their home in order to necessitate a crisis so that *'something would be done'*.
- The Care Package is often only in place at the last minute

### 3. Lack of choice and control

- Support arrangements/care packages can have a major impact on lifestyle and relationships, e.g. one married participant was unable to return to his supported accommodation after 10pm or there would not be anyone to help him get into bed as his care was on a rota.
- One participant had to consider the risk of his family being forced out of family home if he wanted to move out and live independently

- Waiting a long time for adaptations and equipment eg. shower chairs sometimes for years adaptations etc.
- Lack of privacy even when living independently, especially if in a relationship

#### 4. Role of professionals – enablers and disablers

- Some professionals are helpful in contacting services to find out about possible housing options, and some have been key in actually finding accommodation.
- High aspirations of professionals regarding housing for people with DMD are essential to make it happen. For example, one participant compared two social workers who were supporting them: *'I basically had a social worker given to me that was like- 'you're in a nice care home stay here it's the best you can hope for' and then I got a change in social worker who was like very 'This is a fight!'*
- Professionals from different services do not speak to each other and there is no joined up working, especially between Health and Social Care professionals within the same Local Authority. This makes it difficult for participants to *'trust the process'*
- Education, Social Care and Health professionals do not discuss a person with DMD's housing aspirations and Education Health and Care Plans do not include information about housing.

#### 5. Role of parents

- There are expectations from social services that parents will provide care or *'fill the gaps'*
- It is essential that parents support the adult with DMD's aspirations to move out of the family home
- There are improved relationships once the person with DMD is living independently away from home *'mother rather than carer'*

#### 6. Need for skills and confidence to live independently

- There are real challenges managing PAs
- There is a lack of support to help with administration of care when living independently
- There can be difficulty recruiting PAs - due to lack of workforce, and low wages
- There is a variation of support in different areas

## Conclusions from qualitative and quantitative research

Our research clearly shows that many adults with DMD are unable to meet their aspirations in terms of living independently in their own place. We were pleased to hear some success stories and to learn of the positive outcomes in some cases.

Both the survey and focus groups identified that the lack of information on accessible housing and the challenges involved in getting a care package were major barriers to people with DMD finding homes that meet their needs.

The survey also indicated that most respondents have found a lack of accessible homes overall. For some, even when they have a 24-hour care package and all the information available regarding how to find accessible homes, they cannot overcome the lack of accessible housing in the areas they want to live. This supports recent research data from the English Housing Survey which shows that 91% of homes do not provide the four main features that would make it even 'visitable' by a disabled person.

Respondents told us that securing a care package is integral to getting the housing you want. Without an appropriate care package, it is impossible for many people with DMD to live alone. And while adults with DMD are still living with their parents, there is an expectation that this will continue indefinitely and as such, social services are often unwilling to provide a care package that facilitates independence. This becomes a "chicken and egg" situation which significantly hampers the ability of adults with DMD to get the housing they need, find work, have relationships and maintain good mental health.

Expecting parents to continue caring for their 30- to 40-year-old children has a detrimental impact on unpaid carers' health and well-being. Failure to prepare for failing health or death of unpaid family carers simply stores up complex crises that, when they occur, distress everyone involved and costs more for services to resolve.

In several cases, the only way progress was made in supporting adults with DMD to access housing or get a care package was during such a crisis. This could indeed be the death or illness of an unpaid carer, or a sudden increase in health needs prompting CCG involvement. This crisis-only approach puts adults with DMD and carers at significant risk from avoidable crisis moments, and increases costs associated with putting a care package in place at the last minute. Where appropriate housing or care cannot be found, others with DMD can be required to stay in expensive hospital settings until this is resolved.

Multiple respondents spoke of the difficulty involved in managing a care package once they had one. For those using care agencies, they spoke of the frustrations involved in not having choice and control over who provided the care and at which times. Some spoke of the lack of staff provision requiring them to wait significant amounts time to use the toilet or go to bed. For those employing their own PAs, they spoke of the challenges of

recruiting PAs due to a lack of job applicants and poor wages. Respondents identified the need for greater information and support in managing personal assistants, in order to better facilitate independent living. This suggests that training for employers of personal assistants could be valuable.

