# Proposed Disability Commissioner (Scotland) Bill – Jeremy Balfour MSP

# **Summary of Consultation Responses**

This document summarises and analyses the responses to a consultation exercise carried out on the above proposal.

The background to the proposal is set out in section 1, while section 2 gives an overview of the results. A detailed analysis of the responses to the consultation questions is given in section 3. These three sections have been prepared by the Scottish Parliament's Non-Government Bills Unit (NGBU). Section 4 has been prepared by Jeremy Balfour MSP and includes his commentary on the results of the consultation.

Where respondents have requested that certain information be treated as "not for publication", or that the response remain anonymous, these requests have been respected in this summary.

In some places, the summary includes quantitative data about responses, including numbers and proportions of respondents who have indicated support for, or opposition to, the proposal (or particular aspects of it). In interpreting this data, it should be borne in mind that respondents are self-selecting, and it should not be assumed that their individual or collective views are representative of wider stakeholder or public opinion. The principal aim of the document is to identify the main points made by respondents, giving weight in particular to those supported by arguments and evidence and those from respondents with relevant experience and expertise. A consultation is not an opinion poll, and the best arguments may not be those that obtain majority support.

Copies of the individual responses are available on the following website <a href="https://www.jeremybalfour.org.uk/disability-commissioner-scotland">https://www.jeremybalfour.org.uk/disability-commissioner-scotland</a>. Responses have been numbered for ease of reference, and the relevant number is included in brackets after the name of the respondent.

A list of respondents is set out in the Annexe.

# Section 1: Introduction and Background

Jeremy Balfour's draft proposal, lodged on 11 May 2022 is for a Bill to:

establish a Disability Commissioner for Scotland.

The proposal was accompanied by a consultation document, prepared with the assistance of NGBU. This document was published on the Parliament's website, from where it remains accessible:

Proposals for Bills – Scottish Parliament | Scottish Parliament Website

The consultation period ran from 12 May 2022 to 3 August 2022.

Jeremy Balfour sent the consultation document to all members of the Scottish Parliament Cross-party Group (CPG) on Disability and to relevant CPG Conveners such as the Conveners of the CPGs on Multiple Sclerosis, Muscular Dystrophy, Stroke and Visual Impairment, asking them to inform their delegates of the consultation. The consultation document was also sent directly to a number of third-sector organisations

Jeremy Balfour gave a presentation on the consultation at the CPG on Disability and at the CPG on Learning Disability. The Member also held a roundtable meeting in the Scottish Parliament with key third sector organisations and visited some third sector organisations, including MACS (Mobility & Access Committee for Scotland) and focus groups led by Alzheimer Scotland. He also attended a "Have Your Say" meeting at Capability Scotland and held an event at Camphill Scotland community at Tiphereth to coincide with the launch of the consultation. In addition, Jeremy Balfour has held numerous meetings, both in Parliament and virtually with third sector organisations.

The consultation exercise was run by Jeremy Balfour's Parliamentary office.

The consultation process is part of the procedure that MSPs must follow in order to obtain the right to introduce a Member's Bill. Further information about the procedure can be found in the Parliament's standing orders (see Rule 9.14) and in the *Guidance on Public Bills*, both of which are available on the Parliament's website:

- Standing orders (Chapter 9): <u>Standing Orders | Scottish Parliament Website</u>
- Guidance (Part 3): Part 3: <u>Stages of Bills special cases | Scottish Parliament Website</u>

# Section 2: Overview of Responses

In total, 207 responses were received. Of those, 194 were received via Smart Survey, and 13 by other means (such as email). The responses can be further broken down as follows:

- Forty (19%) from third sector organisations (charitable, campaigning, social enterprise, voluntary, non-profit)
- Five (2%) from public sector organisations [two local authorities, the Equalities and Human Rights Commission, the Independent Living Fund and the Mobility and Access Committee Scotland]
- Three (1%) from representative organisations [the Law Society of Scotland, the Royal Pharmaceutical Society and the Scottish Association of Social Work]
- One (<1%) from a commercial organisation [Highland Home Carers]</li>
- Sixty-six (32%) from individuals with lived-in experience of a physical disability;
- Forty (19%) from individuals with lived-in experience of other types of disability than physical;
- Seventeen (8%) from professionals with experience in a relevant subject;
- One (<1%) from an academic with experience in a relevant subject;
- One (<1%) from individual politicians (MSPs, councillors);
- Thirty-three (16%) from individuals without a disability.

### Of those responses:

- Fifty-six (27%) were anonymous submissions;
- Twenty-nine (14%) of submissions were "not for publication".

Over half of all responses (and 67% of individual responses) were from people with lived experience of disability. Just under a quarter of responses came from organisations, with a large majority of those coming from third sector organisations (82% of organisational responses) This was reflected in the content of responses, where people's personal experiences, and those of third sector organisations supporting disabled people, were evident throughout.

The vast majority (90%) of respondents were supportive of the proposal to establish a Disability Commissioner. There were similar levels of support expressed for the other elements of the proposed bill, including that the Commissioner should: cover all disabilities (92%), have a role in reviewing relevant laws and policies (93%) promote best practice and learn from service providers, key stakeholders and the third sector (89%) and encourage the

involvement of disabled people and disabled persons organisations in the Commissioner's work (95%).

When asked which groups, if any, the Commissioner should be able to investigate, a strong preference was expressed for this to extend to both Scottish public bodies and service providers (83%).

The array of challenges faced by disabled people was highlighted throughout responses, with the need for the Commissioner to have a full understanding of those challenges frequently referred to. Many respondents called for the Commissioner to be a disabled person.

Some potential areas of concern regarding the proposed bill were also highlighted, by those supportive of the proposal, those opposed to the proposal and those who were not in a position to express a view. For example, questions were raised as to how the Commissioner's remit could effectively cover all the different types of disabilities. Other responses suggested that the remit of the Commissioner did not go far enough in the consultation and should be expanded further.

A number of responses questioned how the Commissioner would function in practice. For example, some responses questioned how the Commissioner could feasibly cover all disabilities and fulfil all of the functions listed in the consultation. Some responses questioned the power and leverage that the Commissioner would have in practice, including on improving service provision. A number of responses also highlighted that there was a duplication of function with existing bodies (such as the Scottish Human Rights Commission) and questioned how the Commissioner's work would interact with those of existing bodies such as commissions.

Three responses have not answered the individual survey questions but instead indicated in other ways whether or not they supported the general aims of the proposed Bill, they have been included in the qualitative analysis of responses received to the consultation but have not been included in the statistics. This means these responses are not included in the percentages used throughout this document. However, where appropriate, comments made in those responses have been included in the textual analysis of responses. [The relevant responses are from the National Autistic Society, the Scottish Dementia Working Group and National Dementia Carers Action Network<sup>1</sup> and the Scottish Commission for People with Learning Disabilities]

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<sup>&</sup>lt;sup>1</sup> As a joint response.

# Disclaimer

Note that the inclusion of a claim or argument made by a respondent in this summary should not be interpreted as verification of the claim or as endorsement of the argument by the Non-Government Bills Unit.

# Section 3: Responses to Consultation Questions

This section sets out an overview of responses to each question in the consultation document.

# General aim of proposed Bill

The <u>consultation document</u> outlined the aim of the proposed Bill and what it would involve. Respondents were asked:

# Question 1: Which of the following best expresses your view of the proposed Bill (Fully supportive / Partially supportive / etc.)? Please explain the reasons for your response.

Two hundred and four respondents (99% of the total) answered this question. (Three responses - the National Autistic Society, the Scottish Dementia Working Group and National Dementia Carers Action Network, and the Scottish Commission for People with Learning Disabilities indicated in other ways whether or not they supported the general aims of the Bill. As mentioned above, these responses have not been included in the statistics, but have been included in the qualitative analysis where appropriate.)

# Of those who responded:

- One hundred and fifty-seven (77%) were fully supportive of the proposal<sup>2</sup>;
- Twenty-six (13%) were partially supportive;
- Twelve (6%) were neutral;
- Four (2%) were partially opposed;
- Four (2%) were fully opposed;
- One (<1%) did not wish to express a view.</li>

# Reasons for supporting the proposed Bill

### Challenges faced by disabled people

Many respondents considered that disabled people in Scotland are not given enough respect or support and that the establishment of a Disability Commissioner is therefore necessary and overdue. It was suggested by some respondents that the needs of disabled people are not given sufficient

<sup>&</sup>lt;sup>2</sup> Disability Equality Scotland was fully supportive of the proposal but also provided a breakdown of levels of support amongst its 1,400 members for individual consultation questions – these levels of support can be viewed in the full response which is available here: <u>Disability Equality Scotland Submission.pdf</u> (jeremybalfour.org.uk)

prioritisation, including in policymaking and legislation, with existing strategies and services sometimes considered to be insufficient. David Renton, an individual with lived experience of a disability, stated:

"Currently there are a vast number of hoops through which Disabled people must jump to be enabled to live something even approaching an Equal life. There are too many dead-end routes down which Disabled people may be pointed, and the services that do exist are often disjointed, underfunded and understaffed. Those of us who fight for a readily comprehensible and easy to access joined-up system are often unpaid." (Response number 162, SS ID:196758368)

In discussing the need for a Disability Commissioner, respondents highlighted issues faced by disabled people in their day-to-day lives, with many discussing their own experiences, or the experiences of their children. Disability Equality Scotland's response, which included the views of its members, made reference to difficulties in obtaining "fair and equal access to housing, employment, transport and justice." (Non-Smart Survey response) It quoted one of its members as follows:

"We need a voice where our worries and fears are passed over. We need a voice to tell the government about ALL the problems we face whether it be housing, bullying, access, etc. We need to tell the government that we are not second-class citizens and we matter. I am fed up living in a country where we have to plan our journeys and days. It is virtually impossible for us to be impulsive and just go somewhere."

