

Cross party group minutes

Meeting minutes:

Cross Party Group Title	Wales Cross Party Group on Muscular Dystrophy and Neuromuscular Conditions
Date of Meeting	July 5 th , 2022
Location	Zoom

In attendance:

Name:	Title
Rhun Ap Iorwerth	Chair of the CPG on Muscular Dystrophy and Neuromuscular Conditions
Heledd Roberts	Office of Rhun Ap Iorwerth
Alicja Zalesinska	Chief Executive Officer, Tai Pawb
Alex Osbourne	Disability & Equality Officer, Disability Wales
Eleanor Marsh	Consultant Neurologist
Gwenno Davies	Occupational Therapist
Ann Jones	Person living with a muscle-wasting condition
Morvenna Richards	Person living with a muscle-wasting condition
Carolyn Middleton	Person living with a muscle-wasting condition
Joanna Williamson	Person living with a muscle-wasting condition
Stewart Ross	Person living with a muscle-wasting condition
Richard Haselgrove	Person living with a muscle-wasting condition
Paul Magness	Person living with a muscle-wasting condition
Dan Dowsett	Person living with a muscle-wasting condition
Rebecca Brown	Person living with a muscle-wasting condition
Sylvia Evans	Person living with a muscle-wasting condition
Julia Davage	Person living with a muscle-wasting condition
Cerianne Haines	Person living with a muscle-wasting condition
Brenda Gibbins	Person living with a muscle-wasting condition
Eleri Morgan	Person living with a muscle-wasting condition
Gareth & Katherine Hutchinson	Parents to an individual living with a neuromuscular condition
Stephen Hiles	Person living with a muscle-wasting condition

Michaela Regan	Head of Policy and Campaigns, Muscular Dystrophy UK
Matthew Rose	Health Policy Manager, Muscular Dystrophy UK
Bianka Zabarylo	Policy and Campaigns Assistant, Muscular Dystrophy UK
Rob Burley	Director of Campaigns, Care and Support, Muscular Dystrophy UK
Lucia Gillespie	Advocacy & Information Officer – Wales, Muscular Dystrophy UK

Apologies: None were received

Full notes:

- 1) Summary of Senedd debate on additional flexibilities for people with Motor Neuron Disease in Wales
 - Rhun Ap Iorwerth, Chair of the CPG on Muscular Dystrophy and Neuromuscular Conditions provided an update on the debate that took place in December 2021 in the Senedd regarding additional flexibilities for motor neuron disease. He said that:
 - Housing adaptations can make a big difference to people's independence, but there is difficulty obtaining and accessing these.
 - The impact of these delays was a feature of the debate and there was a call for the Welsh government to simplify how people can access adaptations by having a fast-track process, and by abolishing the means tested element.
 - In the debate, he described the current system as not 'fit for purpose' and highlighted a lack of consistency in how people are able to access adaptations.
 - The COVID-19 pandemic has exacerbated delays with waiting lists now even longer than they were before the pandemic.
 - The Welsh government agreed to the motion to simplify how people can access adaptations through a fast-track process and abolishing the means tested element.
 - The government pledged to ensure disabled people with any motor-neuron, neurological or neurodegenerative diseases acquire accessible and affordable housing with all the adaptations and devices they may need.
 - They also pledged to grant an additional £1 million in funding for medium adaptations such as chair lifts, accessible showers, and ramps. Since then, regulations have been changed to allow local authorities to apply for grants without means testing.
 - It was suggested that the voices of people living with a muscle-wasting condition need to be heard in the Senedd in a similar way but the group was advised that these people will already benefit from the pledges made by Welsh government as the pledges are intended for everyone with a disability.

- Stewart Ross asked if the scope of this conversation will apply to public spaces like shops, because they are also inaccessible. Secondly, he noted that even with home adaptations, the specialist staff are not available.
- It was explained this debate was only related to home adaptations but suggested that wider adaptations should be included in future correspondence.