For many of our respondents, securing a care package was simply the first hurdle. Even with a care package where all needs are met by paid carers, some respondents were still unable to access the housing they needed.

Housing, social care and health professionals all play a vital role in supporting young people to become independent adults and find a place in society. As many of our respondents were not in work, social workers and Local Authority housing officers are the key points of contact for most adults with DMD in regard to housing options. Yet the integration of these teams and the support they provide is often poor or absent altogether.

Education, Health and Care plans were intended as a means to integrate teams around the needs of young adults in transition to adulthood. However, without any link to housing, even where people have an EHC plan, professionals involved in the plan have no means to support young adults to achieve their aspirations.

Adults with DMD require professionals with high aspirations, working across departmental boundaries to provide a joined-up service. They need to be more than simply a signposting service to services that the individual must access for themselves. Our research suggests this is rarely happening. Without effective support from professionals, adults with DMD are only likely to realise their aspirations if they can advocate for themselves or have a family member who is able to be a strong advocate.

According to our participants, information on the accessibility of housing is lacking in both the private and social housing market. Mainstream sites such as Rightmove and Zoopla do not include accessibility information, requiring people to visit many inaccessible properties in their search. On Local Authority housing registers many people are expected to bid on housing register properties without knowing if they are accessible to them.

Information about the process of finding homes is also lacking. According to the survey, few people knew about the options of shared ownership and many were uncertain about whether they would be eligible for a mortgage. Respondents in the interviews also talked about the difficulty of navigating the housing register and being unclear of their status on the register. As these were all options that at least one of our respondents had successfully used, it's clear this information is needed.

In interviews, we spoke with people who wanted to move out but who were constrained by a system that inhibits their choice and control. One participant was afraid of moving out because of the impact that would have on his family who might be forced to leave their existing accessible social housing home. Another was unable to move into a home



with his wife because without accessible social housing he was stuck in sheltered accommodation which restricted their visiting hours. Another wanted to move to live with his girlfriend but was inhibited from doing so because she lived in a different Local Authority area, and he wasn't able to get onto the housing register.

In social housing, there is a clear inertia of professionals and service providers in finding appropriate solutions. Housing solutions focus predominantly on the availability of housing and prefer to discourage and inhibit demand, rather than considering the lives, needs and rights of the people needing homes.

Importantly, not all adults with DMD required solutions in social housing. Some were in work and in a position to rent homes and in a few cases take on a mortgage.

Interviews and comments on the survey highlighted that renting on the private market was rarely a viable option. The survey shows that most respondents needed a ceiling hoist and a wet room, facilities not available in the vast majority of rental properties. Installing these features would be considered a structural adjustment which, under the Equality Act, landlords are not obligated to allow. In addition, the lack of security provided when renting, and the overall rarity of accessible properties on the rental market, meant that if adults with DMD were expected to find a new accessible property for rent at short notice, they would likely be made homeless.

In terms of buying, the lack of awareness of shared ownership suggests this is not often considered as a solution. This could potentially open up greater options for adults with DMD. To achieve full home ownership, this typically requires a sizeable mortgage which may be out of the reach of adults with DMD who work part-time.

Young adults with DMD want the same opportunities as their peers, to form relationships and move into a home. However, they are prevented from doing so by the overall lack of accessible housing, inability to adapt homes on the private rental market, poor quality information, financial barriers due to limited capacity for work, and the difficulty of accessing a care package. These are all issues that their non-disabled peers do not have. As such, adults with DMD are significantly discriminated against and achieve poorer outcomes overall. There is a clear need for changes to be made to ensure the few success stories in this report can be realised for the many adults with DMD who want to live independently.

## Case studies

### Ryan O'Leary



Ryan was a residential student at Treloar's College for three years, but when he was planning to move to higher education there was no suitable accommodation available. He requested to move into the independent living flats (known as Campbell Court) which had been used previously by Treloar's, but was told this wouldn't be possible because the flats were going to be demolished. Still not having anywhere to live for university, Treloar's agreed to let Ryan live in one of their boarding houses while they held discussions with Hampshire County Council about the viability of renting out the Campbell Court flats to outside tenants. One year later Treloar's began their Independent Adult Living accommodation programme and Ryan moved into one of the flats with 24/7 care provided by an external company and continued to live there throughout his university degree.