A number of respondents highlighted the challenges experienced by disabled children, for example, in accessing suitable education and in having suitable adjustments put in place in an educational setting. An individual respondent, Julie Kelly, stated:

"My child is openly discriminated against in most areas of her life. She doesn't have equal schooling, equal access to healthcare and is excluded from developmentally appropriate activities for various reasons, many of which I believe to be discriminatory. She is vulnerable and can't complain. I am exhausted caring for her without support, I need someone else to fight for her rights." (Response number 134, SS ID: 196121958)

Reference was also made to the disproportionate impact that the COVID-19 pandemic has had on disabled people. In its response, Inclusion Scotland discussed this matter:

"COVID-19 has meant that 2020 delivered thousands of additional deaths of disabled people globally, and intensified social isolation and mental ill-health, personal and community poverty, and economic and social instability and insecurity for disabled people. While it has also seen communities rally to support local disabled residents and neighbours, the advent and impact of Coronavirus and the consequences of the ensuing pandemic have revealed the trenchant

inequalities in Scotland for disabled people that existed before COVID-19 arrived.

Our own research, and that of other Disabled People's Organisations, has shown that disabled people and their families were harder hit by Covid-19, not only because they may be at greater risk of severe illness – but equally or more so – because Covid-19 has 'supercharged' the existing inequality they already face and made new inequality likely." (Response number 164, SS ID: 196790626)

### Potential benefits of a commissioner

Many respondents discussed the positive impact that they believed that a Disability Commissioner working hard to understand, prioritise and promote the rights and needs of disabled people could have. Respondents considered that there was a need for disabled people to have "a voice" (Epilepsy Scotland, Response number 116, SS ID:195519501), "a champion" (Linda Bamford, Response number 43, SS ID:191812333) and someone to "fight their corner". (Aberdeen Independent Multiple Sclerosis, Response number 136, SS ID: 196129000)

Further to this, it was suggested that the establishment of an office of the Commissioner could provide a single "point of contact" (Scottish Personal Assistant Employers Network (SPAEN), Response number 4, SS ID:191207876) and a streamlined way for disabled people to access the services that they need. (Karen Procek, Response number 165, SS ID: 196819777)

Johnny Timpson OBE, an individual with lived-in experience of disability, set out his view on the potential positives of establishing the Commissioner role:

"With a higher number of people living with disabilities and greater disability employees' gap than other regions of the UK, Scotland not only has the opportunity to catch up, but to take a lead in embracing inclusion by design, cognitive diversity, intersectionality, equity, equality, access and embedding the social model of disability. This Commissioner role is pivotal in identifying, enrolling and bringing together all stakeholders and sectors together to work collaboratively, and be accountable and responsible for deliver change, improving outcomes and sharing best practice. The Children & Young People's Commissioner an example of what can be done." (Response number 19, SS ID:191303959)

The Scottish Association of Social Work also set out various potential benefits of the role:

"SASW believes that having a dedicated Disability Commissioner would be a positive step in helping to amplify the voices of disabled people across all aspects of society and ensuring that decisions taken at policy level always consider the needs, views and experiences of disabled people. The role could help strengthen participation of disabled people in all aspects of decision making by establishing an important link between disabled people and decision makers, including politicians and public bodies. The Disability Commissioner could also act as a point of contact and representative for disabled people and, crucially, would work to represent and promote all disabilities." (Response number 170, SS ID: 194922236)

### Considerations in establishing a commissioner

Many respondents highlighted matters that they believed should be taken into consideration in establishing the commissioner role, and in the ongoing work of the Commissioner. For example, Epilepsy Scotland discussed the need for the Commissioner to be independent:

"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." (Response number 116, SS ID:195519501),

It was emphasised that disabled people are not a homogenous group, and that different people will have vastly different experiences. (Rosa Hardt, Response number 21, SS ID: 191410043) It was therefore considered important that the Commissioner take account of the many different types of disabilities – including those that are 'hidden' or fluctuating. (Scottish Association of Social Work, Response number 170, SS ID: 194922236)

While supportive of the aims of the proposed bill, some respondents expressed concerns regarding how the commissioner role would work in practice. For example, some respondents questioned how the Commissioner would work in conjunction with other organisations. Enable Scotland stated the need for more information on how the role of the Commissioner will interact with the provisions of the Scottish Government's proposed Learning

<sup>4</sup> Examples of fluctuating conditions include rheumatoid arthritis, myalgic encephalitis (ME), chronic fatigue syndrome (CFS), fibromyalgia, depression and epilepsy. <u>Disability: Equality Act 2010 - Guidance on matters to be taken into account in determining questions relating to the definition of disability (HTML) - GOV.UK (www.gov.uk)</u>

<sup>&</sup>lt;sup>3</sup> A non-visible or 'hidden' disability can be defined as "a disability or health condition that is not immediately obvious. It can defy stereotypes of what people might think disabled people look like." Living with Non-Visible Disabilities - The Disability Unit (blog.gov.uk)

Disability, Autism and Neurodiversity Bill, including the potential inclusion of Learning Disability and Autism Commissioner. (Non-Smart Survey response)

Other respondents expressed concern that the Commissioner would not have enough power to make any meaningful changes. For example, the Independent Living Fund stated that:

"We have indicated [that we are] partially supportive of the Bill as the role needs further consideration, particularly the level and need for appropriate powers to enforce action when identified. Our concern is that in the absence of appropriate powers, the role becomes tokenistic and no real, substantive change is realistic for disabled people." (Response number 191, SS ID: 196937504)

# Reasons for opposing the proposed Bill and other comments

One individual considered the proposed bill to be a "waste of money", particularly given the rising cost of living (Scott Wilson, Response number 32, SS ID: 191564597) Another considered that there are already too many public sector jobs and did not want more to be created by the establishment of a Disability Commissioner (Helen Keith, response number 189, SS ID: 196956356)

Down's Syndrome Scotland, which was partially opposed to the proposal, considered that more emphasis should be placed on the needs of people with learning disabilities. It stated:

"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." (Response number 184, SS ID: 196921375)

The ME Association was also partially opposed to the proposal, but stated that it would support it "on the basis that powers are embedded in this independent office to ensure that full social integration of disabled lives across all ranges and forms of disabilities gets driven forward in all aspects of our society. Constriction of the scope and authority of the proposed office would easily devalue the project." (Response number 158, SS ID: 196623337)

An individual respondent with lived-in experience of a physical disability, Elizabeth Richardson, suggested an alternative to a Disability Commissioner, stating:

"I do not want a Disability Commissioner. I want and need what Ireland has...a National Disability Authority (<a href="https://nda.ie/about/h">https://nda.ie/about/h</a>) with its statutory Centre of Excellence for Universal Design (the only centre of its kind in the world). In my opinion, this is the best approach." (Response number 185, SS ID:196924275)

Two organisations took a neutral view based on concerns related to the existing bodies performing functions that overlap with the roles and responsibilities of the proposed commissioner and also on the grounds of concerns relating to legislative competence.

Given the relevance of the role of the Equalities and Human Rights Commission, their position is set out in some detail below:

"The Equality Act 2006 places a number of duties on us and gives us various powers. The Equality Act 2010 provides a single legal framework to tackle discrimination and harassment, and contains provisions to protect disabled and other people from unlawful treatment and promote a fairer and more equal society. Together, the Equality Acts set out a robust legal framework with an independent regulator to address discrimination against, and promote equality for, disabled people. It is essential that any new Disability Commissioner complements, and does not duplicate, existing roles and functions.

We have a number of questions about how this role might work and therefore, at this stage and in lieu of the necessary detail, we do not have a particular view in favour of or against the proposed Bill. While recognising that the proposals are in an early form, it is not immediately clear to us which of the powers or functions proposed for the new Commissioner are not already held or covered by one or more existing organisations. We are not immediately persuaded that legislation is necessary, given the existing legal framework and associated institutions. The principle of legal certainty means that new legislation should avoid 'cross-over in remit and responsibilities', as anticipated in the proposals.

