

# Silence in our sector: Disabled lived experience at board level

## Introduction



**Millie Hawes**, *Head of Just Purpose at Fieldfisher LLP and disability rights activist*



**Paul Roberts**, *NED and Independent Housing Consultant*



**Hattie Llewelyn-Davies**, *Chair Eastlight Community Homes. Founder Member NHS Disabled Directors Network. (DNDN)*

Elyse Hodges, Associate Director at [Adecco](#) and ED&I committee chair, chaired this discussion on “Silence in our sector: Disabled lived experience at board level”. Firstly, Millie Hawes, Head of Just Purpose at Fieldfisher LLP and disability rights activist shared her experiences, focusing on the ‘S’ in ESG as followed by Paul Roberts, independent housing consultant, who emphasised disability within the broader framework of all 3 letters of ESG. Finally, Hattie Llewelyn Davies, Chair at Eastleigh Community Homes and founding

member of the NHS Directors Disability Network, focused on the importance of breaking the silence surrounding disability.

The focus of the session was on breaking the silence surrounding disability, amplifying disabled voices, and moving that into action, with changes to positively affect disabled tenants and employees.

## Millie Hawes

Millie, whose role at Field Fisher focuses on embedding ESG strategies and disability inclusion within ED&I strategies, shared her recent experience of the difficulties in finding affordable housing as a disabled person.

Disabled people are the biggest minority group in the UK – there are 14.6m disabled people in the UK and 21% of working adults are disabled. However, often disability conversations focus on the over 55' and finding housing for people with access needs is disproportionately geared towards those over 55.

Accessible housing is not just a home to live in independently. It's about the impact on wider society such as the opportunities for a career (being able to find accommodation near to your workplace) and mental wellbeing. **For example, only 5% of homes can be visited by wheelchair users, which reduces the ability to socialise with friends and family.**

Often organisations don't see the value in developing a disability-inclusive approach in terms of customer service delivery.

However, the '[Purple Pound](#)' is the value attributed to what disability brings to society, which is **£274bn a year**, demonstrating that disability inclusion is not just a cost, it's the money organisations get in return for being more inclusive.

Studies highlighted that only 9% of housing stock has very basic access for people with disabilities. 1/5 deemed houses were deemed indecent and 4/5 wheelchair users are in unsuitable accommodation i.e. they cannot access all rooms of the house. On paper, 100% of new builds were to be designed for disabled standards but only 79% are. 60% of councils outside London have no standards or work to outdated ones. It had no media spotlight or attention.

People don't always understand what a disability means: historically, we relied on the medical model of disability i.e. a medical diagnosis seen as a problem to be cured. Over the last 30-40 years we've moved towards the social model of disability: defined

through societal barriers instead – i.e. the disabling feature may be a lack of a ramp (an issue society has caused) as opposed to the fact an individual cannot walk.

Millie had suspected that shared ownership in a Housing Association would be beneficial given that a high proportion of Housing Associations house tenants with disabilities or families that have disabilities. However, barriers Millie has faced included:

- Customer service issues – incorrect information used in advertisements. Properties were advertised as wheelchair adaptable (M43) but in reality, these access features have been ‘value engineered’ out i.e. upon completion they were no longer wheelchair adaptable but are still called that due to ticking the boxes earlier on.
- Availability - some properties are sold to people who don't have those access needs and no effort is made by Housing Associations to emphasise these properties are M43.

Following questions, Millie explained that trends in barriers for disabled people highlight a misunderstanding of disability funding grants, which are heavily means tested. Additionally, different pockets of the sector each shift the blame to another area as opposed to working together. Looking to centralise the voices of people with a lived experience of a disability could involve creating co-creation panels with advisory groups of disabled people who help with the design and planning. **The key is to talk to disabled individuals from the start and ensure to remunerate them for their contributions as opposed to seeking it for free.**

## Paul Roberts

Paul Roberts explained that disability often does not get the same level of mention as other aspects of ED&I. There is much silence on this but that doesn't serve the sector well. It's seen as a non-mainstream function of the sector and there are often not many conversations about it.

Paul and Millie linked up at a conference in July in Manchester and met with the University of Stirling to discuss what could be done to share best practices and facilitate change in the sector. A round-table took place in December on 'discrimination by design' – i.e. the discrimination may be unconscious, but it's causing difficulties, and it was discussed what could be done differently to understand what engagement and involvement could be done. A paper will be put out on the back of that.