ACTION: MDUK to consider access to public spaces as a topic of discussion at a subsequent meeting

2) Overview of Back the Bill – the right to appropriate housing for all in Wales:

- Alicja Zalesinska, the Chief Executive Officer of Tai Pawb spoke about the rights of all people to appropriate housing in Wales:
 - Alicja said that Tai Pawb are part of a coalition called ‘Back the Bill’ which seeks to incorporate the right to adequate housing into Welsh law through a bill.
 - The bill would require the state to ensure a ‘Minimum Standards of Housing’ for all.
 - Alicja described key aspects of what ‘adequate housing’ entails, including: availability, affordability, accessibility, habitability, legal security of tenure, suitable location, and cultural adequacy.
 - It was highlighted that there is a “chronic shortage” of housing – there are not enough different types of housing for the different types of needs disabled people have.
 - A key issue is that the government does not know the need for different types of housing –
 - there are no national estimates of who has what conditions and what would be an adequate housing adaptation for them
 - Additionally, only 50% of local authorities have an accessible housing register.
- Research into accessible housing in Gwent showed a shortage of occupational therapists, and that allocation systems work best when housing is proactively assessed and the same is done for applicants. The survey particularly found:
 - 60% of people were waiting between 6 months and 2 years for housing forms.
 - Only 50% of the people interviewed said that the housing they acquired was suitable, whereas, 30% said that it was partly suitable and 20% said that it was not suitable.
 - It was felt that the adaptations survey standards need to be better monitored and more refined to ensure their individual needs are met.

- The right to housing bill could help increase the amount of suitable housing, by:
 - Prioritising funding for disabled people
 - Failure to provide effective mechanisms to access one's home would be considered a breach
 - Failure to make progress would be considered a breach
 - Ministers would need to clearly indicate how they have given proper consideration to disabled people's right to housing
 - Disabled people would have the right to hold ministers to account
 - Depending on the model, a disabled person would be able to bring judicial proceedings for breach of right to housing.
- Attendees were encouraged to support the campaign. The full research findings will be launched in September which will include additional information on housing adaptations (such as the costs and benefits).

3) Rights to support for accessible housing

- Alex Osbourne, a Disability and Equality Officer from Disability Wales, provided insight into the work of Disability Wales, a national association of disabled peoples organisations in Wales striving to achieve the rights and equality of all disabled people :
 - The main aims of Disability Wales are to see more information being shared and to raise awareness to landlords of what their legal duties are. Disability Wales provide information on how people can use their rights to get quicker adaptations (like the right to an independent life).
 - They are aware a high number of people are waiting for adaptations which has an impact on people's mental health and wellbeing, for example if they can't leave their home for months because of no ramp.
 - The view from Disability Wales is that the application process is inaccessible to some disabled people – there are numerous documents to read and sign, inappropriate for people who struggle with sight or hearing loss. Alex shared packs which detail people's rights with members using the chat function.
 - In the private sector, people can go through the whole process of applying for accessible housing, but if the landlord refuses, they are met with a 'brick wall'. There is a gap in the support available for this.
 - There is a lack of registers for accessible housing meaning people are not aware of where they can move to, and a lack of awareness in the community about the rights and choices that they have. This leads to people living in unsuitable and potentially unsafe housing.
 - Over ¾ of applicants in a study of 150 people said they were not aware of how accessible housing is allocated
 - 40% found the application process difficult.

4) Disabilities Facility Grant experience from parents with a child with a neuromuscular condition

- Gareth and Katherine Hutchinson, parents to an individual living with a muscle wasting condition, shared their experience, particularly emphasising:
 - The process to get the adequate adjustments for their son was long. This was particularly due to the tender process and their sons needs not being understood (to keep costs down, proposals entailed no adaptations to bathrooms, for example).
 - Additionally, assessment was based on their son's ability at the time and not aligned with the progressiveness of the condition or what the future may hold. This meant they had no hoist, for example when he became non-ambulant. He had to sleep on the floor in the conservatory for a month.
 - Councils need to recognise the needs of this population in making assessments.
- Stephen Hiles, a member of the public living with a muscle wasting condition, provided insight into his experience with the council:
 - The house had been altered, but not adequately and after a while the alterations broke.
 - A key issue is that housing standards need to be more catered to individuals
- Paul Magness said from his perspective there is no consistency with local authorities, and asked what plans there are to standardise local authorities. It was suggested by Rhun that this should be included in a letter to the Minister.
- Julia Davage also had concerns about the council being inconsistent in their delivery.
 - Carolyn Middleton raised concerns as to whether adaptations are well thought through in terms of fire safety, and also wanted to know whether the authorities would take accountability if something went wrong in this respect.

ACTION: A point about standardisation of local authorities to be included in a letter from Rhun to the Minister regarding housing adaptations.