Our role covers all conditions and impairments which are specified, or meet the definition, in the Equality Act 2010. It would be open to the Scottish Parliament to apply a broader definition in this context should it so wish. The Scottish Government has committed to the introduction of a Learning Disabilities, Autism and Neurodiversity Commissioner. This would appear to overlap significantly with these proposals.

The Equality Act 2006 explicitly gives us a statutory duty to 'monitor the law'. Similar provision is in place with respect to the SHRC. There is therefore significant scope for overlap with the proposals and, potentially, different or even conflicting advice....

The investigatory power in the proposals appears both to overlap with our powers and at the same time be significantly weaker. There is a risk that this proposed power strays into consideration of conduct prohibited by the Equality Act 2010 and therefore outwith devolved competence." (non-Smart survey response)

The Law Society of Scotland, which also took a neutral view on the proposal, raised similar points as the basis for their neutral position.

"The Consultation appears to be focused largely on the Equality Act and the definition of disability in terms of that Act. The Equality Act is a reserved matter. We would suggest that any Scottish proposals should be focused more on the UN Convention on the Rights of Persons with Disabilities("CRPD"), and the broader concept of disability in CRPD, particularly in view of the policy intention to incorporate CRPD into Scots law.2We suggest that consideration be given to focusing the role of any new Commissioner towards implementing the requirements of CRPD in Scotland.

Scotland already has a rather crowded landscape of Commissioners and of organisations with roles which do, could or should discharge functions relevant to the purposes of the Bill. Such organisations include in particular the Mental Welfare Commission for Scotland, Equality and Human Rights Commission, and Scottish Human Rights Commission. The Scottish Government has also committed to creating a Learning Disabilities, Autism and Neurodiversity Commissioner.3The Bill as presently proposed could become a recipe for confusion, overlapping responsibilities, and inefficient use of resources. The present proposal does not appear adequately to address those concerns. We recommend that there be a clear policy decision as to what the future landscape should look like, and how it should fulfilt he requirements of CRPD in relation to all people with disabilities in accordance with the definition in CRPD, effectively, efficiently and in particular without confusion and duplication as to roles.

On the foregoing basis, and subject to the foregoing points, we have at this stage adopted a largely neutral stance in answering the particular consultation questions below." (Non-Smart Survey response) The Health and Social Care Alliance Scotland (The ALLIANCE) also considered that the Commissioner should give specific regard to the UN Convention on the Rights of Persons with Disabilities (UNCRPD), stating that:

"We specifically welcome the suggestion that the Disability Commissioner should give specific regard to the UN Convention on the Rights of Persons with Disabilities (UNCRPD). This is a widely recognised and understood standard for defining and upholding the rights of disabled people, and will give the role a clear, rights-based grounding. The ALLIANCE, alongside over one hundred other signatories, have called on the Scottish Government to incorporate the UNCRPD into Scots Law, and they have committed to do so in an upcoming Human Rights Bill. The process of legislating for a Disability Commissioner should take appropriate regard of the progress of incorporation." (The ALLIANCE, Response number 171, SS ID: 196889077)

Other respondents that took a neutral view towards the proposal stated that further information was required or were doubtful that the proposal could bring about positive change.

Question 2: 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 / Partially supportive / etc.)? Please explain the reasons for your response.

Two-hundred and one respondents (97% of the total) answered this question. Of those who responded:

- One hundred and seventy-six (88%) were fully supportive;
- Sixteen (8%) were partially supportive;
- Two (1%) were neutral;
- Five (2%) were fully opposed:
- Two (1%) were unsure.

### Supportive responses

In answering this question, many respondents either referred to their answer to question one or reiterated their support for the establishment of a Disability

Commissioner. The challenges facing disabled people were also highlighted in a number of responses.

One respondent with lived experience of disability, Jill Bannister, summarised why she considers a dedicated commissioner to be important:

"I think a dedicated commissioner with time to focus on the very wide range of issues affecting disabled people is long overdue. We are a large group and have not had anyone specifically advocating for our interests. Disabled people are a large, heterogenous group who face diverse barriers to participation in society: there are also overlaps with age, as more people become disabled later in life, and the parents/carers of children are another group who would benefit from political representation." (Response number 61, SS ID: 192508995)

Many respondents considered that having a Commissioner who is dedicated to disability issues would ensure that sufficient focus was given the needs of disabled people. It was suggested that where support is currently offered to disabled people, there is often a lack of consistency in services offered and in clarity of from where the support should be sought: One anonymous respondent noted:

"Things are split across multiple organisations at the moment. When you fall in a gap between services it ends up as being nobodies' responsibility and nothing is done. Treating disabilities as a whole should help ensure that the entire world of disability is considered." (Response number 111, SS ID: 195011944)

It was hoped that having a dedicated Disability Commissioner would bring all disability-related matters "under-one-roof" (Anonymous, Response number 77, SS ID: 193099048) and provide a point of contact for disabled people. (Scottish Association of Social Work, Response number 170, SS ID: 194922236)

As well as the expectation that the Disability Commissioner would ensure that focus was placed on the rights and needs of disabled people, it was suggested that they would have more chance of bringing about effective change, with Susan Lee Kemp, a former Scottish Human Rights Commissioner, stating that "expertise, specificity of focus and ear marked resources are key, and this is only really possible with a dedicated commissioner". (Response number 66, SS ID:192514621) Dyslexia Scotland discussed the Commissioner in the context of the Children and Young People's Commissioner, stating:

"We have seen how the establishment of a Scottish Children and Young People's Commissioner has raised the profile of the rights of this section of the Scottish population, including the development of legislation and policies. We believe a Disability Commissioner could have similar value to the rights of disabled and dyslexic people in Scotland." (Response number 121, SS ID: 195817827)

As with responses to questions one, reference was made to the potential establishment of an autism and learning disability commissioner, with the Scottish Government having suggested this may form part of a proposed Learning Disability, Autism and Neurodiversity Bill. The ALLIANCE noted that consideration would need to be given as to how the Disability Commissioner would interact with such a commissioner, as well as commissions that are currently in place. (Response number 171, SS ID: 196889077)

The National Autistic Society Scotland did not select one of the tick-box options but provided detailed background and information on the proposed Autism and Learning Disability Commissioner. It expressed hope that, should the Disability Commissioner proposed by Jeremy Balfour be put in place, there would be a memorandum of understanding between the two commissioners in order to ensure an "effective and positive working relationship." (Non-Smart Survey response)

A number of respondents discussed requirements they would like to see put in place should a Disability Commissioner be established. For example, Carers Scotland argued that the Commissioner's remit should include unpaid carers, stating that:

"The lives of disabled people and unpaid carers are often closely linked and decisions made by public bodies and/or service providers on a range of issues that affect disabled people can often have a direct impact on the lives of carers."

Carers face poverty and significant impacts on their physical and mental health, ability to work and participate in their communities simply because they support someone." (Non-Smart Survey response)

Other points made in supportive responses, included that:

- the Commissioner should be independent from the Scottish Government; (Kevin Robert McAndie, Response number 18, SS ID: 191281712)
- the Commissioner should have lived experience of disability (Anonymous, Response number 45, SS ID: 191818351);
- the rights and needs of people with "invisible" disabilities should be taken into account by the Commissioner. For example, one respondent stated that "We need this desperately to get better results on appeal for invisible disabilities as the[: "]but you don't look disabled["] or ["]we only provide disabled customers who are in wheelchairs sorry but your not

the correct category of disabled["] is soul crushing." (Dave M Hunter, Response number 75, SS ID:192720471)

# Opposed responses and other comments

Of the limited number of people who answered in this way and provided comment, the views expressed included that there is no need for a Commissioner (Helen Keith, response number 189, SS ID: 196956356) and that money would be better spent on services. (Anonymous, Response number 188, SS ID: 196949829).

The Equality and Human Rights Commission (EHRC), which did not select one of the tick-box options, noted the number of existing bodies and organisations which already have a role in representing disabled people, stating:

"It is not immediately clear to us which of the powers or functions proposed for the new Commissioner are not already held or covered by one or more of these existing organisations."

It went on to note the intersectionality between different characteristics, and the need for a commissioner to be cognisant of such intersections, stating:

"for example, a law or policy may impact differently on disabled women and men, services may meet the needs of White disabled people but not the needs of disabled people from certain ethnic minorities." (Non-Smart Survey response)

# Question 3: Do you think legislation is required, or are there other ways in which this Bill's aims could be achieved more effectively? Please explain the reasons in your response.

One hundred and seventy-six (85% of the total) answered this question.

There was not a tick-box option for this question. Many respondents simply stated that they considered that legislation was, or was not, required in order for the proposed bill's aims to be achieved. Some respondents were unsure, while others stated that they needed more information before reaching a decision.