**Housing providers should be doing everything to consider disability from design and build through to repairs and maintenance service. Governance should focus on co-creation and what is being done to include ED&I into strategy more effectively – that all comes back to knowing customers better.**

Examples of good practice include considering not just where those pockets of vulnerable people are but how they get their voices amplified more effectively and how they get brought into the context of the discussion.

## Hattie Llewlyn Davies

Hattie was born with a range of auto-immune issues – a non-visible disability (2/3 of disabilities are invisible). When you have a non-visible disability, you have to ‘come out’ about it, time after time. It’s not a once-only statement but affects every day of your life. 80% of people develop their disability within their working life – disability is flexible for each individual and their needs for adjustments depend on their health and other matters.

**22% of the NHS workforce have a disability but only 3% of people declare that in their personnel record.** People have a fear of being seen as less able to do things and the discrimination facing them. At the director level at the NHS only 3% have disability – only 17 trusts have 1 disabled director. The NHS Disabled Directors Networks aims to increase representation at every level in the NHS with; training, mentoring, support, good practice tool-kits and recruitment advisers, and a campaigning document – raising awareness every day and every way but have more to do.

Eastlight Community Homes was created from a merger 3 years ago. When looking at the EDI strategy, they chose to practice disability inclusion as it impacts most tenants and staff, most of the time. 77% of Eastlight households have a member with a disability. By prioritising disability, it’s involved a shift to a representative board, a new community structure, making all committees virtual for better access, and stopping the use of charts and the use screen reads and voice recognition. There are 4 residential days a year to look at strategy and need to have carers there.

The customer involvement committee was set up as a driving force for change, including a year-long program speaking with tenants about what would make the most difference to them on their disability. Stock is never easy to make accessible – adaptations, heating, visual doorbells, fencing gardens etc – it’s a person-by-person basis which is never ideal but a better solution is needed, and breaking the silence is the main way. 77% of households can’t be ignored and with housing being the biggest determination of health outcomes, we need to do things very differently.

Hattie emphasised that having a disability means you have to be constantly thick-skinned and say what you will and won’t put up with. To make organisations more welcoming, **we must break the silence and raise awareness every day and in every day.**

## Discussion

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- Any EDI focused session is not as well-attended as other topics in housing so we need to be louder and get more people in these rooms.
- In terms of attracting and encouraging disabled people to join the network, there is no clear pool of people but think about recruitment strategy on better representation. Go back to the basic techniques, reach out to those people and make the process accessible. Just a guaranteed interview does not cover it.
- The board room is where people can make a difference. Committee structures where we hear people's voices and let that influence what happens are crucial. Executive colleagues need to be encouraged to think about how change is brought through and consider the gap in underrepresentation.
- Think which recruitment companies you work with to pursue diverse shortlists from get-go. [Evenbreak](#) is a recruitment organisation for disabled people looking for work or organisation advertising roles and making it inclusive.
- A tenant board member uses a wheelchair and lives in an affordable property and could not attend a stock tour due to being unable to go up 3 flights of stairs. We need to genuinely think about if its accessible each time. It's more than just wheelchair ramps. The organisation commissioned and received a report from Dr Catherine Dean at the University of East Anglia on the access needs of tenants and how the provider was failing to meet them – you have to expose the organisation to direct lights being shone on them before you can make things easier.
- If you're in employment, you get no financial support for housing – it shifts ownership onto local authorities to find housing but someone in full-time employment shouldn't have to rely on local authority.
- Tenants have had issues obtaining accessibility in housing from their landlord in relation to the need for a fire alarm that could be utilised as a deaf person and explained that more needed to be done to understand it as the battle to ensure that he did not incur the costs or damage associated with this had been an uphill battle.

## Other links

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[Accessible homes can help drive health equity and national growth](#)

[The Housing Diversity Network](#)

[Scope: Disability Price Tag 2023: the extra cost of disability](#)

## Join us for the next session:

### Competence and Conduct, the new standard for social housing – what board members need to know

The future of social housing in the UK will depend on well-trained and knowledgeable people with the right qualifications, who demonstrate the right behaviours. In this session, Katherine Sinclair will share with board members her insights on the much-anticipated Competence and Conduct Standard (CCS), which was published for consultation by the Department for Levelling Up, Housing and Communities on 6th February 2024. As board members, having an understanding of what is required under the CCS and how professional qualifications could potentially be funded is imperative in the drive to increase and improve tenant customer service and housing management standards. Katherine will outline what non-executive board members need to know about the new CCS in order to empower them to support it and hold executive leaders to account for the setting of and maintaining benchmarks for behaviours.

**Speakers:** Katherine Sinclair, *Legal Director in the Employment and Pensions Team at Anthony Collins LLP*

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