

Citizen Participation and Public Petitions Committee
Wednesday 17 April 2024
6th Meeting, 2024 (Session 6)

PE1956: Increase the provision of wheelchair accessible homes

Introduction

Petitioner Louise McGee

Petition summary Calling on the Scottish Parliament to urge the Scottish Government to review the existing Wheelchair Accessible Housing Target guidance, and to explore options for increasing the availability of wheelchair accessible housing in Scotland.

Webpage <https://petitions.parliament.scot/petitions/PE1956>

1. [The Committee last considered this petition at its meeting on 28 June 2023](#). At that meeting, the Committee agreed to write to the Scottish Government, and to organisations involved in the Dying in the Margins Exhibition.
2. The petition summary is included in **Annexe A** and the Official Report of the Committee's last consideration of this petition is at **Annexe B**.
3. The Committee has received new written submissions from the Scottish Government, Dying in the Margins and the charity, Marie Curie, which are set out in **Annexe C** of this paper.
4. [Written submissions received prior to the Committee's last consideration can be found on the petition's webpage.](#)
5. [Further background information about this petition can be found in the SPICe briefing](#) for this petition.
6. [The Scottish Government gave its initial position on this petition on 6 September 2022.](#)
7. Every petition collects signatures while it remains under consideration. At the time of writing, 19 signatures have been received on this petition.

Action

8. The Committee is invited to consider what action it wishes to take.

Clerks to the Committee
April 2024

Annexe A: Summary of petition

PE1956: Increase the provision of wheelchair accessible homes

Petitioner

Louise McGee

Date lodged

31 August 2022

Petition summary

Calling on the Scottish Parliament to urge the Scottish Government to review the existing Wheelchair Accessible Housing Target guidance, and to explore options for increasing the availability of wheelchair accessible housing in Scotland.

Previous action

I have tried raising this issue with my MP and MSPs.

Background information

I have been trying to get moved for around 5/6 years due to a neighbour dispute. Midlothian Council say that there aren't enough wheelchair accessible homes to be able to offer me another, more suitable, house.

Annexe B: Extract from Official Report of last consideration of PE1956 on 28 June 2023

The Convener: PE1956, which was lodged by Louise McGee, is on increasing the provision of wheelchair accessible homes. It calls on the Scottish Parliament to urge the Scottish Government to review the existing wheelchair accessible housing target guidance and to explore options for increasing the availability of wheelchair accessible housing in Scotland.

The petition was last considered at our meeting on 23 November 2022, when we agreed to write to the Scottish Government, COSLA and the Scottish Federation of Housing Associations, from which we have now received responses. However, as members will have noted, COSLA asked the Association of Local Authority Chief Housing Officers—it has a marvellous acronym, but we will just stick with that—to provide a response on its behalf.

In its response, the Scottish Government confirmed that it is currently undertaking a review of the adaptations system, which it expects to have completed by the spring of 2024.

The Scottish Federation of Housing Associations noted that the most recent Government statistic for the total number of wheelchair accessible homes developed for social rent was 0.3 per cent for the year 2020-21. The SFHA highlighted that progress on a review of adaptations, new building standards and plans for a new accessible homes standard has been slow.

The Association of Local Authority Chief Housing Officers agreed with the petitioner that the Scottish Government should review the existing wheelchair accessible housing target guidance. It provided information on the wheelchair accessible homes targets that have been set by various local authorities, and went on to say that there is currently no definition of a wheelchair accessible home, which it said is a measure that is needed in Scotland.

In the light of the representations that we sought and have now received, do members have any comments or suggestions?

Alexander Stewart: There is a lot more work to be done. It is quite evident that the numbers are stark for the accessible and adapted properties that are out there in the market for people who use wheelchairs or have mobility issues.

We should write to the Scottish Government, highlighting the stakeholder submissions that we have received and urging it to review the existing wheelchair accessible housing target guidance. It is important to ask whether it can consider national planning obligations on house builders and private developers for a minimum number of wheelchair accessible homes and whether it accepts the case for a national definition of a wheelchair accessible home. We can ask questions on and look into those areas to attempt to unravel the issue.