The Neurological Alliance of Scotland set out its views on this matter as follows:

"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." (Response number 156, SS ID:196556828)

A similar view was expressed by the Royal Pharmaceutical Society, which considered that, if given the legislative power to do so, the Commissioner could affect positive change"

"To have a significant impact and affect change the role would need statutory powers to ensure timely investigation, access to information and compulsion of co-operation that can only be conferred by law. It is also important that this new role is entirely independent to ensure that investigations can be carried out without undue influence by government or employers". (Response number 163, SS ID: 196788596)

It was considered by many that without legislation the needs of disabled people would not be given the focus and attention that is required. Further to this, concern was expressed that, without a legal framework behind it, the work of the Commissioner could be ignored, or the Government, or future Governments, could renege on the decision to have a commissioner. (Anonymous, Response number 68, SS ID: 192522496)

Many responses discussed existing legislation that relates to disabled people. Some felt that legislation which is currently in place is not fully enforced by councils or public bodies (Robert H.Dick, Response number 47, SS ID: 191856339), is ignored by organisations (Anonymous, Response number 111, SS ID: 195011944) or is frequently breached without any consequences. (Mobility and Access Committee Scotland, Response number 106, SS ID:193927925). In its response Scottish Disability Sport stated:

"The Equality Act has put in place the legislation required. However, disability seems to have slipped down the pecking order within the [Equality, Diversity and Inclusion] agenda. Positive policy, strategy, action and resource is now required to redress this balance and seriously address the unique cultural barriers faced by people with disabilities." (Response number 78, SS ID: 193226454)

In addition, the Scottish Personal Assistance Employers Network (SPAEN) discussed this in its response:

"We have had 12 years of a Self-directed Support Strategy; 17 years of a disability employment strategy and many more years of campaigning and fighting for equality in aspects such as housing; education and access to other parts of civil society, all of which have failed to make meaningful progress toward the rights of disabled people.

SPAEN considers that legislation is not only preferable but is absolutely essential if the Commissioner is to meaningfully represent and progress matters for disabled people in Scotland. A Commissioner

without a legislative basis would be yet more 'tokenism'." (Response number 4, SS ID: 191207876)

Some respondents were unsure of whether creating new legislation was the best option or would be enough to bring about change. For example, Rosa Hardt, a support worker who works with adults with learning disabilities, suggested that cultural change would also be needed. (Response number 21, SS ID: 191410043).

As with responses to previous questions, reference was made to the existence of commissions and other organisations which represent disabled people. Some respondents expressed concern that, should a Disability Commissioner be established, there would be a duplication of work, with EHRC stating that:

"While recognising that the proposals are in an early form, it is not immediately clear to us which of the powers or functions proposed for the new Commissioner are not already held or covered by one or more existing organisations. We are not immediately persuaded that legislation is necessary, given the existing legal framework and associated institutions. The principle of legal certainty means that new legislation should avoid 'cross-over in remit and responsibilities', as anticipated in the proposals." (Non-Smart Survey response)

Enable Scotland noted that there may be other routes to achieving some of the aims as set out in the consultation document, for example by creating a dedicated Scottish Government Minister for Disabled People. It stated, however, that such a role would not be independent as the proposed Commissioner is intended to be. (Non-Smart Survey response)

Sight Scotland and Sight Scotland Veterans considered that further legislation was not the key to creating positive change, stating:

"There is currently a wide range of legislation that aims to uphold the rights and ensure support is available for disabled people, however these are not always upheld. It is our view that further legislation would not add value to the existing landscape, and instead more work must be done to raise awareness of current obligations, identifying gaps and needs not being met, as well as highlighting good practice and positive examples. The role of the Commissioner is suited to these functions and would help to achieve the aims of the Bill effectively. In addition, the role of the third sector in service provision is often undervalued; having a Commissioner would allow direct dialogue and improved collaboration and coordination with providers." (Response number 159, SS ID: 193726472)

# Scope of the Disability Commissioner Role

Question 4: Which of the following best expresses your view of the Disability Commissioner role covering all disabilities; physical, mental, hidden and fluctuating conditions (Fully supportive / Partially supportive / etc.)? Please explain the reasons for your response, including how the commissioner could co-ordinate with the work of existing bodies/organisations who support people with these conditions.

Two-hundred and one respondents (98% of the total) answered this question. Of those who responded:

- One hundred and sixty-one (80%) were fully supportive;
- Twenty-four (12%) were partially supportive;
- Three (1.5%) were neutral:
- One (0.5%) was partially opposed;
- Five (2.5%) were fully opposed;
- Seven (3.5%) were unsure.

# Supportive responses

Many respondents discussed the importance of the Disability Commissioner representing all disabled people, noting that every disabled person deserves to be supported. Camphill Scotland stated:

"We believe this is necessary to ensure that the Commissioner is a champion for all disabled people, and that all disabled people are able to seek assistance and support from the Commissioner. It will also provide that the Commissioner's remit covers the full range of issues impacting upon all disabled people." (Response number 179, SS ID:196280242)

It was further noted that to have a Commissioner for people with some disabilities but not others could "risk creating an unhelpful hierarchy of disabilities." (Anonymous, response number 84, SS ID:193861681) Hope was expressed that, instead, the establishment of a Commissioner who's remit

covers all disabilities could create "cohesion" and "unity". (Anonymous, response number 60, SS ID: 192508322)

Some respondents discussed what and who the Commissioner's remit should cover in more detail. For example, reference was made to the social model of disability, with the Drake Music School stating:

"We believe in the social model of disability - that it is the disabling barriers in society that prevent full participation not individuals' conditions. If someone self-identifies as being disabled, then they should be consulted on their needs and more effort needs to be put towards meeting their needs. Ultimately, we will all benefit from this." (Response number 13, SS ID: 191237986)

SPAEN, Enable and others considered that the Commissioner's role should cover disability as defined in the Equalities Act 2010.<sup>5</sup>

However, the Law Society of Scotland did not consider that the definition should be drawn from the Equality Act, noting that it "may exclude some conditions or societal barriers" and was largely based on "a medical model of disability." It noted that disability is an evolving concept, and any definition must allow for that. (Non-Smart Survey response)

The challenges facing people with 'invisible', 'unseen' or fluctuating disabilities was a recurring theme in responses, with Mobility and Access Committee Scotland stating in its response:

"Too often those with hidden disabilities are forgotten and excluded by a narrow interpretation of what it means to be disabled. It's important the commissioner has responsibility for all disabilities but also works closely with the organisations that have the detailed knowledge of the diversity of disabilities included in the role." (Response number 106, SS ID:193927925)

It was hoped that the Commissioner could highlight and educate people on the challenges faced by people with such conditions, with #ME Action Scotland stating that this in turn could help break down the stigma that people with conditions such as ME face. (Response number 175, SS ID: 196910891)

A large number of respondents emphasised the importance of the Commissioner having a thorough understanding of the challenges facing disabled people, with some preferring that the Commissioner has lived

<sup>&</sup>lt;sup>5</sup> The Equality Act 2010 defines a disabled person as a person who has a physical or mental impairment, and the impairment has a substantial and long-term adverse effect on the person's ability to carry out normal day-to-day activities

experience of a disability. (Robert H. Dick, Response number 47, SS ID: 191856339). It was noted that, should the Commissioner cover all disabilities, it may prove difficult for them to have experience and knowledge of all types of conditions. The Neurological Alliance of Scotland's response reflected on this, stating:

"[T]here 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." (Response number 156, SS ID:196556828)

Down's Syndrome Scotland expressed concern that giving the Commissioner such a wide remit could lead to them being spread too thinly:

"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." (Response number 184, SS ID: 196921375)

Many respondents considered that the Commissioner should work with, and employ, people with lived experience of a wide variety of conditions, as well as with the relevant organisations and charities in order to ensure the views and needs of all disabled people are fully represented. MND Scotland discussed how the Commissioner could effectively work with existing bodies, while accounting for the Commissioner's wide-ranging remit:

"Because the scope is so broad, it will be essential that the Commissioner engages with the full range of third sector agencies which support people with this broad range of disabilities. This can be achieved in many ways including regular updates, engagement and communications directly from the Commissioner's office that bodies/organisations can sign up for and ensuring that current third sector membership organisations, for example, the Alliance, also keep their membership up to date." (Response number 178, SS ID:196816851)

Other comments on the extent of the role of the Commissioner, serve to demonstrate the expansive and varied roles envisaged. For example, it was suggested:

- multiple roles could be created to represent different disabilities;
   (Anonymous, Response number 110, SS ID: 194974782)
- the Commissioner's remit should include carers (Karen Procek, Response number 165, SS ID: 196819777) and other people whose lives have been impacted by the disabilities of others; (Law Society of Scotland, Non-Smart Survey response)

# Opposed responses and other comments

Very few respondents who answered in this way gave further comment. Those who did thought that that there are already relevant bodies in place (Helen Keith, response number 189, SS ID: 196956356) or that it was for Jeremy Balfour, as member in charge of the proposed bill, to answer such a question rather than respondents to the consultation. (Anonymous, Response number 188, SS ID: 196949829)

One anonymous respondent with lived experience of disability stated that:

"While I appreciate there is a rise in mental health issues, there are other avenues of support available for those and feel a commissioner solely focused on disabilities would be beneficial and much needed. Perhaps a different mental health ambassador or commissioner role is required for the former. the Commissioner should not cover all disabilities." (Anonymous, Response number 52, SS ID:192172548),

