

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).

#MEAAction Scotland is a grassroots, volunteer-led movement working towards improving the lives of the estimated 21,000 people in Scotland with myalgic encephalomyelitis (ME). We aim to address the health inequalities that people with ME experience in Scotland and our vision is that politicians, health and social care professionals, and the people of Scotland understand and support people with ME and treat them with respect. This response was a collaborative effort by our group of volunteers. We are not yet a registered charity.

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).

#MEAAction 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.

As discussed in the draft proposal, disabled people across Scotland are facing discrimination and neglect on a daily basis. There have been many warm words from the Scottish Government and promises to disabled communities over the years, but this often hasn't translated into action. The proposed Disability Commissioner could play a much needed role in holding the government to account and pushing forward progress. #MEAAction Scotland is in full support of the proposed Bill to introduce this role.

In the case of people with myalgic encephalomyelitis (ME), we have been waiting for the government to act on their own recommendations for development of services for people with ME since they released a report from a short life working group in 2002. Recommendations have been revisited and renewed in 2010 and 2020 and yet the large majority of people with ME in Scotland still do not have access to a specialist service.

In January 2019 the then Health Secretary, Jeane Freeman, said, "We should not wait until we have a better research base and greater clarity on what treatment options might be appropriate. People are living with ME right now" - and yet waiting is exactly what we've been doing. We believe an independent Disability Commissioner, as described in the Bill, could help give a voice to communities who are being ignored and brushed aside and shine a light on the urgent need for change.

We support the idea of modelling the Disability Commissioner role on the existing Children and Young People's Commissioner. This role has been largely successful in championing and progressing children's rights in Scotland, with the notable achievement of the incorporation of the UNCRC into Scots Law. It would be a huge step forward for disabled people in Scotland if the Disability Commissioner was capable of similar achievements.

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

Disabled people have specific, complex needs and a Disability Commissioner is needed to champion our rights. At a time when the country is facing a cost of living crisis that is disproportionately affecting disabled people, and society is beginning to understand that the Covid pandemic has been a mass-disabling event, it is more crucial than ever that disabled people have a voice in decision-making at the highest level.

Also, many disabled people are arguably less able to advocate for themselves than people with some other protected characteristics. For example, 25% of people with ME are severely affected, and are house bound or bed bound. It may not be possible for them to meet with MSPs, send emails or let people know what they are going through. The Disability Commissioner could take the time to understand the issues facing people with conditions such as severe ME, and ensure that their needs are considered and represented. This is currently sorely lacking.

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 legislation is required to secure the independent nature of this role and to ensure a transparent, consultative process.

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.

#MEAAction Scotland appreciates the inclusion of the following specification in the definition of disability in the draft proposal: "impairments with fluctuating or recurring effects such as rheumatoid arthritis, myalgic encephalitis (ME)." People with ME are often forced to explain and/or prove that ME is a real, biological condition and that they are disabled - it is a welcome relief to see this would not be the case with the Disability Commissioner role. By including ME and other hidden and fluctuating conditions, the Disability Commissioner could help educate health professionals and the public on the impact of these conditions and support the ME community to break down the stigma we currently face.

Many disabled people live with co-morbidities and there can be overlaps between different conditions. ME has significant similarities with other energy limiting conditions, such as Long Covid, and including a broad definition of disability gives the role the scope to consider both similarities and differences in the challenges disabled people face and look at the whole picture when working to improve our situation.

It's important for the role to have a real, tangible impact on the ground, as well as in parliament, and so working with existing bodies and organisations providing support will be vital. There are many great organisations in Scotland who have been involved in this work for a long time that the commissioner could collaborate with, such as the Neurological Alliance of Scotland, which #MEAAction Scotland is a member of.

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 Disability Commissioner will bring a unique viewpoint in looking at all law and policy with disabled people in mind. Legislation that does not directly reference disabled people will often still impact the community, and the Disability Commissioner could ensure this is considered.

Having a Disability Commissioner reviewing legislation may also support the education of policymakers to consider how disabled people might be affected by the law or policy at an earlier point and make needed amendments or additions.

Scotland is also facing a crucial juncture in the delivery of benefits, with the provision moving from the UK Department of Work and Pensions to Social Security Scotland. As the government reforms a system that has harmed disabled people for decades, it is vital that disabled people's voices and experiences are at the heart of the process. While we're aware it would take time to set up the office of the Disability Commissioner, the new process should be open to review and scrutiny in the years to come while it's still in its infancy.

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?

It cannot be overstated how important it is for service providers to continue to learn and develop their practice as our understanding of different conditions, and the technology we can use to treat them, develops. We would welcome the Disability Commissioner's input in promoting best practice and believe they should be able to task the government with doing more to support professional development in healthcare.

For people with ME in Scotland, there are tiny pockets of good practice - often centred around one GP or health professional. Sadly, harmful practice is still widespread and so we would be cautious about promoting some service providers. However, there is expertise on good practice across the third sector. ME organisations and charities such as #MEAction Scotland, Action for M.E. and the ME Association work with health professionals and academics who have taken the time to truly listen to ME patients and understand what we need. We would be keen to see these people platformed through online resources and events, like conferences, that the Disability Commissioner could help coordinate and promote.

There is also a need to promote learning and best practice in supporting people with energy limiting chronic illnesses more generally. This includes ME but also other conditions that can affect patients similarly, such as Long Covid, Fibromyalgia and Postural Tachycardia Syndrome (PoTS). Energy limiting chronic illnesses have been overlooked and misunderstood for a long time but, with the tragic explosion of cases of Long Covid in the wake of the pandemic, it's clear that there is an urgent need to develop appropriate treatment and care for people living with these conditions.