There is obviously a massive gap in the market and those people are not being catered for as they perhaps should be by housing developers and organisations that look after housing processes.

Paul Sweeney: There are some major structural issues here. Most notably, in Glasgow, there is no common housing register across all the registered social landlords in the city, so having visibility of adapted housing is challenging and often involves making numerous duplicate applications to various housing associations. That has been a massive public policy failing since the stock transfer in Glasgow, and it has never been addressed in 20-odd years. That is one aggravating factor.

I would also highlight recent engagement that I have had with hospices in Scotland. There was a pretty harrowing exhibition at the University of Glasgow recently, which was called “Dying at the Margins” and which I think is due to come to the Parliament later this year. It presented case studies of people who could have lived out their final days at home but who, because of accessibility issues and lack of willingness of housing associations, councils and housing providers to make adaptations to housing, ended up in hospitals or hospices—often inappropriate settings where they did not want to spend their final days. That was pretty shocking. Often a pretty mercenary calculation was made that, if someone was going to be alive for only another few months, there was no point in paying the money to make adaptations.

There is an aspect of how palliative care is managed in the home, and the hospital at home concept, that merits consideration. The issue causes huge costs to the NHS as a result of delayed discharge. People who are terminally ill are in acute hospital wards, which are a highly medicalised environment and probably not appropriate for them. There are all sorts of aspects that introduce great costs that are not being dealt with. There is a bit of system failure in relation to ensuring that adaptations are efficiently and cheerfully carried out where needed.

The Convener: That is a very good point. I certainly have direct experience of constituents who were diagnosed as being at the end of life and had hoped to stay at home, but were given a date for adaptations that was, by some time, after the expected end of what life they had been given to understand lay ahead of them. That was doubly cruel. They were told, “Yes, it could be done, but not until you are no longer here.” In many ways, that was cruel and defeated the purpose completely.

Mr Stewart made specific suggestions. This is also an issue of delivery and whether there are underlying calculations and a proper appreciation of the overwhelming need that there is to support somebody at that particular moment, when they need it most. I wonder how we might pursue that further. Does Mr Sweeney have any suggestions?

Paul Sweeney: A number of hospices were involved in the production of that exhibition. It might be useful to solicit their views on what policy changes need to happen. That might open up a pathway to other stakeholders that are engaged in the policy area. Marie Curie would be an obvious first stop for those discussions, because it was certainly an anchor organisation in the production of that exhibition and it has highlighted to me this critical issue in the community.

The Convener: The exhibition was called “Dying in the Margins”.

CPPP/S6/24/6/7

Paul Sweeney: Yes. It was at the University of Glasgow, and I believe that it is due to be displayed at the Parliament.

The Convener: It would be helpful if we could track down the groups that were involved in that.

Are we agreed?

Members *indicated agreement.*

Annexe C: Written submissions

Scottish Government submission of 7 August 2023

PE1956/E: Increase the provision of wheelchair accessible homes

I refer to your correspondence of 4 July seeking the Scottish Government's view on the following areas:-

- whether the Scottish Government will review its wheelchair accessible housing target guidance
- whether it will also consider national planning obligations on house builders and private developers for a minimum proportion of wheelchair accessible homes, and
- whether it accepts the case for a national definition of wheelchair accessible home.

Reviewing the Wheelchair Accessible Housing Target Guidance

We are continuing to engage with local authorities through Scotland Housing Network's Local Housing Strategy Group on the implementation of wheelchair accessible housing targets. Good progress has been made by local authorities in not only setting wheelchair accessible housing targets but in delivering more wheelchair accessible homes. There are therefore no plans to review the guidance at this time. Information on the number of wheelchair accessible affordable homes delivered through the Affordable Housing Supply Programme is published in the Affordable Housing Supply Programme Out-turn report. The 2020-21 Out-turn report stated that 716 accessible homes were delivered for older people and disabled people, with 198 of these being wheelchair accessible homes. The 2021-22 Out-turn report demonstrates strong progress being made with 1,315 accessible homes being delivered for older people and disabled people, with 359 of these being wheelchair accessible homes.

