

# 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).**

The Neurological Alliance of Scotland is an umbrella body of organisations that represent people with a neurological condition and those who support them. We work to improve the care and support that people receive. We have consulted with our members for their views and where there are differences of opinion we flag this up in the question response.

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).

The Neurological Alliance of 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.**

As an Alliance, we are supportive of the principles behind the bill. However, our member charities vary in the level of support they have for these proposals. Anything that strengthens the rights of disabled people is welcome.

We note the proposals are for the Disability Commissioner role to mirror that of the Children and Young People's Commissioner in practice and scope. We understand that currently the role is fairly vague in terms of what the commissioner will do and how it does it and this will be formed from this consultation and the debates that follow. Many of our member charities were concerned that many key issues and questions remained unresolved, which made it hard to reach a view.

We have questions about what this proposal means for the proposal to create an Independent Commissioner to protect and uphold the rights of autistic people and people with a learning disability and their families. It will be important to make sure that there is clarity about the extent to which a Disability Commissioner could meet the needs of this community within its remit.

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**

The disparity in living standards and life opportunities between disabled people and those without disabilities is too big, and something must be done to close that gap. We agree that the needs of disabled people have not always been considered in public policy making. People living with neurological conditions and unpaid carers consistently tell us that their needs are not being met.

We are aware that there is potential for overlap with some existing bodies. However, where there is overlap in the work done by the Commissioner with other bodies, we would want to see co-operation and collaboration to enable truly joint working.

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 think legislation is required. The advantage of a Disability Commissioner would be in having a champion for disabled people, backed by a transparent and accountable process that can act on areas of devolved competence, with statutory powers of investigation.

## 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?

Partially 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.**

There are different opinions amongst our members, with some fully supportive of the role covering all disabilities and others having concerns that this makes things too broad, which risks the Commissioner missing the nuances between and amongst different disabilities.

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

We are pleased that neurological conditions including epilepsy, muscular dystrophy, MND and ME are specifically referenced in the background information. However, there are varying levels of disability between different neurological conditions, and also the same condition can affect different people in different ways. Furthermore, some people with neurological conditions may identify more as being unwell than having a disability. Some people with impairments may not identify themselves as disabled. With such a wide remit, it is important that the Disability Commissioner considers the needs of people in all of these overlapping groups.

The commissioner would need to fully understand the range of disabled people's experiences, as well as the nuances between different health conditions - including neurological conditions, which are very complex.

It is also important to recognise that physical health and mental health conditions frequently overlap. Some neurological conditions including Parkinson's and Huntington's include mental health symptoms as part of the condition, while others often cause mental health problems as a result of the stresses and poor quality of life that arise out of living with that condition. We have concerns that the wide range of disabilities covered means the commissioner may not have the expertise to understand how a neurological condition causes different disabilities.

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.**

The commissioner should observe and analyse common themes that cause problems for people with disabilities and part of their role should be to challenge and change outdated laws and policies and tackle laws and policies which have unintended negative consequences for people with disabilities. However, the commissioner role should go further than just reporting on the issues and they should have the legal support and power to act independently in order to act and make tangible improvements.

We recognise that the Scottish Parliament can only legislate in areas of devolved responsibility and recognise that the focus of the Commissioners work should be on areas that are devolved to the Scottish Parliament. However, our members felt that this should not prevent the Commissioner from speaking out when reserved or partially reserved matters such as social security have a bearing on the rights and welfare of disabled people living in Scotland. The Children and Young Person's Commissioner does this, and we believe that it is a welcome part of the role

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?

Partially supportive

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

We would like to know how and to what extent the disability commissioner can promote best practice and learning from others – would it be limited to their annual report to Parliament and perhaps digital comms via a website? Or would promotion of best practice be a more time and resource consuming activity, for instance involving road shows and events?

We wouldn't want so much resource to go into analysing best practice (and worst practice) and the reporting of it to be at the cost of doing something about it. The commissioner needs to be able to hold people to account.

We would also like to know how will it work where there is a conflict of best practice. One example might be recent guidance on the use of Graded Exercise Therapy (GET) in the treatment of ME/CFS. Members questioned whether the disability commissioner would be able to address such conflicts and say how they should be resolved?

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**

However, although there are many active DPOs, they do not always have involvement from people whose impairments arise from long term health conditions. The Neurological Alliance of Scotland has a wide range of organisations within its membership. Some of these are led by people with lived experience of their conditions, while others are health charities that work with disabled people but do not meet the criteria of a DPO. We believe that the Commissioner should also work with health charities to make sure that people with a wide range of conditions and impairments are included and involved in their work.

While organisations or individuals representing all groups of disabilities and caution must be involved, our members were keenly aware that involvement and co-production requires a lot of resource. In light of the very broad remit of the commissioner role, we believe that caution is needed to prevent all of the resources to be committed to managing co-production.

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

Scottish Public Bodies

**Please explain the reasons for your response**

This is a complicated question to answer. All of our members felt that Scottish Public Bodies should be included, but there were different views about whether or not other service providers should be included. There is an unresolved question about the level of investigation that would be needed, how disruptive a formal process of enquiry would be, and who would meet the costs of an investigation.

The lack of a concrete definition of 'service provider' caused concern because this could include a whole host of support - including the provided by individuals not under the auspices of a public body. There was a particular concern that opening investigations to all service providers could put charities off providing lifeline services - especially if they would be subject to costly investigations.

## 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?

a significant increase in costs

**Please explain the reasons for your answer, including who you would expect to feel the financial impact of the proposal, and if there are any ways you think the proposal could be delivered more cost-effectively.**

We imagine that initially there will be a significant increase in costs as the Office of the Disability Commissioner would need to be established and funded and initially there would be increased administration to see how well organisations are performing within the law and within the remit of the commissioner.

Investigations would presumably be funded by the bodies being investigated, rather than from the commissioner's office, although this is unclear from the consultation.

In the longer terms, we would expect to see an indirect reduction in overall costs as services save money by becoming more effective and start to provide the right level support and benefits to all disabled people,

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?

thus diminishing reliance on the NHS and social care services. It may also prevent potential litigation liabilities if matters can be investigated and resolved without individuals taking public bodies to court.

## 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.

It is possible that those in a transitional stage, and/or those with other protected characteristics would get held back due to a process that the Commissioner is involved with. Furthermore, disabled people from deprived socio-economic backgrounds and other marginalised backgrounds including those with protected characteristics may be less likely to engage. Particular efforts may be needed to reach them.

## 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?

Yes, potentially a disability commissioner could help in these areas. With the right advocacy and support, more disabled people should be able to enter the workplace and contribute to the economy. From an energy-crisis perspective, generally speaking, disabled people need more energy to live and a commissioner could think of this in policy discussions. Home adaptations take a long time to agree and co-ordinate, with statutory bodies wrangling over every request. Fast progressing conditions like MND mean there is no time to waste in debating whether or not an adaptation is necessary. This means that if people can't afford home adaptations themselves, they are likely to have to manage without them. A commissioner could ensure that where home adaptations are required, that people can receive them without delay.

## 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)?

Whilst the proposed bill lacks substance and leads to a multitude of questions about the role, powers and funding of the commissioner, and there will be a cost involved to establishing a commissioner, there is a greater cost to not doing anything to address the inequalities that disabled people face.