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

Any work that is undertaken on disabled people's issues must be accessible to disabled people and include the community at every stage. Ideally, the Disability Commissioner should be a disabled person themselves, although we understand it may not be possible to mandate this.

Disabled People's Organisations, such as Inclusion Scotland, will be an invaluable resource in creating and delivering this role and should be funded and consulted throughout the process. To be fully accessible, the role will need to provide a wide variety of options for engagement.

The office of the Disability Commissioner should offer a flexible working environment with access adjustments that enable disabled people to be considered for paid roles. We would also support internships as a development opportunity for people with less work experience, as long as they are paid. An example of this in practice is Inclusion Scotland's We Can Work Internship Programme.

For many disabled people, work is not an option, so there will also need to be opportunities for wider involvement. Creating a panel of lived experience experts who are compensated for their time on an ad hoc basis could give people the chance to input in a way that is led by them and accessible to them - that might be reviewing a document over email, or taking part in a focus group. Payment or compensation would need to take into account the impact it might have on a person's benefits and the overall impact on the individual. This is a model that is used successfully in other areas, such as the domestic abuse sector where the SafeLives Authentic Voice Panel is an example. Processes should be as transparent and accessible as possible to allow other disabled people to follow progress, and this includes providing information in different formats such as large format, braille and BSL.

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

Both Scottish Public Bodies and service providers

Please explain the reasons for your response

No one should be above scrutiny if they are harming people or infringing on their rights. Many parts of our society, including the medical profession, are structured in hierarchies that give power to the most privileged people and silence disabled people's voices and those of people with other protected characteristics.

It's important that the Disability Commissioner has powers of investigation so that influential bodies and providers know that they can be held to account for their actions. For example, in October last year NICE published a new guideline for the diagnosis and management of ME. This included a significant change in removing the recommendation of graded exercise therapy (GET) which teaches patients to 'exercise their way out' of their condition and has been proven to be harmful. However, #MEAAction Scotland are still hearing from people who are being offered this dangerous treatment which is unacceptable. Currently, there aren't effective ways to challenge this practice when it happens and so a Disability Commissioner with the power to investigate service providers would be welcomed.

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?

some 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.

The setting up of the Disability Commissioner would inevitably create some costs with the creation of new roles and premises, and developing fully accessible processes. However, the potential benefit to disabled people in our opinion far outweighs the negative implication of costs that would be felt by the Scottish Government.

Arguably, in the long term this role could lead to a reduction in costs of disabled people to the economy. In 2017, the think tank 2020health found that the average cost per person with ME in the UK is £16,966 per year, which means that a conservative estimate of the cost to the Scottish economy is £356.2 million annually. We believe that with a higher level of understanding among healthcare professionals and better practice and services for people with ME, far fewer people could become severely ill and many would achieve a higher level of independence. This could also be applicable to Long Covid and other energy limiting chronic illnesses, and so if the Disability Commissioner can achieve real change for disabled people there is potential for significant long term reduction in costs which the Scottish Government would benefit from.

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.

The Bill would clearly have a positive impact for disabled people if it became law. It's important that any work towards supporting people with protected characteristics takes an intersectional approach. The Disability Commissioner must actively consider and include disabled people from racialised communities, those who are LGBTQ+ and other disabled people from groups who are marginalised in society, such as refugees and asylum seekers. We would encourage this responsibility to be written into the legislation, to avoid the role only serving the relatively most privileged disabled people by default.

If an intersectional approach is taken, there are opportunities for groups with other protected characteristics to benefit from this role. We know that structural racism, financial difficulty/poverty and gender bias in the health system leads to poorer health outcomes for minority ethnic groups, people in lower socio-economic groups and women. In regards to ME specifically, 75-80% of people with ME are women [Faro et al., 2016] and there is evidence to show that some ethnic minorities are more at risk of ME and are also more likely to be 'silent sufferers' [Dinos et al., 2009].

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?

In our view this role would create a significant opportunity to address both the economic and social costs of disability, and the stigma which can surround it, and therefore make a tangible contribution to the Scottish Government's strategy for sustainable economic growth.

We would also see this as an opportunity to ensure that Scotland really is Getting it Right for Every Child when it comes to ME and other energy-limiting illnesses. While there is unfortunately no reliable data on the prevalence of ME among children and young people, in one large-scale longitudinal study ME was shown to be the biggest single cause of long-term school absence [Dowsett & Colby, 1997]. The illness does not discriminate by age. #MEAction Scotland knows young people who are being failed by the school system here in Scotland and who are not able to realise their potential because of a lack of understanding of the condition in schools, and a lack of infrastructure to support the flexible forms of learning and assessment that these young people need. This is a pressing and growing need here in Scotland, particularly with the increasing and possibly exponential numbers of children and young people facing the same challenges as a result of Long Covid.

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)?

#MEAction Scotland would like to thank Jeremy Balfour MSP for bringing forward the draft proposal. We would be happy to support the process to include the voices of people with ME and would encourage him to contact us if he would like any further information or sources relating to the issues we've touched upon in this response. Below is some general information about #MEAction Scotland to give some background to our work.

About #MEAction Scotland:

#MEAction Scotland, an affiliate of #MEAction UK, is a grassroots, volunteer-led movement working towards improving the lives of the estimated 21,000 people in Scotland with myalgic encephalomyelitis (ME). ME is a complex, chronic disease that presents with symptoms in multiple body systems and is recognised by the World Health Organization as a neurological disease.

Our Vision is that politicians, health and social care professionals, and the people of Scotland understand and support people with ME and treat them with respect. Our aim is to address the health inequalities that people with ME experience in Scotland.

Our Purpose is:

- To build a stronger ME advocacy community in Scotland
- To raise awareness of the devastating impact of ME
- To campaign for effective support for adults and children and young people with ME.