National Planning Obligations

The fourth National Planning Framework (NPF4) was adopted and published by Scottish Ministers in February 2023 following comprehensive public engagement and Parliamentary scrutiny. For the first time, it is part of the 'development plan' alongside Local Development Plans (LDPs), so influences planning decisions across Scotland.

Policy 16, Quality Homes, supports proposals for new homes that improve affordability and choice by being adaptable to changing and diverse needs, and which address identified gaps in provision. It identifies that this could include, accessible, adaptable and wheelchair accessible homes, and homes for older people, including supported accommodation, care homes and sheltered housing.

NPF4 outlines the importance of the close alignment of planning and housing delivery at the local level, through LDPs and Local Housing Strategies. This will support the development of homes that meet the needs of people living in Scotland, in particular older people and disabled people, and help to deliver the right type and mix of homes in the right locations.

Guidance on Ministers expectations for preparing new style LDPs was published in May 2023. It notes that it is a statutory requirement to have regard to an LHS when preparing an LDP and that LDPs should aim to diversify the range and type of homes that are built to meet people's needs and provide more choice for all. It refers that LDPs should address identified gaps in housing provision, informed by the Evidence Report and the LHS, and that this can be as part of wider proposals or through allocation of sites for specific housing types.

National Definition for Wheelchair Accessible Housing

The wheelchair accessible housing target guidance states that the provision of targets to support the delivery of wheelchair accessible homes across all tenures means that homes should be suitable for wheelchair users to live in. The guidance also states that these homes should – as a minimum – comply with the design criteria indicated as a 'basic' requirement for wheelchair users, as outlined in the Housing for Varying Needs design guide. The design criteria indicated as 'desirable' are also strongly encouraged wherever possible. Where a local authority seeks to apply a higher standard than that specified within Housing for Varying Needs for wheelchair users, it would be expected to make clear its approach and to provide specific guidance on any additional aspects required. Any approach would also be expected to demonstrate value for money and deliverability.

In June, the Scottish Government published a [consultation](#) on proposed changes to Part 1 of the [Housing for Varying Needs](#) design guide. The consultation also introduces the principles which we consider underpin the all-tenure Scottish Accessible Homes Standard – as well as setting out our proposals for updates to building standards and guidance which will apply to all new build homes and homes delivered through the conversion of non-residential buildings into housing.

While the Scottish Accessible Homes Standard will further improve the accessibility, adaptability and usability of new homes for a wide range of users, including wheelchair users, the consultation paper highlights that the update to Part 1 of the Housing for Varying Needs design guide will continue to provide design criteria for housing designed specifically for wheelchair users. Although these criteria will not be directly transposed into building standards, the Building Standards Technical Handbooks will signpost use of these design criteria where a home is being designed specifically for wheelchair users. Where such dwellings are to be included within a residential building, it will also be expected that all common areas are

designed to meet the relevant 'as standard' requirements set out within the updated Housing for Varying Needs design guide.

The Scottish Government has provided additional information below in relation to the written submissions from both the Association for Local Authority Chief Housing Officers and the Scottish Federation of Housing Associations.

It is the responsibility of local authorities through their Development Plans and Local Housing Strategy to determine the appropriate housing required in their area, based on the findings of their Housing Need and Demand Assessment (HNDA). The HNDA evidence base informs a Local Housing Strategy (LHS) that set out the local authority's priorities and plans for the delivery of housing and housing related services. A local authority should consider the number, location, type, size and tenure of housing required to address the need in their communities. Where an LHS identifies a strategic requirement for a particular type of home, including wheelchair accessible housing, projects to support delivery of these homes are expected to be included in the local authority's Strategic Housing Investment Plan for delivery through the Affordable Housing Supply Programme.

Scotland has led the UK in providing affordable housing, with recently published quarterly statistics showing that since April 2007, we have delivered 122,201 affordable homes, over 86,000 of which were for social rent, including 22,370 council homes.

