

Proposed Disability Commissioner (Scotland) Bill

Introduction

A proposal for a Bill to establish a Disability Commissioner for Scotland

The consultation runs from 12 May 2022 to 3 August 2022

All those wishing to respond to the consultation are strongly encouraged to enter their responses electronically through this survey. This makes collation of responses much simpler and quicker. However, the option also exists of sending in a separate response (in hard copy or by other electronic means such as e-mail), and details of how to do so are included in the member's consultation document.

Questions marked with an asterisk (*) require an answer.

All responses must include a name and contact details. Names will only be published if you give us permission, and contact details are never published – but we may use them to contact you if there is a query about your response. If you do not include a name and/or contact details, we may have to disregard your response.

Please note that you must complete the survey in order for your response to be accepted. If you don't wish to complete the survey in a single session, you can choose "Save and Continue later" at any point. Whilst you have the option to skip particular questions, you must continue to the end of the survey and press "Submit" to have your response fully recorded.

Please ensure you have read the consultation document before responding to any of the questions that follow. In particular, you should read the information contained in the document about how your response will be handled. The consultation document is available here:

[Consultation Document](#)

[Privacy Notice](#)

I confirm that I have read and understood the Privacy Notice which explains how my personal data will be used.

On the previous page we asked you if you are UNDER 12 YEARS old, and you responded Yes to this question.

If this is the case, we will have to contact your parent or guardian for consent.

If you are under 12 years of age, please put your contact details into the textbox. This can be your email address or phone number. We will then contact you and your parents to receive consent.

Otherwise please confirm that you are or are not under 12 years old.

No Response

About you

Please choose whether you are responding as an individual or on behalf of an organisation.
Note: If you choose "individual" and consent to have the response published, it will appear under your own name. If you choose "on behalf of an organisation" and consent to have the response published, it will be published under the organisation's name.

on behalf of an organisation

Which of the following best describes you? (If you are a professional or academic, but not in a subject relevant to the consultation, please choose "Member of the public".)

No Response

Please select the category which best describes your organisation

Third sector (charitable, campaigning, social enterprise, voluntary, non-profit)

Optional: You may wish to explain briefly what the organisation does, its experience and expertise in the subject-matter of the consultation, and how the view expressed in the response was arrived at (e.g. whether it is the view of particular office-holders or has been approved by the membership as a whole).

MND Scotland is the leading Scottish charity providing care and support to people affected by MND, as well as funding research into finding a cure.

We deliver a number of vital services for people affected by Motor Neurone Disease in Scotland, including: Grants, Counselling, Benefits Advice and Advocacy. We also invest millions of pounds into ground-breaking MND research in Scotland and across the UK.

As a member of the International Alliance of ALS/MND Associations we share best practice across the global MND community, learning from other nations and sharing the ways we are innovating here in Scotland.

We campaign and raise awareness to help improve the lives of people affected by MND, and to provide hope for a world without MND.

Please choose one of the following:

I am content for this response to be published and attributed to me or my organisation

Please provide your Full Name or the name of your organisation. (Only give the name of your organisation if you are submitting a response on its behalf).

(Note: the name will not be published if you have asked for the response to be anonymous or "not for publication". Otherwise this is the name that will be published with your response).

MND SCOTLAND

Please provide details of a way in which we can contact you if there are queries regarding your response. Email is preferred but you can also provide a postal address or phone number.

We will not publish these details.

Aim and approach - Note: All answers to the questions in this section may be published (unless your response is "not for publication").

Q1. Which of the following best expresses your view of the proposed Bill? (Please note that this question is compulsory.)

Partially supportive

Please explain the reasons for your response.

We are partially supportive of the proposed Bill. We believe that a Disability Commissioner would be very positive as long as the role has the power to effect real change. Our recent report, No time to lose: Addressing the housing needs of people with MND, highlighted, for example, that while many local authorities have targets for building accessible homes, very few of them meet these targets. Ideally, to have much needed impact, the Disability Commissioner would have the power to hold local and national government to account on such matters.

Q2. Which of the following best expresses your view on whether there is a need for a specific, dedicated commissioner focussing solely on people with a disability?

Fully supportive

Please give the reasons for your response

We agree that there is a need for a dedicated commissioner focusing solely on disability. The numbers of people affected by disability in Scotland warrant this. MND is a rapidly progressing and disabling terminal illness. Average life expectancy is just 18 months from diagnosis. People with MND face continual barriers when trying to access help and support such as social care, adaptations to their homes, equipment such as hospital beds, and much more.

As highlighted in our response to the previous question, MND Scotland recently launched a report highlighting the lack of accessible housing across Scotland and the horrendous waiting times for essential home adaptations endured by people with MND and other disabilities. Our report made a total of 37 recommendations directed at national and local government which highlights the scale of the challenge in just one policy area; housing. We believe that accessible housing and the needs of disabled people in this policy area have been overlooked for far too long. People with MND don't have time to wait.

As stated, this is just one policy area. Scotland's social care system, for example, is widely reported to be in crisis and we have long highlighted how the current care system is failing people with MND. Many wait far too long for the care they have been assessed as needing to be put in place, putting themselves and their loved ones in danger of falls and injury. As with the lack of an accessible home, going without much needed care deprives people with MND of living with the dignity that everyone is entitled too. The National Care Service Bill has just been launched and a Disability Commissioner, with the power to directly influence its development, could prove beneficial to disabled people.

We believe having a dedicated commissioner, focused solely on disability is a hugely important step. There needs to be greater accountability to ensure that people with disabilities have their rights recognised and protected.

Q3. Do you think legislation is required, or are there other ways in which the proposed Bill's aims could be achieved more effectively? Please explain the reasons for your response.