There were mixed views from respondents who were neutral or unsure and who provided further comment. Some considered that more information was needed (for example, Linda Campbell, Response number 101, SS ID: 194785517), while others considered it could be difficult for the Commissioner to cover all disabilities. Reference was also made to the difficulties that disabled people often face, with one respondent with lived-in experience of disability, Faith Ougham, stating:

"Try and get people to talk to each other and have person centred care for disabled people, instead of talking down to disabled people and treating disabled people as shite..." (Response number 161, SS ID: 196723846)

Fiona Rogan, an individual with lived-in experience of disability, was neutral towards the question, but expressed some concern:

"I do worry that it can get messy. Physical disability is more crucial because of the barriers. But there are other issues like hidden

disability. I do worry about mental health- seems difficult to know where to stop." (Response 33, SS ID: 191568487)

The Scottish Dementia Working Group and National Dementia Carers Action Network questioned whether the Commissioner would be able to represent all disabilities effectively, given the broad spectrum that this would cover, and expressed concern that hidden or fluctuating conditions such as dementia may be given lower priority. It called for a clear definition of disability to be set out. (Non-Smart Survey response)

Question 5: 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 / Partially supportive / etc.)? Please explain the reasons for your response.

One hundred and ninety-nine respondents (97% of the total) answered this question.

Of those who responded:

- One hundred and seventy-one (86%) were fully supportive;
- Fourteen (7%) were partially supportive;
- Three (1.5%) were neutral;
- Two (1%) were partially opposed;
- Four (2%) were fully opposed;
- Five (2.5%) were unsure.

### Supportive responses

Many respondents considered that giving the Commissioner a role in reviewing laws and policies that might impact on disabled people would ensure that matters affecting disabled people are given the focus and priority that is needed. Muscular Dystrophy UK set out its view on the potential benefits of the Commissioner performing such a role:

"It is important for the Commissioner to be aware of changes to any laws and policies proposed that might impact on disabled people. Additionally, they can be the vehicle between the leading governmental team (who is putting forward the policies) and the disability representatives. You can discuss these changes with the community to identify gaps or barriers that have been overlooked. It will also provide people with a disability with a key contact to approach to share their

concerns or address queries relating to new or existing policies." (Response number 56, SS ID:192443488)

It was suggested that the Commissioner should review both new and preexisting laws and highlight where improvement is needed. Suggestion was made that the Commissioner could undertake to review all law and policy with a view to ensuring that the needs of disabled people are represented every law and policy. (Epilepsy Scotland, Response number 116, SS ID:195519501)

It was noted that some organisations, such as those in the third sector, already undertake work to review laws and policies. However, one respondent noted that such work is "piecemeal" with the view expressed that "a strong and full resourced Commissioner, with real and extensive powers, to provide informed, consistent and comprehensive input into such policies and laws." (David Renton, Response number 162 SS ID:196758368)

As with responses to the previous questions, the importance of the Commissioner having working knowledge and/or lived-in experience of the challenges facing disabled people was stressed by a large number of respondents. The need for disabled people to be consulted as part of the review process was also highlighted. The Royal Pharmaceutical Society stated:

"The role of commissioner would require a working knowledge of the discrimination that disabled people face on a day-to-day basis. This knowledge could be enhanced through working with people with lived experience, and expert groups who can provide a view on the impact their disability has on daily life. All this knowledge brought together should enable the commissioner to provide insight to those writing laws on the potential impact of them on those with disabilities and will give a stronger voice to those living with a disability.

It may also encourage those writing the laws and policies to be more mindful of the impact of what they are producing on all those who have protected characteristics." (Response number 163, SS ID: 196788596)

Some respondents focused on the need for the Commissioner to be "impartial and a-political" (Anonymous, Response number 34, SS ID:191570083) while others gave a more detailed explanation of how they envisioned the Commissioner carrying out the role of reviewing policy and legislation. For example, the Scottish Association of Social Work (SASW) stated:

"It is crucial that all proposed legislation is considered and scrutinised from the perspectives of disabled people. SASW envisions the Disability Commissioner having an important role in engaging disabled people in consultation processes on proposed legislation, being called to provide evidence to committees and providing advice to government ministers and officials on legislative proposals. The Disability

Commissioner should also promote ways that disabled people can engage individually in the legislative process, including bringing forward petitions and how to engage with their MSPs, MP and local councillors." (Response number 170, SS ID: 194922236)

The role of existing commissioners was referenced by other respondents, with some noting that precedent had been set for a commissioner to have a role in reviewing laws and policies by the Children and Young People's Commissioner. (Sight Scotland and Sight Veterans, Response number 159, SS ID: 193726472)

Some respondents expressed concern that a reviewing role would not go far enough and emphasised the need for the Commissioner to have power and authority in order to effect real change. For example, RNID stated:

"We would...ask the Commissioner to go further than reviewing laws and policies. We would want the Commissioner to involved in the design and formulation of laws and policies – ensuring the needs of disabled people are built-in from the start and not included retrospectively through a review process.

We therefore hope that the Commissioner would consider part of their role as being to open-up policy making and to support the facilitation of genuine co-production between the Scottish Government and disabled people." (Non-Smart Survey response)

## Opposed responses and other comments

Of the respondents who chose this option, only three provided further comments. One was marked as not for publication, one stated that a change to the law was not necessary (Helen Keith, response number 189, SS ID: 196956356) and one stated their reason for opposition as being "experience." (Anonymous, Response number 188, SS ID: 196949829)

The EHRC, which did not select a tick-box option, noted that it already has a duty to monitor the law, and that similar provisions related to the Scottish Human Rights Commission. It noted that:

"the [Equality Act] 2006 explicitly gives us a statutory duty to 'monitor the law', including advising Scottish Ministers in relation to the effect of Acts of the Scottish Parliament. Similar provision is in place with respect to the SHRC. There is therefore significant scope for overlap and, potentially, different or even conflicting advice." (Non-Smart Survey response)

Some respondents who took a neutral view to this question considered that further information was required or questioned whether the Commissioner could make a difference should they review laws and policies. One anonymous respondent stated that the Commissioner should "advise on and

suggest revisions but not have a lead role in reviewing." (Response number 96, SS ID: 194277460)

Question 6: 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 / Partially supportive / etc.)? Please explain the reasons for your response, including how you envisage this work being undertaken?

Two hundred respondents (97% of the total) answered this question.

Of those who responded:

- One hundred and sixty (80%) were fully supportive;
- Eighteen (9%) were partially supportive;
- Five (2.5%) were neutral;
- Three (1.5%) were partially opposed;
- Five (2.5%) were fully opposed;
- Nine (4.5%) were unsure.

# Supportive responses

Respondents generally considered it important that the Disability Commissioner learns from those with relevant knowledge and experience, whilst promoting best practice. Suggestion was made that the Commissioner could collate and disseminate information about best practice, (The ALLIANCE, Response number 171, SS ID: 196889077) with the RNIB stating that the Commissioner should "operate as the model of best practice." (Non-Smart Survey response)

The need for the Commissioner to have good communication skills and a willingness to regularly consult with others was frequently raised in responses. For example, SPAEN stated:

"To gain the full benefit of having a Commissioner, the post-holder must ensure they engage with and learn from key stakeholders (disabled people) whilst also promoting and encouraging the widespread adoption of best practice. Indeed, SPAEN would like to see the Commissioner championing best practice across local and national government; the public, private and third sector on behalf of and in partnership with disabled people." (Response number 4, SS ID: 191207876)

It was considered by some respondents that the Commissioner should learn from the 'ground up' rather than from the 'top down' in order to engage with a wide range of people. (Anonymous, Response number 34, SS ID:191570083) In its response, Epilepsy Scotland stated:

"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 and facilitate sharing of best practice." (Response number 116, SS ID:195519501)

Many respondents praised the good work that is already being carried out by third sector organisations and service providers and emphasised that existing work should not be undermined by the work of the Commissioner, or unnecessarily duplicated. (Down's Syndrome Scotland, Response number 184, SS ID: 196921375) The ALLIANCE set out an example of how the sharing of best practice could work in practice:

"Giving the Disability Commissioner a role in promoting this information would mean there is a clear, central resource that anybody could access. One way of delivering on this goal would be to have dedicated staff in the commissioner's office that can work with anyone wanting to share best practice and learning, to collate the information and make it available. In addition, ensuring that there is adequate funding to, for example, have documentation appropriately and professionally designed, as well as translated into a range of accessible formats, would help to disseminate the information to the widest possible audience." (Response number 171, SS ID: 196889077)

Some concerns were raised regarding how the promotion of best practice would work. For example, it was suggested that ideas of what constitutes best practice do not always translate in a way that makes a difference "on the ground" (Anonymous, Response number 25, SS ID:191445769), while others considered that there may be conflicting views of what represents good practice. (Anonymous, Response number 84, SS ID:193861681)