We remain committed to delivering our target of 110,000 affordable homes by 2032, of which at least 70% will be available for social rent and 10% will be in our remote, rural and island communities. A total of 11,570 homes have now been delivered towards the 110,000 affordable homes target, of which 9,121 (79%) are homes for social rent and of these 3,595 (39%) are council rent. In 2022-23 we delivered the highest number of affordable homes since records began in 2000. And we are making £3.5 billion available in this Parliamentary term towards the delivery of more affordable and social homes.

We are aware of the global issues affecting construction which are impacting the pace of housing delivery and are working closely with the construction industry and housing partners to mitigate this where possible.

Through our Affordable Housing Supply Programme, we have flexible grant funding arrangements which ensure that specialist housing provision, which is identified by local authorities as a priority, can be supported. Therefore, when applying for grant assistance at tender stage to deliver affordable homes for wheelchair users, local authorities should be requesting the minimum level of grant required for a project to be financially viable for their organisation whilst ensuring rent affordability.

We are taking forward a review of the current housing adaptations system and will make recommendations on how best to improve and streamline the system. The Scottish Government also published updated practical guidance on the delivery of adaptations and equipment services in January of this year. This guidance will contribute to the housing adaptations review. We anticipate that the review will be concluded later this year, with any changes that Ministers agree being implemented thereafter.

With respect to the Dying in the Margins project policy briefing, Scottish Government officials have discussed with Marie Curie and we will consider the housing related recommendations contained within the policy briefing.

Dying in the Margins submission of 9 August 2023

PE1956/F: Increase the provision of wheelchair accessible homes

The evidence below is from the University of Glasgow research study: [Dying in the Margins: Uncovering the Reasons for Unequal Access to Home Dying for the Socio-Economically Deprived](#), conducted in collaboration with Marie Curie and funded by the Economic and Social Research Council and UK Research and Innovation (grant no. ES/S014373/1). This was a qualitative, participatory and longitudinal study which involved in-depth research following a small number of people who were at the end of life over a long period of time, as well as interviewing bereaved relatives and health and social care professionals.

1. High Rise Flats

“You see about the stairs, right, the stairs are a big, big problem.”

Findings from our study show that for those approaching the end of life who live above ground level, there can be issues accessing outside space in the final months of life, resulting in not only physical but also social isolation and a sense of feeling “trapped”. It was challenging for these study participants to get any fresh air.

For some of our study participants, the lift in their block was unreliable and had been known to break down. This resulted in difficulties getting in and out of the flat, for example, to attend medical appointments:

“I almost missed my appointment yesterday as my lifts aren’t working again. The Uber left us and charged us for not coming. I’m trying to move house. I’ve had enough. This house isn’t suitable for me anymore.”

In one case, the individual lived on the 14th floor of her tower block in Dundee, but the lift stopped at the 13th floor. Her daughter is in no doubt that the inaccessibility of her flat meant she could not die at home as she wished. Living high up in a high-rise block also presented issues with installing medical equipment for some of our

participants e.g. a bed fitted with hydraulics, breathing apparatus. This situation could be compounded by a lack of space to accommodate both equipment and carers within flats themselves.

2. Inadequate Number of Plug Sockets

We conducted interviews with nurses providing care to people experiencing financial hardship at the end of life ([Quinn et al. 2022](#)). Several nurses raised the problem of being able to power electrical equipment. Some patients had an insufficient number of plug sockets to power the amount of equipment they needed to help support them to stay at home.

3. Moving too Late in Life

Some of our participants lived in newly built socially rented accommodation which had access to outside space and was wheelchair accessible. However, there were issues around: 1) new housing estates lacking local amenities and 2) people being moved into accessible accommodation either too late or outside/away from their community and their established networks of support. As one participant who had mobility issues and was nearing the end of her life commented:

“I feel like a prisoner in my own home. I really feel like that. Nobody to go and see, I just need to sit here, basically.”