After finishing university, he didn't want to move home so applied to remain at Campbell Court and he was successful. He continued to live in Campbell Court for five years after university, reapplying each year. After five years, Ryan was ready for a change and started looking for somewhere closer to his family home. His care company, who also provides accommodation, told Ryan that a property would be ready for him to move into in 2020

but due to the Covid-19 pandemic the funding fell through. No longer wanting to live so far from his family, Ryan has moved into his Mum's house and remains hopeful that a property will become available soon because after living away from home for eleven years he wants to continue having the independence he has experienced.

Ryan has stated that the biggest obstacle for him getting his independent accommodation is funding and when asked what advice he would give someone else he said:

"It's complicated, but you need to persevere with it because eventually it will happen, but it may take a lot of fight and effort. I would definitely make sure that you get your social worker on side, because if you haven't got a social worker that's on your side it's very difficult in my experience."

## Mitch Coles



In his early twenties Mitch decided that he wanted to move out from the home he shared with his Mum and sister and pursue independent living. He applied for social housing, but the process was not an easy one. Along with needing to justify every aspect of his housing needs he also had to navigate through the social housing bidding system. Mitch found that though he won on a few of the bids on properties, when he was able to find out more information on them, they were not accessible properties with no prospect of being able to make them accessible.

After one year of trying to get a suitable home, which Mitch acknowledges is lucky considering the length of time people can spend trying to get a property, in 2014 he moved into his two-bedroom bungalow in Bristol. Now with the addition of two young children in his home, Mitch is uncertain whether he wants to go through the stress of trying to move house once his children outgrow their current space or try and convince the authorities to extend their home.

Talking about the process of moving out from his childhood home, Mitch voiced that no one spoke to him about the prospect of moving and if he hadn't pursued it, he doesn't think anyone would have broached the subject with him. He hopes that has changed now for people, but when he was 18 there was no support there regarding independent living.

Mitch also felt that the lack of information on accessibility for the properties in the social housing bidding system made the whole process difficult and delayed things unnecessarily.

Mitch says “Independence is super important you know? As much as I love my family, it just came to the point where I thought I can’t live with these people forever”

The advice that Mitch would give is “Just fight, don’t let people forget about you”

## Mark Chapman



Mark has been living independently in a Housing Association property with a team of PAs in Scotland for the last 25 years, but his experience of getting his home is not too different from those going through the process today. After spending his teens in a residential disabled school, Mark began his independent living journey when he started college in Edinburgh. His family home was in a very rural area, and he wanted to live somewhere near his friends and with more opportunities.

Mark and his parents spent a year fighting for funding for appropriate accommodation and support from community service volunteers to attend college. They had to get their local MP involved to ensure everything was agreed by the Local Authority and put in place. Luckily, Mark's parents received a phone call from the parents of a school friend about a new supported housing scheme in Edinburgh called Freespace. His friend was looking for someone to live with and the scheme was exactly what Mark was looking for, the funding was then agreed. The housing consisted of six houses, and a flat for an office for the staff. Mark spent the first two months of college living in a residential home for disabled people until the new housing was ready.

Not needing 24/7 support at this stage of his life, the supported housing scheme was ideal. Mark lived there throughout college and beyond but a few years later his needs began to change, and it was at that point he began to think about 24/7 support and hiring PAs rather than having support from Freespace. Once he began hiring a team of PAs, Mark started looking for housing more suited for his growing needs. He was placed on all the housing lists he was eligible for, and visited a few properties, but none were suitable.

Mark eventually found his current home through someone who knew of a housing association that had an accessible home available; the bungalow, one of two accessible terrace bungalows, is part of a collection of retirement sheltered housing for older people. The property needed adaptations to make it more accessible for Mark and it had great potential for further changes. Over the next 25 years as his condition progressed, Mark has had various adaptations done to his home, not without a fight, including a ceiling hoist and a roll in shower.

When discussing the possibility of moving house again, Mark said that he would like a bigger house but there are not enough accessible houses available and he's happy living in the location he is in. Being unable to extend is a compromise he accepts. He says he would rather adjust his present home anyway.

Talking about independent living and what he would say to someone just starting out, Mark voiced: "It's one of the best things you can do, it's not easy and the transition phase is quite difficult but with the right support and funding, that needn't be a big issue, and if you get those things right there's no reason why not."