Further points made related to service provision already in place and the need for further information on how the commissioner role will operate:

 service provision was often lacking, particularly since the COVID-19 pandemic; (Anonymous, Response number 148, SS ID: 196264075)

- service providers may not always have the best interests of those they provide a service to at heart; (Ask Autism North East, Response number 94, SS ID: 194256187)
- further information was needed on how the Commissioner could hold service providers, key stakeholders and others to account if their services do not deliver; (Cerebral Palsy Scotland, Response number 120, SS ID: 194641358)
- further information was required on how the work in promoting best practice could be linked to informing policy; (Jane Edwards, Response number 112, SS ID:195188856);
- the Commissioner must ensure that service providers are "fully and reliably funded and staffed on and ongoing basis, that stakeholders be enabled to have input at all relevant times, and that the third sector be resourced sufficiently to provide the input it would then be capable of doing;" <sup>6</sup>(David Renton, response number 162, SS ID: 196758368)
- the Commissioner's time could be better spent on policy and advocacy work. (MS Society, Non-Smart Survey response)

# Opposed responses and other comments

Of those who answered in this way and provided further comment, some queried whether third sector organisations and service providers were best placed to provide examples of best practice. For example, one anonymous respondent took the view that:

"Service providers, and the third sector in many cases curb best practice. They do this by being more focused on proving the need for more funding, than in enabling their clients. This has long been witnessed, for example, in meetings of Integrated Joint Boards, where public and third sector bodies come together, and exclude addressing what would help their clients or the wider community of people with special or increasing needs." (Anonymous, Response number 20, SS ID: 191396599)

Others stated that they did not think it would be useful for the Commissioner to carry out the task or that it was the role of service providers to do so. (Helen Keith, response number 189, SS ID: 196956356)

Some respondents who took a neutral view or were unsure stated that they were unsure what was meant by the question or that they required more information in order to reach a view. Other respondents who answered in this way commented further on the challenges facing disabled people.

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<sup>&</sup>lt;sup>6</sup> The components of the proposed bill are set out in the consultation document: <u>disability-commissioner-consultation-final.pdf</u> (parliament.scot)

Question 7: 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 / Partially supportive / etc.)? 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.

One hundred and ninety-eight respondents (97% of the total) answered this question.

### Of those who responded:

- One hundred and seventy-nine (90%) were fully supportive;
- Nine (4.5%) were partially supportive;
- Three (1.5%) were neutral;
- One (<1%) were partially opposed;
- Two (1%) were fully opposed;
- Four (2%) were unsure

### Supportive responses

Many respondents believed it to be vital that the Commissioner engages with disabled people and Disabled Persons' Organisations (DPOs), considering that there would be little value in establishing a Disability Commissioner who did not listen to and represent disabled people. It was noted that people with lived-in experience of disability would be best placed to highlight issues of relevance and to help shape the work of the Commissioner. One respondent with lived-in experience of disability, Linda Bamford, commented on the need to draw on the expertise of DPOs:

"I fully support this approach and would suggest that any approach other than this would be poor. It is key that a Disability Commissioner engages with DPOs and uses this resource to designs laws and policies that will advance equality for disabled people. DPOs have a wealth of knowledge and experience and are aware of the current inequalities and solutions to address it. It is critical that these voices are brought to the forefront." (Response number 43, SS ID:191812333)

Down's Syndrome Scotland expressed concern that the consultation document for the proposed bill referred to "encouraging" the involvement of

disabled people in the work of the Commissioner. It was of the view that the proposed bill should instead "set out clear mechanisms (or clear expectations) for the active involvement of disabled people in the work of the Disability Commissioner." (Response number 184, SS ID: 196921375)

It was pointed out that there are many different kinds of disabilities, and that the Commissioner should therefore engage with a wide range of disabled people and DPOs. For example, Jill Bannister stated:

"The diversity of the disabled population is such that no one individual or group could possibly advocate for them all without grassroots participation, which has always been a priority of the disability movement. Nothing about us without us!" (Response number 61, SS ID: 192508995)

Others indicated that there is a need to ensure that the views of those with "unseen" or fluctuating disabilities are represented, with MND Scotland also highlighting the need to seek the views of people who may not identify themselves as disabled. (Response number 178, SS ID: 196816851)

It was suggested that some people would be unlikely to engage with the work of the Commissioner. For example, RNID noted that nearly a third of deaf people do not have internet connection and that such people will "have substantively different needs from the digitally literate and have different experiences and face different barriers when accessing goods and services." (Non-Smart Survey response)

As with responses to previous questions, many respondents considered that the Commissioner should be a disabled person, with RNID also suggesting that disabled people should be involved in the recruitment process for the Commissioner (Non-Smart Survey response). One anonymous respondent stated:

"A commissioner without the lived or expert experience of disability would be both unrepresentative and offensive. It's crucial that any commissioner has a deep understanding of disability beyond the textbooks. There should be efforts made to recruit disabled people to the commissioner and rules about ensuring their involvement in all decisions." (Response number 60, SS ID: 192508322)

It was further suggested that the office of the Commissioner should employ disabled people, with Guide Dogs Scotland, for example, stating that it would welcome "positive action to encourage a diverse and representative staff team in the office of Disability Commissioner." (Response Number 160, SS ID: 196642935) Employing disabled people, including through paid internships, was considered to be a good way of involving disabled people in the work of the Commissioner, while sending a strong message and improving "employment opportunities and experience for those with disabilities as well

as their skills, independence and relationships." (Anonymous, Response number 26, SS ID: 191481716)

#MEAction Scotland provided an example of how engagement between disabled people and the Commissioner could work in practice, as well as emphasising the need for accessibility:

"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." (Response number 175, SS ID: 196910891)

Edinburgh Access Panel suggested that DPOs could continue their work as they do at present, with the Commissioner having oversight:

"The DPOs would continue to highlight and run with issues, escalating to the Commissioner as required. The DPOs would probably provide high level updates to the Commissioner (eg quarterly highlights and lowlights) to help the Commissioner maintain a holistic view of issues." Edinburgh Access Panel, Response number 22, SS ID: 191428695)

Volunteer Scotland emphasised the need for the Commissioner to work collaboratively with the volunteering sector "acknowledging existing pressures and helping them to leverage the resource required to provide inclusive volunteering opportunities for disabled people." (Non-Smart Survey response)

Other points that were raised by supportive respondents included that:

- carers should also be able to feed into the work of the Commissioner; (Carers Scotland, Non-Smart Survey response)
- the Commissioner's office should have a flexible working environment and suitable access arrangements for disabled people; (#MEAction Scotland, Response number 175, SS ID: 196910891)
- any paid work undertaken by disabled people should not compromise the welfare rights or support packages of those

- involved; (Anonymous, Response number 20, SS ID: 191396599)
- any engagement between DPOs and the commissioner should be ongoing; (Mobility and Access Committee Scotland, Response number 106, SS ID:193927925)
- there must be adequate resourcing to "ensure that individuals have the training and support to participate, including from groups who traditionally have been "seldom heard." (Carers Scotland, Non-Smart Survey response))

# Opposed responses and other comments

Only one respondent who was opposed provided further comment, stating that "[d]isabled people and their Organisations can already lobby MPs, MSPs and parliament." (Helen Keith, response number 189, SS ID: 196956356)

Very few respondents who were neutral or unsure provided further comment. One such respondent stated that DPOs can "see themselves as experts without justification." (Linda Campbell, Response number 101, SS ID: 194785517)

Question 8: Who should the Disability Commissioner be allowed to investigate? (Scottish Public Bodies/Service providers (any person providing services for disabled people)/ Both Scottish Public Bodies and service providers/The Commissioner should not have power to carry out investigations) Please explain the reasons for your response.

One hundred and ninety-one respondents (93% of the total) answered this question.

### Of those who responded:

- Nine (5%) considered that the Disability Commissioner should be allowed to investigate only Scottish public bodies;
- Ten (5%) considered they should be allowed to investigate only service providers;
- One hundred and sixty (83%) considered they should be allowed to investigate both Scottish public bodies and service providers;
- Twelve (6%) considered the Commissioner should not have the power to carry out investigations.

# Power to investigate Scottish public bodies

Of the limited number of respondents who answered in this way only a few gave further comments. It was considered that being able to hold public bodies fully to account could lead to improvements in the lives of disabled people, with MND Scotland noting that:

"This would be a good starting point for the Disability Commissioner to investigate Scottish Public Bodies. If necessary, the commissioner's role could be widened to others, for example, service providers." (Response number 178, SS ID:196816851)

However, the Neurological Alliance of Scotland, which consulted its members in preparing its response, raised some queries and concerns regarding the investigative process:

"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." (Response number 156, SS ID:196556828)

## Power to investigate service providers

It was considered that there should be a way of holding service providers accountable for their actions. (Anonymous, Response number 28, SS ID:191510643) Another suggestion was that while the Commissioner should have an oversight role, people with relevant expertise should also have a role in the investigative process. (Anonymous, Non-Smart Survey response) The MS Society stated that giving the power to investigate may lead to duplication of work, noting that:

"It is important the Disability Commissioner is empowered with the ability to investigate the complaints of or issues that arise for disabled people and we would hope a Commissioner would be able to investigate public bodies.

