

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).

Epilepsy Scotland works with people living with epilepsy to ensure that their voice is heard. An estimated 55,000 people living in Scotland have epilepsy.

To ensure our response represents the experiences of the epilepsy community in Scotland, we conducted a survey based around the themes of this consultation. 28 people with epilepsy completed our short online survey. The survey responses together with our extensive experience of working with people affected by epilepsy have informed our response to this consultation.

Please choose one of the following:

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

If you have requested anonymity or asked for your response not to be published, please give a reason (Note: your reason will not be published):

This response has drawn on the views and lived experience of our survey respondents and our own expertise in the field, as an organisation dedicated to supporting and representing the voices and needs of people affected by epilepsy in Scotland. Our organisation provides a free and confidential helpline service, as well as offering wellbeing support and welfare rights advice to people affected by epilepsy. Through these wide-reaching services, we have a clear understanding of the issues and barriers the epilepsy community face.

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).

Epilepsy 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.)

Fully supportive

Please explain the reasons for your response.

The proposed Bill will allow the opportunity for the role of a Disability Commissioner to be seriously considered. The benefits of establishing the role are already evident, giving a voice to a marginalised community, having a clear avenue for advocacy for people with disabilities, and strengthening the rights of disabled people. This hinges on the proposed aims of the Commissioner outlined in the consultation document.

It is vital this role is independent. This will be important in achieving the aims of having a function in reviewing and assessing laws, policy and practices and carrying out investigations. However, it is equally important this role is held to account and required to report to the Scottish Parliament, and able to be effectively involved in legislative reform and policy development.

This role should hold to account existing failings which negatively impact people with disabilities and address new policies to ensure disabled people are recognised and represented. By creating the space for co-production, the Disability Commissioner should collaborate with disabled people across Scotland to improve their experiences.

To do so effectively, it is essential the Commissioner encourages the involvement of those with lived experience, with inclusive communication and regard for the United Nations Convention on the Rights of Persons with Disabilities. One of our survey respondents commented, 'It's about time people with a disability have their voice and views heard'.

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

It is clear the existing systems in place to support, represent and advocate for disabled people do not work for everyone. We know that people with disabilities in Scotland struggle to have their voices heard and needs met. This is true for the estimated 55,000 people living with epilepsy in Scotland. People with epilepsy consistently experience stigma and discrimination caused by a lack of understanding of the condition.

A clear example of this is in employment. The employment gap between people with epilepsy and non-disabled people is over 44%. In a recent Epilepsy Scotland survey 39% of respondents said they had faced discrimination at work because of their epilepsy. It is clear that existing legislation is not working for every disabled person and more is needed to be done to support these people.

70% of our survey respondents did not feel the voices and rights of disabled people are represented at a

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national level (i.e., in the Scottish Government or Scottish Parliament). 26% were unsure. Only 4% felt their voices were represented. This demonstrates the need for change, a need for better representation.

One survey respondent said: 'The most vulnerable in society are always overlooked and an easy target for a reduction in services as they are so overwhelmed and exhausted by the conditions they live with that they often have no fight left in them'. This comment highlights the need for a dedicated Commissioner, solely focused on the needs of disabled people.

Another sentiment from the survey was the lack of action. One respondent commented 'they talk a good talk, but after that they don't follow it up'. The Disability Commissioner should have the remit to hold people to account, ensuring action is taken, and words and commitments come to fruition. It is also important the Commissioner is required to report to the Scottish Parliament to ensure the work is held accountable.

A dedicated Commissioner focussing solely on people with disabilities is a long overdue step to ensuring the rights of disabled people are heard and represented.

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.

It is our view that legislation is required to establish a Disability Commissioner for Scotland. Legislation would allow the Commissioner the powers to effectively execute the function of the role. The functions of Children & Young Person Commissioner are set out in legislation and we believe, based on the success of this Commissioner in supporting children and young people, this is important to consider and learn from.

Further, a clear sentiment amongst our survey respondents was the lack of action. It is our feeling enshrining this role in law will help combat this and create positive change. Legislation could ensure the Commissioner has the powers to investigate and scrutinise those in power.

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.

The Disability Commissioner should cover all disabilities. Not to do so would further discriminate against already marginalised groups. While all disabilities are different, there should be one central voice representing everyone. 78% of our survey respondents believed that if there were a Disability Commissioner for Scotland, they should be responsible for representing all disabilities (i.e., physical, mental, hidden, and fluctuation conditions).

Comments from our survey highlighted that 'all disabilities should be taken into account'. Many comments noted the sentiment that 'all disabilities have equal importance, so it is essential that they are all represented.' One respondent was clear: 'You can't pick and choose which disabilities are valid or not for a disability commissioner. It's either them all or don't bother creating the role.'

However, caution must be taken to ensure the Disability Commissioner understands the individual needs and impacts of all disabilities and does not take a universal approach to representing disabled people. This was echoed in the responses to our survey. One respondent commented: '[We] Need someone who knows what they're talking about, no point having someone as commissioner that only specialises in physical disabilities as they wouldn't know how invisible disability affects people'.

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

When considering how this may work, one respondent commented: 'Ideally there should be more than one in order to fully represent the wide range of mental and physical disabilities - it is a broad and complex subject. They should have in-depth up to date knowledge of the conditions, research, treatment and current challenges faced by people of each group.' Other respondents commented: 'Not all disabilities are supported appropriately so breaking conditions down into groups would allow for more focus.'; 'There should be a group of people with voice from each of the categories otherwise the impact will be diluted'.

Including the specialist groups from the third sector in the development and function of the role would help ensure the specifics of all disabilities, including lesser known and understood disabilities are considered and represented. Combining direct lived experience with indirect experience, via the third sector and specialist organisations, would help give a voice to as many people with disabilities as possible.