## Information for Adults with DMD - Housing Options

### Social/Council Housing

Social housing or Council housing is where you apply to your local council or housing association for a place to live. You are assessed on your needs and placed on a waiting list for a property to become available either to be offered to you or for you to bid on.

#### Pros

- Rent is often lower than privately renting
- More likely to get a property suited to your needs
- You may not need to search for a property, the council may offer properties to you for your approval

#### Cons

- Long waiting lists which can be up to 5-10 years
- Being able to make large adaptations can be limited
- Limited on choice of where you live – must have connection to the area

### Supported Living

Supported living is where your local council, a charity, housing association or commercial company provide accommodation with the support you need to live there. Supported living is stereotypically for older people, therefore you need to look for organisations that include young people.

#### Pros

- Rent is often lower than privately renting
- More likely to get a property suited to your needs
- You don't need to search for a property, the organisation will search for you

#### Cons

- Long waiting lists
- Limited on choice of where you live
- Less control over who is providing your care

### Private Renting

Private renting involves paying a private landlord money, typically every month, to live in a property they own. To find privately rented properties you can look on estate agent's and property websites and visit estate agent shops to find a home to rent on the open market.

#### Pros



- You can choose the location of where you live
- You may have a greater choice of property
- Less of a waiting time

#### Cons

- You must search for a property yourself and deal with people who may not understand your needs
- Being able to make large adaptations, for example fitting a wet room, are often not possible
- Can be expensive depending on location, and housing benefit may not be sufficient to cover the costs

## Shared Ownership

Shared ownership is where you buy a share of your new home (between 10% or 25% and 75%) usually with a mortgage and pay rent on the rest. You can get a shared ownership home through a housing association as well.

#### Pros

- An avenue into ownership your own home
- More flexibility on location, but some schemes may require a local connection
- Schemes available for disabled people

#### Cons

- National housing shortage limits your options
- You need financial security
- Permission is required to make large adaptations

## Buying a home

Buying your own home means that you have full ownership of that property. Unless you have the money to pay for the property in full you will need to obtain a mortgage, which is a loan from the bank to pay off the cost of the property. To find properties to buy you can look on estate agent and property websites and visit estate agent shops.

#### Pros

- You own the home so have complete control on what you can do with it, if planning permission is granted
- No restriction on location
- You may have a greater choice of property

#### Cons

- It is expensive. Even if you can get a mortgage, you still need to have enough money to make a deposit
- You need financial security
- You must search for a property yourself and deal with people who may not understand your needs

## Links to advice resources on Pathfinders

### **Council Housing**

Information on how to get onto the local council housing waiting list and advice on what you need to know to be successful in getting a property, including information on medical priority forms and the differences that can occur between local councils.

[\[Council Housing article\]](#)

### **Shared Ownership**

A guide on what shared ownership is, who is eligible to get shared ownership and information on how to obtain shared ownership as a disabled person.

[\[Shared ownership article\]](#)

### **Where to find accessible properties**

A short collection of links with information on where you might find accessible residential properties available to rent, buy or for social housing in your area.

[\[Where to find accessible properties\]](#)

### **Supported Living**

A guide explaining what supported living is and how to access this type of accommodation.

[\[Supported Living article\]](#)

### **Mortgages**

Advice on how to get a mortgage when you are disabled, covering which benefits are more likely to be approved as income, what you need to do as a disabled person looking for a mortgage and signposting to different resources for further information.

[\[Mortgages article\]](#)

### **Adapting your home when renting: Your rights**

Explaining what your legal rights are around adapting your home while socially or privately renting and indicating where you can find more information.

[\[Adapting your home when renting\]](#)

### **Disabled Facilities Grants**

A guide on the Disabled Facilities Grants process, who is eligible and how to apply for one, with information on similar grants and support for adapting your home in Scotland.

[\[Disabled Facilities Grants\]](#)

## Schemes and Programmes for finding homes

There are a few schemes and programmes available for those who have DMD that might help them access housing. Each scheme available is purposely directed to disabled people therefore should have a general understanding of the complexities of living with a long-term disability and what that means for obtaining a home.