We are not opposed to the principle of the Disability Commissioner having the remit to investigate all service providers in the interests of disabled people however we are aware this could lead to duplication of work. Depending on the care provider the CARE Inspectorate or a respective health professional's council will be a more appropriate

investigatory body and in those cases the Commissioner should refer to them. (Non-Smart Survey response)

# Power to investigate both Scottish public bodies and service providers

Many respondents were of the view that the Commissioner would not be able to perform their role successfully without having the power to investigate both Scottish public bodies and service providers. It was hoped that doing so would ensure that the needs of disabled people were met and that relevant parties would be held accountable for their actions. One respondent with lived-in experience of disability, Terry Robinson, stated that:

"Government and Service providers have a duty to serve all, including disabled people. It is through a failure to do this properly that disables us. Any effective commissioner must investigate and strive to prevent or eliminate such failures." (Response number 50, SS ID: 192061092)

Some respondents pointed to the discrimination that disabled people face, and considered that the Commissioner should be able to investigate such instances:

"Camphill Scotland is aware that disabled people are discriminated against in many areas of their every day lives, including education, housing, welfare and employment, and that this discrimination occurs across many different sectors. It is, therefore, essential that the Commissioner should be allowed to investigate both Scotlish Public Bodies and service providers." (Camphill Scotland, Response number 179, SS ID: 196280242)

It was noted that the work of public bodies and services providers are often interlinked, with both having a duty to uphold disabled people's rights and it was therefore considered necessary that the Commissioner should have the power to investigate both. Epilepsy Scotland stated:

"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." (Response number 116, SS ID:195519501)

The Royal Pharmaceutical Society discussed the importance of the Commissioner being able to investigate both public bodies and services providers, in order to support improvement:

"It would be important for the commissioner to be able to investigate both Scottish Public Bodies and service providers to ensure consistency in the approach to how disabled people are considered. It is also important that the commissioner supports anyone it investigates to gain relevant knowledge on how to make improvements, to change their practice and make reasonable adjustments to remove the barriers to disabled people and ensure an inclusive environment for all." (Response number 163, SS ID: 196788596)

A recurring view was that the power to investigate should be extended, with SPAEN, for example, suggesting that "this should extend to beyond just public bodies and service providers and include DPO's and any other bodies representing or working with disabled people who might argue they are outside the scope of a "service provider" where they do not necessarily provide "services" in the legal definition of the term." (Response number 4, SS ID: 191207876)

Concerns were raised that, should the Commissioner not have the power to enforce consequences where examples of poor service were found, then the work would be "toothless." (Jane Edwards, Response number 112, SS ID:195188856) In its response, the ALLIANCE suggested that the power to enforce recommendations would be limited, but that investigations would still be of importance:

"In order for the Disability Commissioner to fully act as a champion for disabled people, they must have the broadest possible powers of investigation. Although there is likely to be limited scope for enforcing recommendations emerging from any investigations into service providers that are not Scottish Public Bodies, the very act of having investigated an issue and the ability to 'name and shame' providers that have breached the rights of disabled people is likely to encourage change." (Response number 171, SS ID: 196889077)

Both Guide Dogs Scotland (Response Number 160, SS ID: 196642935) and the Scottish Association of Social Work (Response number 170, SS ID: 194922236) suggested that the process of investigation should be in line with that of the Children and Young Persons Commissioner<sup>7</sup>. Other suggestions

The Commissioner can't investigate a case if a case if:

<sup>&</sup>lt;sup>7</sup> The Children and Young People's Commissioner Scotland can investigate enquiries around if service providers have failed to:

<sup>•</sup> uphold the rights, interests and views of individual children and young people when taking actions or making decisions that affect them, or

<sup>•</sup> uphold the rights, interests and views of a group of children and young people when taking actions or making decisions that affect them.

made included that guidance should be published "to identify a clear procedure and governance for such investigations" (Muscular Dystrophy UK, Response number 56, SS ID:192443488) with the RNIB noting the need for investigations to be "fully transparent and avoid conflict of interests." (Non-Smart Survey response)

Some potential issues were raised in regard to the investigation process. For example, Inclusion Scotland, which took the views of its members and staff team in formulating its response, noted that those who were more sceptical about the Commissioner's power to investigate felt that:

"[I]nvestigative powers alone will not lead to the policy and legislative changes necessary to protect and promote disabled people's rights, as even when existing organisations such as the EHRC have investigative powers, as well as legal and enforcement powers using the court and tribunal systems, this has not resulted in the necessary policy and legal changes for disabled people." (Response number 164, SS ID: 196790626)

It was noted that organisations such as EHRC and Scottish Human Rights Commission (SHRC) already have a range of powers and that consideration should be given to how the power for the Commissioner to investigate would work in conjunction with these, with suggestion made that there may be unnecessary duplication of work. (RNID, Non-Smart Survey response)

Susan Lee Kemp, former Commissioner of the Scottish Human Rights Commission, considered investigative powers to be important but suggested the process would require "staff, funding, time and access to information." (Response number 66, SS ID:192514621)

# The Commissioner should not have power to carry out investigations

The view was expressed that while the Commissioner should not carry out investigations, they could instigate an investigation by another body, such as Audit Scotland (Anonymous, Response number 20, SS ID: 191396599) or could initiate a consultation or review of services (Anonymous, Response number 82, SS ID:193757872). One respondent, while happy for the Commissioner to look into relevant issues, considered that the term "investigate" holds negative connotations. (Marjan Sikkel, Response number 92, SS ID: 194129250)

<sup>•</sup> it relates to matters reserved to the UK Government,

<sup>•</sup> it concerns the decision-making of a court or tribunal in a particular case, or

<sup>•</sup> it concerns a case currently before a court or tribunal

<sup>•</sup> another body in Scotland is able to investigate it.

EHRC, while not expressing a view as to who the Commissioner should have the power to investigate, cautioned that the investigative powers must only be limited to the devolved powers of the Scottish Parliament, stating:

"There is a risk that this proposed power, not least in relation to 'individual' investigations, strays into consideration of conduction prohibited by the Equality Act 2010 – particularly discrimination – and therefore outwith devolved competence." (Non-Smart Survey Response)

EHRC also called for more detail about how investigations would be carried out. It stated that:

"As noted elsewhere in this response, we have powers of investigation in relation to suspected unlawful acts under the EA 2010. We can compel evidence and it is an offence not to comply, enforceable in the courts. The investigatory power in the proposals appears both to overlap with our powers and at the same time be significantly weaker. It is also unclear how any issues identified by an investigation by the proposed Commissioner would be addressed. For example, following a CYPCS [Children and Young People's Commissioner Scotland] investigation into restraint in Scottish schools, we worked with CYPCS to use our legal powers to support a judicial review of the Scottish Government to address some of the findings. This approach would not have been available to CYPCS alone.

There is a risk that this proposed power, not least in relation to 'individual' investigations, strays into consideration of conduct prohibited by the EA 2010 – particularly discrimination – and therefore outwith devolved competence.

We would also welcome more detail about what it means for an investigation to be 'carried out in public'. We have in the past conducted evidence sessions in public, but our experience is that there can be legal and other reasons why this is not desirable or, in some cases, possible." (Non-Smart survey response)

## Financial implications

Question 9: 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/some increase in cost/ no overall change in costs)

One hundred and eighty respondents (87% of the total) answered this question.

## Of those who responded:

- Nineteen (10%) considered that there would be a significant increase in costs:
- One hundred and three (57%) considered that there would be some increase in costs;
- Thirty-one (17%) considered that there would be overall change in costs;
- Twenty (11%) considered that there would be some reduction in costs;
- Eight (4%) considered that there would be significant reduction in costs;

#### Increase in costs

Many respondents made reference to the costs involved in setting up the office of the Commissioner, for example, in paying their salary, the salary of their staff and ongoing administrative costs. Further costs noted included setting up a physical office that was accessible for all (Anonymous, Response number 91, SS ID: 193836082) and the use of inclusive communications. (ALLIANCE, Response number 171, SS ID: 196889077)

Some comparison was made to the Children and Young People's Commissioner, which was estimated to cost £1.3 million per year to run. (For example, Camphill Scotland, Response number 179, SS ID: 196280242) Enable Scotland noted that the Children and Young People's Commissioner model was a helpful comparison but stated that costs may increase further should the Commissioner's role be expanded to provide other services such as a helpline or individual casework. (Non-Smart Survey response)