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 have a role in reviewing laws and policies that might impact on disabled people. It is therefore vital the Commissioner has a robust understanding of legislation and policy development in Scotland to succeed in this role.

36% of our survey respondents did not feel the voices and rights of disabled people are currently heard in the decisions surrounding the development of policies and laws which impact on disabled people. 36% believed they were sometimes heard and only 5% believed they were heard all of the time. 23% were unsure. When commenting on this, some respondents commented on the role of the third sector in helping to have their voices heard: 'the only way I have been asked to contribute is via charity consultations such as this one [Epilepsy Scotland's survey conducted to help shape response to this consultation]', while another commented 'with the help of charities such as Epilepsy Scotland our voices are heard'. It is clear more is needed to be done to directly involve people with disabilities in the development of legislation and policy.

The role of the Disability Commissioner should primarily involve reviewing new laws and policies which are being established to ensure people with disabilities are considered and represented from the beginning.

Further, there should also be a role in analysing existing laws and policies to ensure they are as effective and represent the needs of disabled people. We know this is not routinely happening with the Equality Act and employment as many people with epilepsy still face discrimination despite this law. The Commissioner should have a role in identifying areas for improvement and advocate for the needs of disabled people.

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?

Collaboration is key in this role. Creating systemic change will not happen with the Commissioner alone. It will require collaboration with all partners involved in supporting disabled people. Most importantly, the Commissioner should be informed by those with lived experience. The Commissioner should proactively seek this out in a variety of ways: one to one, focus groups, larger surveys. The Commissioner should establish a network of partners from the third sector and service providers to properly share best practice amongst the various stakeholders. One way to do this might be by creating a forum to listen to all voices

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and facilitate sharing of best practice.

Further, it is important to learn from the functions of existing Commissioners, like the Children & Young People's Commissioner. As set out by law, this role must promote best practice by service providers.

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

The involvement of disabled people and DPOs is very important to this role. In order to effectively represent and advocate for people with disabilities, there needs to be the inclusion of the views and voices of disabled people.

When our survey asked who respondents thought would be best suited to represent the voices of disabled people, 57% of survey respondents believed it was disabled people themselves. 38% said third sector organisations who work with disabled groups. Only 5% said the Scottish Government would be best suited to represent the voices and rights of disabled people. No one believed the NHS/medical professionals or local authority service providers would be best suited. Comments highlighted the importance of valuing lived experiences: 'You have to live with the condition on a daily basis before you really know what it is like to live with the impact of a diagnosis.'; 'Unless you have personally dealt with a disability or cared for someone it's not the same'.

We asked our survey respondents if, given the opportunity, they would wish to be involved in the work surrounding the development of a Disability Commissioner, and in the work of the Commissioner once established. 63% said they would want to be involved. 35% were unsure. When asked how they would like to be involved, suggestions included being consulted on new policies, taking part in surveys, being involved in focus groups, and being given a voice in specialist groups.

Survey respondents also highlighted the importance of the third sector in representing those who are unable to advocate for themselves: 'Third sector agencies have the expertise to advocate and articulate thoughts and opinions of those who may struggle otherwise', 'Third sector charities help the voices of disabled people be heard and do lots to promote awareness and make these things a priority. Not all people with disabilities want or are able to speak up and it's not necessarily a priority for NHS, local authorities, etc.'

We feel it is important that there is the opportunity for all voices to be heard, across all disabilities. This would be directly from people with lived experience, and indirectly, through DPOs. However, when it comes to involving people with disabilities, it is important it is recognised that being involved is a big commitment and actions are taken to ensure no one is excluded on account of this. This could be addressed in the amount of time taken to be involved, and compensation for involvement.

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

Both Scottish Public Bodies and service providers

Please explain the reasons for your response

This role should have powers for basic level of inquiry. The Commissioner should be able to provide scrutiny while exercising caution as to not waste time and money on extensive investigations with little output. For example, when considering individual cases, the Commissioner should be able to act on the complaint, inquire and get action and report on the outcomes.

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

To investigate only Scottish Public Bodies or only service providers would create a potential risk of people falling through the cracks the Disability Commissioner aims to repair and will not allow for a fully functioning protective Commissioner. Furthermore, many service providers work in collaboration with public bodies, and many disabled people seek support from multiple avenues, which can cut across Scottish Public Bodies and service providers. It is therefore important to take steps to ensure the Commissioner can fully investigate all areas.

When comparing the proposed Disability Commissioner with the Children and Young People's Commissioner (CYPC) and their roles in investigation, we can see the CYPC is unable to investigate an issue if another body in Scotland is able to investigate it. It is therefore important to consider how the Disability Commissioner will work with the Equality and Human Rights Commission, as well as other bodies, to ensure the work is both collaborative and effective.

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.

Introducing the role of Disability Commissioner for Scotland will have a positive impact on improving the inequalities faced by disabled people. This encompasses not only health inequalities, but socioeconomic inequalities. Advocating for the rights of disabled people will help address some of the deep rooted problems which negatively impact on disabled people.

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?

No Response

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)?

When establishing a Disability Commissioner, close consideration should be given to their background. While they will need to have a robust understanding of policy and legislation to effectively contribute to this role, some responses to our survey also highlighted the importance of lived experience, and of recognising all the impacts living with a disability can have on a person's life.

"It seems to me that a disability commissioner should come from a background of either living with a disability or having cared for someone with a disability or have close contact with some form of disability in their life. I feel that only someone who has been immersed in the disabled world in some way can truly comprehend the difficulties people face."

"Please make sure that it's not a case of one cap fits all especially with people that suffer with epilepsy"