

# 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).**

This response is submitted on behalf of Down's Syndrome Scotland (DSS) a membership organisation representing the interests of approximately 1,300 members across Scotland. Formed in 1982, DSS is the only organisation registered in Scotland that is solely concerned with the needs of people with Down's syndrome. We provide a range of services in support of families, people with Down's syndrome and we work closely with an extensive range of professionals who are involved in the lives of people with Down's syndrome and their families. We campaign for the rights and equality of people with Down's syndrome and we promote their value and potential at every opportunity. It is estimated that there are between 4,500 and 5,000 people with Down's syndrome living in Scotland and one baby with Down's syndrome is born in every 1,000 babies born in Scotland. We believe the number of people with Down's syndrome is under-recorded. In preparing this response we have revisited recent engagements with our members where the issue of a Commissioner role has been discussed and debated.

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).

Down's Syndrome 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 opposed

**Please explain the reasons for your response.**

DSS supports the view that disabled people have been amongst the hardest hit within the pandemic years and their voices and views have not been fully heard, respected or fully valued in this time of crisis. Inequality for disabled people has deepened throughout this period and a strong independent advocate for disabled people's rights is now needed, more than ever. We believe that the proposal to establish a Disability Commissioner should not be defined solely by what has occurred in the past two years - inequality, injustice and discrimination existed before COVID-19 came along; the pandemic years have amplified and exacerbated the inequality. For our community, people with Down's syndrome, the most stark example of that inequality is that they will die 28 years younger than the general population (20 years for people with learning disabilities) and that in just about all cases of early and premature death in our community, most of these deaths are preventable. While there are some positive examples of people with Down's syndrome being more fully included in society (education, employment and culture), it remains the case that the vast majority of people with Down's syndrome remain excluded from mainstream society. For these reasons, our support for the proposal to establish a Disability Commissioner is contingent on the explicit recognition that people with a learning disability (and in our case people with Down's syndrome) continue to experience the greatest level of exclusion and discrimination of the many groups that make up the pan-disability arena. It is vital that any Bill coming forward to facilitate the introduction of this new role explicitly acknowledges this fact. We feel that the consultation document is heavily weighted to the needs of the physically disabled community and we would want more explicit recognition of the needs of the diverse and multi-faceted learning disability community. People with learning disabilities tell us that they always feel that they are at the very back of the queue when it comes to support, recognition and inclusion. Acknowledging the diversity of the learning disability community will be hugely important and, for our community, we would want to see the Down's syndrome community explicitly referenced within the Bill. Anything less will simply reinforce the view held by our members that people with Down's syndrome (and people with learning disabilities more generally) are not seen as equal within the pan-disability arena.

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 support the view that the Equality Act has not delivered in a way that was envisaged for disabled people and that the absorption of the Disability Discrimination Act has, in fact, led to a weaker focus on disability issues. If evidence was needed to support this view, our members would point to the discrimination, inequality and disregard for their human rights that was witnessed throughout the past two years in particular. In promoting a pan-disability Commissioner role, it is vital that people with learning disabilities and people with Down's syndrome do not find themselves as the 'poorer cousins' within the overall focus of this role. It will be important for the Bill to set out how it will take steps to ensure that the needs of people with learning disabilities, including people with Down's syndrome, will be addressed with equal consideration and focus within a pan-disability approach. It would be unfortunate and a retrograde step if the perceived dilution of disability issues in the Equality Act world were simply transferred onto the learning disability community within a pan-disability approach. For this reason we will continue, in the interim, to support Scottish Ministers' proposals to establish a Commissioner for Learning Disability, Autism and Neurodiversity within the proposed Learning Disability, Autism and Neurodiversity Bill. We would hope that positive and constructive dialogue could take place between the architects of these two

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Bills to ensure that the needs and rights of people with Down's syndrome (and people with Learning disabilities more generally) are fully understood and fully addressed by these new arrangements.

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 a Commissioner role without legislation (and clear legislative powers) will not achieve the systemic change that is needed for people with learning disabilities and disabled people more generally. We also believe that legislation on its own is unlikely to deliver the transformational change that is needed to bring about the full inclusion of disabled people, including people with learning disabilities, in all aspects of Scottish society. Our families speak of the constant fight to secure even the most basic of support and recognition. It will be important to ensure that the Bill and the Commissioner role are defined as positive enablers to change and not just about holding authorities to account for failing to deliver on the powers and policy intentions of the Bill. As the Bill progresses, it will be critical to engage with existing legislation and powers and explain the interaction between different pieces of legislation in relation to the Bill's powers and the Commissioner's role. This is especially the case in the aforementioned Learning Disability, Autism and Neurodiversity Bill and the work currently progressing to review the various Human Rights provisions at UK and Scotland level. It would be regrettable if the powers of the proposed Commissioner Bill were undermined and diluted by changes to the Human Rights Act across the UK. In Scotland, it will also be important to engage with the current review of Mental Health Law and understand how those changes might need to impact any Commissioner role and associated legislation.