We believe that legislation is required. The role of a Disability Commissioner is too important to be left to policy, which can be subject to frequent change and is generally less transparent.

Scope of the Disability Commissioner Role

Q4. Which of the following best expresses your view of the Disability Commissioner role covering all disabilities; physical, mental, hidden and fluctuating conditions?

Fully supportive

Please give reasons for your response, including how the commissioner could co-ordinate with the work of existing bodies/organisations who support people with these conditions.

We agree it is important that all disabilities are represented by the Commissioner. This is particularly important for people with hidden disabilities as well as for those with profoundly disabling conditions who have complex needs, such as people with MND. Because the scope is so broad, it will be essential that the Commissioner engages with the full range of third sector agencies which support people with this broad range of disabilities. This can be achieved in many ways including regular updates, engagement and communications directly from the Commissioner's office that bodies/organisations can sign up for and ensuring that current third sector membership organisations, for example, the Alliance, also keep their membership up to date.

Q5. Which of the following best expresses your view of the Disability Commissioner having a role in reviewing laws and policies that might impact on disabled people?

Fully supportive

Please explain the reasons for your response.

We believe that reviewing the impact of laws and policies on disabled people would be a very important role for the Disability Commissioner. This is particularly the case in relation to, for example, local authority policies, which are often difficult to find (on websites) and unclear. MND Scotland's recent report 'No time to lose: Addressing the housing needs of people with MND' uncovered huge variation in local authority policy making relating to accessible housing and adaptations. Many of these policies have a very negative impact on the lives of people with this devastating and extremely disabling terminal illness, for example, not allowing a person with MND to join a waiting list for a ramp until the point of need, in the knowledge that this person will deteriorate significantly while sitting on the waiting list for up to 9 months. A Disability Commissioner with responsibility for reviewing laws and policies, working with the third sector, could help ensure greater transparency, consistency and showcase examples of best practice. The Disability Commissioner, however, should also have the power to enforce necessary change.

Q6. Which of the following best expresses your view of the Disability Commissioner promoting best practice and learning from service providers, key stakeholders and third sector?

Fully supportive

Please explain the reasons for your response, including how you envisage this work being undertaken?

We are fully supportive of this approach and believe that, as highlighted above, promoting best practice and learning can be a great way to achieve change. It is essential that the third sector and people with

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disabilities are included in this process as they are often best placed to identify what best practice is out there and what can achieve the best outcomes for disabled people.

Q7. Which of the following best expresses your view of encouraging involvement of disabled people and DPOs (Disabled People's Organisations) in the work of the Disability Commissioner?

Fully supportive

Please explain the reasons for your response. Please discuss how you think this would work in practise – would this be through focus groups, internships, paid roles etc

It is essential that disabled people are enabled to be involved in the work of the Disability Commissioner, particularly those who may not identify themselves as such. There is much good practice from organisations on how to best involve the individuals they represent and an involvement strategy should be devised. Measures which can be taken include ensuring that enough time is given for disabled people to contribute directly and that several methods of contributing are identified and provided to help ensure that they are not excluded from engagement.

It is essential that the work of the Commissioner is guided and informed by all charities and organisations supporting people with the wide range of disabilities included in its remit, alongside broader disabled people's organisations. This will help ensure the inclusion of 'hard to reach' disabled people. In addition, charities like MND Scotland, for example, are best placed to ensure the Commissioner understands how the needs of some disabled people may differ from others. For example, the rapid speed in which MND progresses, its deteriorating nature, and that it is terminal means services need to be put in place for those with the condition very quickly.

Q8. Who should the Disability Commissioner be allowed to investigate?

Scottish Public Bodies

Please explain the reasons for your response

This would be a good starting point for the Disability Commissioner to investigate Scottish Public Bodies. If necessary, the commissioner's role could be widened to others, for example, service providers.

Financial Implications

Q9. Any new law can have a financial impact which would affect individuals, businesses, the public sector, or others. What financial impact do you think this proposal could have if it became law?

No Response

Equalities

Q10. Any new law can have an impact on different individuals in society, for example as a result of their age, disability, gender re-assignment, marriage and civil partnership status, pregnancy and maternity, race, religion or belief, sex or sexual orientation.

What impact could this proposal have on particular people if it became law? If you do not have a view skip to next question.

Please explain the reasons for your answer and if there are any ways you think the proposal could avoid negative impacts on particular people.

We believe that a new law, putting in place a Disability Commissioner, could greatly benefit disabled people for the reasons outlined in earlier responses. We cannot foresee any negative impact on other groups of people protected by equalities legislation.

Sustainability

Q11. Any new law can impact on work to protect and enhance the environment, achieve a sustainable economy, and create a strong, healthy, and just society for future generations.

Do you think the proposal could impact in any of these areas? (If you do not have a view then skip to next question)

Please explain the reasons for your answer, including what you think the impact of the proposal could be, and if there are any ways you think the proposal could avoid negative impacts?

We believe that a new law, putting in place a Disability Commissioner, has the potential to achieve a more just society for future generations. If disabled people are enabled to live as full lives as Scotland's able bodied population, the positive outcomes for all would be enormous. For people with MND, to be able to live their precious final months as fully as possible is not only hugely beneficial for them, but for the loved ones they will leave behind too.

General

Q12. Do you have any other additional comments or suggestions on the proposed Bill (which have not already been covered in any of your responses to earlier questions)?

The Disability Commissioner role is being modelled closely around that of the Children's Commissioner. It would be interesting to know if there has been any research carried out on the effectiveness of the Children's Commissioner and if any valuable lessons from that could be incorporated into the development of a Disability Commissioner.