Our findings show that there can be an issue of dislocation if someone is moved outside of their area very close to the end of life, as happened to the above participant. Participants who had no choice but to move to a hospice in the final weeks of life (due to housing issues) could also experience dislocation, because the hospice was usually not in their local area, and friends and relatives struggled to undertake, or afford to undertake, the long journey to visit them. This dislocation can leave people socially isolated as they are dying and in an unfamiliar setting.

This signals the importance of both planning and foresight, given a population which is ageing and where the number of people dying is also rising dramatically. It should also be pointed out that the incidence of chronic multi-morbidity (and therefore mobility issues faced as a result) is higher in more deprived areas, so taking an equity-informed approach would mean prioritising such areas for the development of new housing, or retrofitting existing housing, which is suitable for the ageing-dying continuum.

Timely Adaptations

Findings from our study show that people can experience significant barriers and delays when it comes to necessary adaptations. Examples from the study include accessible baths or showers not being fitted in a timely way, or at all, prior to someone's death.

There was also evidence from professionals we interviewed that nurses were reluctant to reveal to occupational therapy if their patient had a signed DS1500 (now BASRiS) form. This was because they felt that this would *deprioritize* them for adaptations such as stairlifts and wet rooms due to cost considerations. The 'Assessment Guidelines' for occupational therapists state that "OTs must think about the cost of an option so they can help as many people as possible with limited funding." If a person is nearing the end of their life, they may not use the adaptation for very long and this may be considered 'limited usage' and factored into a cost-benefit analysis. We also heard from professionals about concerns about the timeliness of adaptations when people's time is limited, and when patients' homes are not big enough to be adapted for wheelchair usage.

Some of our participants spent considerable time in the last months of their life lobbying their social housing provider to make the necessary adaptations, not always with success. There is no doubt that this caused them distress, and consumed limited time left. This is time that could have been better spent on existential questions or on relational and legacy work known to improve people's experiences of dying.

4. Disabling Urban Environment

While the focus of this consultation is on accessible homes, outside public spaces also need to be wheelchair and mobility scooter accessible so that people who are nearing the end of their lives can continue to participate in society for as long as their illness allows. One of our participants could access the street from her house, but once on the street struggled to use her wheelchair on the poorly maintained pavement:

"The pavement's sort of smashed to smithereens. I've got to go on the road."

Once again, this is an equity issue as those people who are dying at home in more deprived neighbourhoods are more likely to become physically and socially isolated further in advance of death than those living in less deprived areas where the local environment is better maintained and has better wheelchair access.

Key Policy Recommendations

- 1. Scottish Government should take an equity-informed approach to its new Housing Standard and Scottish Accessible Homes Standard to reflect the needs of terminally ill people living with multi-morbidities for both existing and new homes. This should include a single definition of 'accessible homes' which is co-produced with people with lived experience of dying, death and bereavement, Local Authorities and Housing Providers.**
- 2. Scottish Government should provide ringfenced funding for social housing and local government to support building more accessible homes.**

3. Local authorities should use the BASRiS form to fast-track housing maintenance, adaptations and moving requests for terminally ill people, their families and carers.

Marie Curie submission of 11 September 2023

PE1956/G: Increase the provision of wheelchair accessible homes

Key issues

- Home environment plays a crucial part in enabling terminally ill people to be cared for at home, and to die there if that is their wish.
- Existing housing stock is often unsuitable for supporting terminally ill people's needs at home, and they experience significant barriers, delays and costs for housing maintenance and adaptations which they cannot afford. This is particularly acute for people living with multi-morbidities whose needs vary and are often complex, as well as for their families and carers.
- By 2040, up to 10,000 more people will be dying with palliative care needs, and two thirds of all deaths will take place in community settings; in people's own homes, care homes and hospices.

What needs to happen?