## 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.**

Our families and people with Down's syndrome remain anxious that an all-encompassing, pan-disability approach might not sufficiently prioritise or address their needs as members of the learning disability community. The consultation document has cemented that anxiety as the language and the references to the people with learning disabilities and their needs and circumstances appears quite light. In terms of language, while we recognise the explanation of using the term 'mental' (drawn from the Equality Act definition), we would strongly recommend the use of more contemporary language in the drafting of the Bill - the more acceptable and current terms are 'learning disability' in the UK and 'intellectual disability' more commonly used internationally. For our community, people with Down's syndrome (the largest identifiable group within the learning disability community), we would want to see the term 'people with Down's syndrome' appear within and throughout the draft Bill. This is a matter of identity and inclusion and our families and people with Down's syndrome tell us that they frequently feel invisible to services and statutory authorities. This was certainly our experience throughout the pandemic as we, DSS, sought to identify many individuals with Down's syndrome who were simply not included in local data sets and therefore not included in shielding arrangements nor prioritised for vaccination. We would move our support to 'fully supportive' if and when we see 'people with Down's syndrome' included in the scope and definitions of the Bill and we see subsequent improvements in the language of the Bill. We stand ready to help in this regard with any appropriate drafting. As a final note, it will be important to recognise that for many people with Down's syndrome (and for people with learning disabilities generally) it is common for them to have additional conditions (comorbidities) and this needs to be taken into account in any Commissioner arrangements going forward. It is not uncommon for people with Down's syndrome to also have a dual diagnosis of autism and a significant number of our members will have underlying health conditions including cardiac conditions and respiratory issues. It will be vital for the Office of Disability Commissioner to recognise the expertise that is available within the third sector in particular and to work

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collaboratively with existing charities to understand the particular needs of defined communities. While we support the need for pragmatism, the experience of our families and people with Down's syndrome is that 'pragmatism' often translates to prioritisation and people with learning disabilities including people with Down's syndrome, rarely get sufficiently prioritised within a pan-disability approach. This is a central issue of concern for people with Down's syndrome and their parents/carers.

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.**

It will be important to recognise and review the existing powers and legislation that is already in place in Scotland and for the Disability Commissioner to consider their efficacy and application in practice. The intersection between the proposed new Bill and existing legislation (and powers) and additional new legislation, including the Learning Disability, Autism and Neurodiversity Bill, will need full exploration and clarification. It is our view that the proposed Bill will also have to engage with the current reviews of Human Rights legislation and the current review of Mental Health Law in Scotland.

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 understand the idea of a Disability Commissioner is about tackling inequality, injustice and discrimination. While that agenda can be advanced in part by promoting examples of good practice, we recognise that many organisations currently promote and drive the adoption of good practice approaches and we would not want a Disability Commissioner to duplicate that effort. There are other 'regulators' in this space who also promote good practice in this area including the Care Inspectorate, the Scottish Social Services Council, Health and Education Inspectorates, so it will be important to build on their current efforts in this area. Many charities already recognise and award examples of good practice and in our community the most obvious is the Scottish Learning Disability Awards run by the Scottish Commission for People with Learning Disabilities (SCLD). While we believe the legislation to introduce a Disability Commissioner needs an enabling element, it will be a question of balance between this and holding people/authorities to account for non-compliance. In all of this work, it will be vital to ensure that the voices, views and experience of disabled people is front and centre in all considerations. It is commendable that the consultation document recognises that inclusive communication is a key consideration at the outset and that for significant numbers in the learning disability community, their communication support needs are profound. To ensure their voices are heard requires a more creative approach which takes time and resources. This is the community whose voices and views are rarely heard yet their needs are often the most profound.

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

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?