### HOLD

HOLD, or Home Ownership for People with Long-Term Disabilities, is a Government scheme in England that helps disabled people with long term conditions buy their own home through shared ownership. This scheme can be used on any property for sale on the open market, not just those in shared ownership schemes.

Shared ownership means you buy a percentage of your home, typically between 10% and 75% of the home's value, then pay rent on the remaining cost of the property. To be eligible for HOLD you must have a long-term disability and have a household income of £80,000 a year or less outside London, or a household income of £90,000 a year or less in London, and either be a first-time buyer, used to own a home but can't afford to buy one now, or are an existing shared owner looking to move.

To apply to the HOLD scheme, contact the Help to Buy agent in the area that you want to live. <https://www.ownyourhome.gov.uk/scheme/find-a-help-to-buy-agent/>

You can only apply to the 'HOLD' scheme if properties on other shared ownership schemes are not suitable for your needs, for example, you need a level access property.

#### Pro

- Allows any property on the open market to become a shared ownership property
- Specific for long term disabilities
- A potentially affordable way into home ownership

#### Con

- Means tested (income based)
- Could be costly
- Only available if properties on other shared ownership schemes are not suitable for your needs

### Mysafehome

Mysafehome is an organization that helps disabled people with complex needs who cannot work to find mortgages when they move house and into a shared ownership scheme, such as HOLD. It is open to people who receive the higher or middle rate of Disabled Living Allowance or the equivalent rate of Personal Independence Payments, but they also have further strict criteria which are:

- 18+ years old with clean credit history and no outstanding debts
- In the ESA Support Group or Universal Credit equivalent
- Unable to work in conventional employment
- In possession or in the process of arranging a suitable Care & Support package, either with a Local Authority, a private care provider or their family
- Able to prove their mental capacity or have Court of Protection or Lasting Power of Attorney in place
- Looking to live on their own – they can share but with caution!
- Able to put down a deposit and pay fees associated with buying their new home – this costs c. £15,000 - £20,000 (this includes a 10% deposit on the property PLUS getting them ready for home ownership and ensuring it's sustainable) AND able to contribute to their housing costs of c. £30 per week. **NB: Mortgage products and deposit requirements can and do change, so please contact mysafehome to find out the very latest information.**

For more information you can visit <https://mysafehome.info/home-ownership/qualifying-criteria>

#### Pro

- Mortgage organisation with disability knowledge
- A potentially affordable way into home ownership
- More support than regular mortgage companies

#### Con

- Strict eligibility criteria
- Large start-up costs
- Care must be in place

## Habinteg

Habinteg Housing Association is a registered social housing provider. Founded in 1970 by the organisation now known as Scope, they began providing integrated and accessible homes for disabled people. Now, Habinteg own and manage over 3300 homes in 86 Local Authorities throughout England and Wales.

Habinteg try to match suitable housing to everyone who applies to live in one of their properties, however they also look at the possible future needs of each client so that their home can be adaptable for any changes in their circumstances. All the housing that Habinteg build are accessible, over a quarter of which are built for wheelchair users with the rest designed to be adaptable. Also, as Habinteg is a Housing Association, they will be your landlord and will be there to provide any housing management needs you may have on a day-to-day basis. The mission of Habinteg is to create independence and inclusion into the community by facilitating accessible homes.

To apply for a Habinteg home, visit their website where you can be put on a waiting list and they will contact you if a home suitable to your needs becomes available.

<https://www.habinteg.org.uk/find-a-home>

Habinteg advise you to keep an eye on their social media platforms as they sometimes advertise vacancies there too.

This is a great organisation for someone with DMD because Habinteg understand the needs of people with complex disabilities and will work with you so that your home works for you, both in the present and for your evolving future.

#### Pro

- A housing association that build and run accessible homes
- Excellent knowledge on the needs of someone with a long-term disability
- Available for support continuously

#### Con

- There is a waiting list
- No guarantee of property
- Only available for rent

## Golden Lane Housing

Golden Lane Housing is one of the leading supported housing organisations for those with a learning disability. They were established in 1998 by Mencap as an independent charity to support people with learning disabilities with the challenges of finding a suitable home. Since then, they have helped over two thousand people who have a wide range of needs into more than one thousand properties across England, Wales, and Northern Ireland. Every year, Golden Lane Housing find homes for one hundred people and *“continually find innovate ways to provide suitable housing solutions in this ever-changing society.”*

The housing services that Golden Lane Housing offer help people with learning disabilities live happily and safely in their homes. The housing management services they provide include:

- Liaison and advocacy
- Assistance to keep safe and build an independent life
- An individualised approach to assisting with tenancy and housing management matters based on the needs of the tenant
- Information and advice on finances and access to benefits
- Ongoing housing support to maintain a successful tenancy
- A 24-hour emergency helpline

All these services are facilitated by highly trained staff.