1. Scottish Government to take an equity-informed approach to its new Housing Standard and Scottish Accessible Homes Standard to reflect the needs of terminally people living with multi-morbidities for both existing and new home, with a single definition of 'accessible homes', co-produced with people with lived experience of dying, death and bereavement, Local Authorities and Housing Providers.
2. Scottish Government to provide ringfenced funding for social housing and local government to support building more accessible homes.
3. Health Boards must improve data capture to include terminally ill people using medical equipment to better inform place-based approaches to community support needs.
4. Local authorities to use BASRiS forms to fast-track housing maintenance, adaptations, and moving requests for terminally ill people, their families and carers.
5. Scottish Government to provide greater financial support for people affected by dying, death and bereavement, to support increased costs brought on by terminal illness.

The cost of dying

A UK Research and Innovation (UKRI) funded study called Dying in the Margins, undertaken by University of Glasgow and Marie Curie, examines barriers to, and

experiences of, dying at home for terminally ill people, their families and carers living with financial hardship and deprivation through photography and digital storytelling.

Key findings to date relevant to the committee are around existing housing stock often being unsuitable for supporting terminally ill people's needs at home, and they experience significant barriers, delays and costs for housing maintenance and adaptations which they cannot afford.

This is particularly acute for people living with multi-morbidities whose needs vary and are often complex, as well as for their families and carers.

This is Linda's story, told by her daughter Nicola from the Dying in the Margins study:

My mum lived on the fourteenth floor of a tower block. The lift only went to the thirteenth floor. Moving back home with all the equipment she would have needed would have been practically impossible. The space would have been too small for me, my mum and three children and we couldn't afford childcare to allow me to focus on caring for her.

In the end, she was transferred to a hospice ten days before she died. The hospice was brilliant, and I'm so glad she didn't die in hospital, but I know she would have wanted to be at home. I just couldn't do that for her with what we were offered.

This highlights the unsuitability of current housing stock for terminally ill people and its impact on multiple aspects of end of life experience. As a result of this, Linda did not have the death she wanted- to die at home.

Fast and suitable adaptations:

While building more accessible homes would be welcome and is necessary, the first preference of many terminally ill people living in unsuitable accommodation is that their current home is adapted to suit their needs to enable them to die there if that is their wish.

Marie Curie Nurses and Healthcare Assistants across Scotland reported to our internal 2021 survey that they regularly visited terminally ill people who use a wheelchair, but living in homes with doors too small for them to fit through. Every effort must be made to ensure people can stay in their own homes, with adaptations, at the end of life if that is their wish:

"A man who is an amputee was told by an OT that he would be unable to get adaptations to his home in the first instance so should be putting his name onto the housing list for sheltered accommodation. Whilst this was happening he had then gone back into hospital."

Marie Curie Healthcare Assistant, Fife.

Long waiting periods for adaptations are also common for people living with terminal illness. This has been exposed by MND Scotland in their “No Time to Lose” report which found people with an MND diagnosis waiting over a year for the installation of ramps and wet rooms. Motor Neurone Disease, and other terminal conditions, can be unpredictable and mean patients can deteriorate rapidly.

Local Authorities must work more proactively by adding terminally ill people to waiting lists for accessible homes as soon as they receive their diagnosis.

We believe they can do this by identifying people who have a terminal illness through use of BASRiS forms. These forms replaced DS1500 forms in Scotland and are used to allow people to be fast-tracked when applying for specific social security benefits, including Adult Disability Payment.

Some local authorities already use BASRiS forms to fast-track adaptation requests from terminally ill people and this should be the standard process across Scotland.

Cost is another factor preventing people from having the necessary adaptations in place. Marie Curie and Loughborough University research has found that over 8,200 people die in poverty at the end of life every year in Scotland.

This equates to one in four working age people, and one in eight pensioners.

The double burden of income loss and increased costs brought on by terminal illness, including home adaptations and higher energy bills, mean people are being forced below the poverty line. A 2023 Marie Curie study has estimated that working age people in the UK can face a 75% rise in their energy bills after a terminal diagnosis and having to give up their job at the same time.

This also applies to carers, and can have a cumulative effect that means even subsidised adaptations through Local Authorities’ scheme of assistance, designed to provide grants to help with excess costs, are too costly at the end of life.