**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**

Our view and the view of our families and people with Down's syndrome is that this is not negotiable (nothing about us without us). It is also our view that this rarely happens to best effect - good intentions often fall well short of what is needed to meaningfully involve people with learning disabilities. People with Down's syndrome know that this is not easy to accomplish but they stand ready to engage in ways that will work for them and the Commissioner. It will be important for the Disability Commissioner to work closely with DPOs but also to recognise that a number of charities (our own included) have existing mechanisms in place to facilitate the views of our members. A 'one-size-fits-all' approach will not work for the majority of our members and will be perceived as a tokenistic approach. There is an opportunity for the Disability Commissioner to adopt a new, more inclusive approach and we would encourage early adoption of the Rapporteur model at SCLD and its 'Include For Good' Programme - putting people with lived experience at the heart of decision-making and in leadership roles. We note the language of the consultation document refers to 'encouraging' the involvement of disabled people - we hope the draft Bill will go further and set out clear mechanisms (or clear expectations) for the active involvement of disabled people in the work of the Disability Commissioner. The UNCRPD (Articles 4.3 and 33.3 on Participation) would be a good starting point for the Disability Commissioner.

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

Both Scottish Public Bodies and service providers

**Please explain the reasons for your response**

Our view is that it will be important not to limit the powers of the Disability Commissioner to just Scottish Public Bodies, though they will be centrally important to the work of the Commissioner and the drive to promote equality of opportunity and much better outcomes for all disabled people including people with learning disabilities in particular. It is not clear what is meant by the term 'service providers' and it will be important to define that more clearly in any Bill coming forward. To bring about the systemic change needed in society for our community will require the Disability Commissioner to engage with all sectors in Scottish society including and not limited to the public sector, those providing public services; the private sector including employers and business; and the third sector including service providers in terms of social care provision. In this latter regard, the plans to bring forward a National Care Service (and the legislation to enable this development) will need to interact with the legislation to deliver the Disability Commissioner.

## 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.**

It is our view that the Disability Commissioner would need to be provided with sufficient new resources to undertake their duties effectively and impactfully. It is likely that there will be an increase in costs associated with compliance and also with the provision of effective inclusive communications. The view of our families and of people with Down's syndrome is that society and its various institutions and leading organisations are currently missing out on the value, contribution and the potential of people with learning disabilities by not including them more significantly and appropriately within their services and their workforces. The commitments to Equality, Diversity and Inclusion (EDI) and the established economic

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arguments that support an EDI approach, need to extend to include people with learning disabilities. In considering the 'cost' of introducing this legislation it will be important to acknowledge the real benefits of including people with learning disabilities and the dis-benefits of not doing so. The current estimated spending power of the disabled population in the UK (sometimes referred to as the purple pound) is identified as £249 billion (2020).

## 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 will be important to undertake an Equality Impact Assessment (EQIA) of the proposed legislation and to understand the impact across the very many communities that make up the very diverse disabled people's population in Scotland. Any EQIA undertaken should take care to recognise and assess the impact of the pan-disability Commissioner role on the community of people who have learning disabilities and our own members who have Down's syndrome. This assessment should recognise the very wide spectrum of needs (including communication support needs) of people with Down's syndrome across Scotland and people with learning disabilities more generally.

## 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?

A key aspect of any proposals to improve the wellbeing and inclusion of disabled people and people with learning disabilities, needs to recognise that if we 'get it right' more systematically throughout all sectors in Scotland, then there are very significant costs that could be saved if families and people with learning disabilities were better and more consistently supported early on. Many charities, including Down's Syndrome Scotland, support families and people with Down's syndrome at times of acute pressure and crisis in their lives. Our support and intervention can often draw families back from crisis and therefore reduce the call on the resources of, already stretched, statutory services. In this respect, our work and the work of a Disability Commissioner could be argued as critical 'preventative spend' and therefore lead to a more sustainable economy and certainly a more healthy and just society.

## 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)?

Down's Syndrome Scotland, its members including parents/carers and people with Down's syndrome, welcome all and any efforts that seek to address the inequality, injustice and discrimination experienced on a daily basis in their lives. The proposal to establish a Disability Commissioner could have a profound and positive impact on them and their daily lived experience. It is our belief that Scotland is currently missing out by not including people with learning disabilities more systematically and more consistently in all aspects of Scottish life. Our members are clear about the potential a Disability Commissioner to tackle the inequality they experience. They are equally clear however that their daughters and sons are often at the back of the queue when it comes to making provisions and securing their human rights when a pan-disability approach is adopted. Our support for a Disability Commissioner, as proposed, is contingent on understanding more clearly how people with learning disabilities, including people with Down's syndrome, will have their needs and rights met within a pan-disability approach. We are very grateful to Jeremy Balfour MSP for his consistent support for disabled people and for putting forward this proposal at a time when disabled people more generally, and people with learning disabilities more particularly, have experienced a deepening of inequality and a reduction in their rights and services as we emerge from the pandemic. We look forward to working with any team involved in preparing this Bill in due course.