Anyone wishing to apply for Golden Lane Housing must have a package of support that is agreed and funded by the Local Authority adult social care team. Once that is in place,

hopeful applicants can look for housing vacancies on their website or contact them with an enquiry.

<https://www.glh.org.uk/live-with-us/housing-vacancies/>

Though Golden Lane Housing would support someone with DMD, a learning disability must be present with all applicants.

Pro

- A housing association that is specific for those with a learning disability
- Whole person approach to allow people to live independently with the support they need
- Available for support continuously

Con

- Only available for people with a learning disability
- No guarantee of property
- Care must be in place
- Only available for rent

## Branch Properties Accessibility Specialists

[www.branchproperties.co.uk](http://www.branchproperties.co.uk)

Branch properties is the leading specialist and only Estate Agent letting agent with a service specifically aimed at meeting the accommodation needs of disabled people. Branch specialises in selling, letting, providing, finding and promoting properties that are fully adapted, partly adapted or not at all.

Branch properties operates as a conventional estate agent and also provides a management service for landlords of accessible properties.

## Potential campaign and project partners

### Commonweal Housing

<https://www.commonwealhousing.org.uk>

Commonweal Housing is a registered charity dedicated to challenging social injustices with housing solutions. Born out of Sir John Mactaggart's legacy, in 2003 Commonweal Housing was founded. Commonweal use charity resources to test various housing models to discover different answers to particular social injustices. They also support research and studies of social injustices where housing could be a part of the solution.

Commonweal have worked on projects dealing with issues such as, domestic abuse, homelessness and unemployment, housing for destitute migrants and housing for young adult carers. They have also funded research studies. In particular relevance to this report, they have supported Abode Impact in investigating the lack of private homes to rent for wheelchair users in the UK.

### Abode Impact

<https://www.abodeimpact.co.uk/about-us>

Abode Impact aim to “change the way the UK thinks about accessible housing”. They consult with tenants, developers, local Government, lettings agents, investors, and fund managers on how to better integrate accessible housing into mainstream private-rented sector housing portfolios.

They are doing this by operating portfolios of accessible housing in key locations across the UK, working with investors and other sources of capital, advising existing owners of let residential property on including accessible housing within their mix of properties, and helping them to access demand from wheelchair users and their families for a long-term, properly configured home they can enjoy.

### Habinteg

<https://www.habinteg.org.uk>

As well as being a housing association committed to building and renting out accessible homes, Habinteg actively campaign for better provision of accessible homes at Government policy level by influencing decisions. Habinteg have an Insight group which is made up of disabled campaigners who aim to use their voices and lived experience to increase the supply of accessible homes.

Every September Habinteg run an action week, titled #ForAccessibleHomes. This week is devoted to making an impact and growing awareness around the issue of the accessible home shortage in the UK. Habinteg is also a member of the HoME coalition, a group of organisations dedicated to tackling the severe and expanding scarcity of accessible homes.

## HoME coalition

<https://www.ageing-better.org.uk/home-coalition>

Housing Made for Everyone (HoME) is a coalition of ten charities and housing organisations calling for urgent action to tackle the UK's acute and growing shortage of accessible and adaptable homes. The ten organizations that founded the HoME coalition are: Centre for Ageing Better, Habinteg, Age UK, Care & Repair England, Disability Rights UK, Housing LIN, RIBA, the National Housing Federation, the Chartered Institute of Housing, and the Town and Country Planning Association.

They are campaigning for the Government to raise building standards so that the 'accessible and adaptable' design standard is the mandatory baseline for all new homes, and enough homes are built for wheelchair users. The HoME coalition is not currently accepting new members or actively campaigning.

The aims for the coalition are:

Charter - 7 actions to transform new housing:

1. We believe that central Government should set a higher regulatory baseline for accessibility of all new homes (M4 Category 2), and, where need can be demonstrated for M4 Category 3 (wheelchair user), the Government should lower the current high bar needed to introduce relevant planning policies. This will provide a level policy playing field across the country and the certainty that developers want, enabling them to build homes that meet the future needs of our ageing population.
2. Central Government should collate and make publicly available data from every planning authority on the number of new homes built to each of the Categories set out in Approved Document M4 Volume one (access to and use of buildings), alongside sufficiently resourcing planning authorities to effectively monitor this.
3. Local Authorities should be bold and confident in their planning policies for accessible housing, utilising MHCLG guidance and best practice approaches to evidencing need.
4. Homes England, in line with action already taken by the Greater London Authority, should give priority to current development bids for homes that meet M4 Category 2 standards. These should also include a number of Category 3 wheelchair accessible



properties. If necessary, the additional costs should be recognised in the Value for Money assessment and grant awarded for affordable housing.

5. Local Authorities should review and keep up to date with the accessibility of housing in their area in preparation for an accessible housing database that will make finding the right home easier for people with specific requirements.

6. Estate Agents and their membership body ARLA should work with the Government and others to create and deliver standard accessibility ratings, similar to the environmental rating, which is displayed for every home sold.

7. The home building industry should join our call for legislative change for higher accessibility standards. They should proactively seek out good practice among their members and disseminate this widely to encourage greater engagement from members who don't yet see accessible homes as good business.

## Potential new projects for neuromuscular charities

Following discussions with organisations and housing professionals, Pathfinders have identified a number of proposals for further projects that Duchenne UK, Pathfinders or others might consider funding. Alongside Pathfinders' housing campaign, these could potentially disrupt the inertia of existing provision.

### Information and awareness raising for the community and providers (e.g. estate agents)

Project funding could be sought to work with estate agents and housing providers to improve the availability of accessibility information on homes. To be successful, buy-in would need to be secured from a major online provider and an estate agent to run a feasibility study on the provision of access information. This could potentially be tied into work currently being done by Habinteg to improve accessibility information in the housing association sector. Where feasibility could be established, this would strengthen the case for provision of this information being required under the Equality Act 2010.

### Creation of independent living test flats

Commonweal have expressed interest in funding a project focused on transitions, in particular the transition of adults with DMD and other muscle weakening conditions to living independently in the community. This funding could potentially be used to secure a number of properties that can be developed as independent living test flats. These flats could provide short term accommodation (6-12 months) where a combined model of independent living and care agency provision could support adults with DMD to become more independent.

While in the test flats, adults with DMD could be supported through professional advocacy to secure care packages and accessible homes that facilitated independent living. In a time-limited test flat setting rather than the family home, it would be easier to ensure Local Authorities put in place appropriate care packages rather than relying on parents. In addition, training and mentoring could be provided to support adults with DMD to develop independent living skills, such as managing a home, employing personal assistants and finding employment and volunteering opportunities.

This project would require partnering with an experienced housing provider or managing agent who would manage the maintenance and leasing of properties to the adults with DMD.

## Setting up a dedicated housing association

Both the Habinteg and Golden Lane Housing stories provide an ambitious model for improving the provision of accessible housing. Charities in the neuromuscular space could consider setting up an independent charity or housing association to support people with DMD and other neuromuscular conditions to find an accessible home. This organisation could then purchase, adapt and rent properties to adults with DMD. This would obviously require significant initial backing and professional experience of operating in the housing association space.

There is significant complexity in setting up an organisation appropriately, in particular in regard to facilitating access of tenants to enhanced housing benefit. This is key in making any approach affordable and an attractive prospect for investors, who will be required to fund the purchase of properties.

## Working with an existing housing association to ring-fence properties for people with DMD

It might be possible to partner with an existing housing association to purchase, adapt or build properties that would be suitable for adults with DMD, and to ring-fence them to this community. However, for a housing association to exclude applicants without DMD from a set of properties, they would have to receive something in return. This might be new investors, land or a relationship with a Local Authority or housing provider they do not have. As Pathfinders does not currently have anything to offer, this is not an avenue that has been explored. However, it remains a potential route in the future to increase the availability of accessible housing.