Some respondents noted that such costs would be funded through individuals as taxpayers. There was also some discussion of costs that might be borne by the public sector or by businesses. For example, should an organisation be investigated by the Commissioner, there may be costs involved in the staff and resources required in order to provide requested information. (Independent Living Fund, Response number 191, SS ID: 196937504) Others considered that —either following an investigation, or as part of their role in advocating for disabled people — the Commissioner could require organisations to make changes to their services. (Barbara Graham, Response number 99, SS ID,194684850) For example, it was suggested that organisations could be required to undertake disability equality training. (Graham Monteith, Response number 86, SS ID:193985031)

Carers Scotland considered that there may be costs involved should the Commissioner fulfil their role of representing the rights of disabled people and improving their lives, for example through advocating for the improvement of social care services. (Non-Smart survey response)

Several respondents considered that any costs incurred by establishing a Commissioner would be offset by the long-term benefits of doing so and that cost "shouldn't be a barrier" (Laura Rutherford, Response number 58, SS ID:192451483)

### No overall increase

Some respondents who answered in this way commented that they were unsure what the cost impact of establishing a Commissioner would be. It was again expressed that any costs would be offset by long-term benefits. For example, Deaf Links stated that:

"Having a Commissioner 'with teeth' will hopefully ensure public bodies, agencies, services and business will do things right the first time, which will save them all staff, HR, legal and managerial time/expenses when complaints are made for inappropriate/inaccessible/discriminatory service provision." (Response number 55, SS ID:192373167)

The RNID noted that the proposed bill would not impose new duties or requirements on organisations, but instead "create a mechanism by which existing duties and responsibilities could be monitored and delivered." It was therefore of the view that, other than the costs of setting up and running the office of the Commissioner, there would not be a substantive cost to other bodies. (Non-Smart Survey response)

### Decrease in costs

Again, respondents considered that the establishment of a Commissioner could lead to long-term savings. For example, an individual respondent with lived-in experience of disability, Terry Robinson stated:

"We need to consider the broad implication of failure on the economy. Failure of service leads to greater cost somewhere. I could elaborate, though I'm sure others have real figures on this. I'd posit that the provision of services and infrastructure that meets the needs of disabled people would enable them to play a much greater and productive part in the Economy and Society. I believe this would lead to reduced overall cost. We need to view this across the patch rather than considering the immediate cost of a post or department. I'd see the appointment of a Commissioner as an investment in the Economy and Society rather than yet another burden on the Public Purse." (Response number 50, SS ID:192061092)

It was suggested that, in the long-term, there may be improvements to people's mental and physical health, which in turn would lead to savings for health services. (Margarita Sweeney-Baird BEM, Response number 74, SS ID: 192661659) Others, such as David Renton, discussed the potential for more disabled people to be join the workforce, which would in turn benefit the economy. (Response number 162, SS ID:196758368) It was also considered that long-term change brought about, at least in part, by the establishment of the Commissioner, could allow more disabled people to live independently which could result in savings. (Cerebral Palsy Scotland, Response number 120, SS ID: 194641358) Ask Autism North-East stressed the importance of early intervention leading to long-term gains:

"[We] believe costs would be reduced because of there was accountability at an earlier stage then the correct support will be provided. Too many disabled children (and adults) are wrongly excluded which can lead to self harm, unemployment, drug or alcohol use, criminal conduct. This is because these people are misunderstood and left behind. A commissioner could ensure the proper support is in place giving the disabled person the best chance in life." (Response number 94, SS ID:194256187)

Other respondents suggested that the establishment of a Commissioner could lead to services being under one umbrella and efficiency savings being made as a result. (Anonymous, Response number 110, SS ID: 194974782) Reference was also made to a potential reduction in the number of compensation claims and tribunals being brought, resulting in a reduction in costs. (Jane Edwards, Response number 112, SS ID:195188856)

Question 10. 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. One hundred and six respondents (51% of the total) answered this question. There were no tick-box options for this question, the comments made by respondents are summarised below.

Many respondents expressed hope that the proposal would have a positive impact on disabled people, with Camphill Scotland, for example, stating that:

"We believe that the Bill will make a significant contribution to tackling discrimination against disabled people, and to promoting and protecting their rights." (Response number 179, SS ID:196280242)

## Further to this, the ALLIANCE stated:

"The creation of a Disability Commissioner is intended by its very nature to have a positive impact on disabled people and their rights. The ALLIANCE agree that the role is likely to have a net positive equalities impact by raising awareness of the rights of disabled people and offering a mechanism by which breaches of those rights can be highlighted, challenged and addressed." (Response number 171, SS ID: 196889077)

It was considered that the proposed bill would promote an inclusive society, where the voices of disabled people are both heard and represented, with Edinburgh Access Panel suggesting it could lead to practical changes, such as improved access. (Response number 22, SS ID: 191428695)

A number of respondents pointed out that there is often intersectionality between 'protected characteristics', with one anonymous respondent stating that:

"Disability intersects with all protected characteristics so, at a fundamental level, benefits all. For example, many women like me have never had the opportunity to consider pregnancy or maternity as an option due to lack of health support with disabilities." (Response number 84, SS ID:193861681)

There was some criticism of the question, with an individual respondent, John McGovern, stating that it was "negative and exclusive, it sees disabled people as only belonging to one particular minority group." (Response number 8, SS ID: 191210342) Johnny Timpson OBE also cautioned against focusing on characteristics rather than individual needs:

"It's important that we change the Inclusion and Diversity conversation and mindset that has developed in recent years and introduce Intersectionality and Equity. We are all individuals and present with a number of characteristics, it's key we consider all of them and not focus on individual characteristics." (Response number 19, SS ID: 191303959)

Some respondents made reference to existing legislation, with Skye and Lochalsh Access Panel noting that the Equality Act 2010 has strengthened the rights of disabled people, but that it was difficult for a disabled person to ensure that their rights were upheld. (Response number 114, SS ID: 195370596)

Other points made included that:

- an Equalities Impact Assessment (EQIA) should be carried out on the proposed bill; (Down's Syndrome Scotland, Response number 184, SS ID: 196921375)
- steps must be taken to mitigate any unconscious bias on the part of the Commissioner and their team; (Royal Pharmaceutical Society, Response number 163, SS ID: 196788596)
- people from deprived socio-economic groups or other marginalised backgrounds may be less willing to engage with the Commissioner and efforts should be made to avoid this; (The Neurological Alliance, Response number 156, SS ID:196556828)
- the focus on other protected characteristics should not be diminished as a result of the establishment of a Disability Commissioner. (Royal Pharmaceutical Society, Response number 163, SS ID: 196788596)

# Sustainability

Question 11. 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?

One hundred and two respondents (49% of the total) answered this question. There were no tick-box options for this question, the comments made by respondents are summarised below.

Most respondents considered that the proposed bill could have a positive impact on sustainability. It was suggested that the establishment of a Commissioner could contribute towards a more inclusive, fair and just society for current and future generations. Many respondents highlighted the need for disabled people to be given the same opportunities as everyone else and to be empowered to fully participate in society:

"When disabled people are empowered to live full and productive lives, as equal participative citizens, this benefits the social, cultural and economic life of the community." (Independent Living Fund, Response number 191, SS ID: 196937504)

Reference was made to current legislation and policies, which some respondents considered are not inclusive of disabled people. For example, one respondent expressed the view that environmental policies, such as active travel, can exclude disabled people. (Elizabeth Richardson, Response number 185, SS ID: 196924275) Another respondent with lived-in experience of disability considered that more must be done to improve sustainable heating for disabled people:

"[There is a] [n]eed to provide more sustainable heating for disabled people, such as heat source pumps to save on heating. I have chronic pain and need the heating on during the winter. When I asked the housing association for heat source pump and solar panels, to cut down heating/electric costs and be more sustainable. The reply was the the housing association cannot afford it. This would have tackled fuel poverty and be more sustainable. Would prefer to be sustainable but have to deal with agencies who are not sustainable." (Faith Ougham, Response number 161, SS ID: 196723846)

A number of respondents spoke of the need for adaptions to be made to housing and the built environment, with the access problems often experienced by disabled people highlighted in a number of responses. One parent of a disabled person spoke of issues such as a lack of suitable toilets, or two people who use wheelchairs being unable to travel by train together due to a lack of wheelchair spaces. (Anonymous, Response number 25, SS ID:191445769) Another anonymous respondent discussed the need for adaptations to housing:

"Scotland has a real problem in making 'adaptations' to its housing, as these are required for people with special needs and increasing needs: and those may arise from physical or mental aspects, and be exacerbated by increased fuel costs and by increased flooding due to adverse impacts of climate change. So look at easing the way for people with disabilities in the wider context of ensuring adaptations may be made. For example, how will households with disabled people ever be able to afford to change their heating systems without relevant policies being evolved?" (Anonymous, Response number 20, SS ID: 191396599)

It was suggested that the establishment of a Disability Commissioner could result in more disabled people being able to access employment, which would have a positive impact on the economy. (Anonymous, Response number 34, SS ID:191570083)

A small number of respondents considered that the proposal would have little or no impact on sustainability, with one stating that a sustainable economy could not be achieved via such legislation:

"This proposed new law would not produce a sustainable economy. What we need regarding a just society for the future are decisions that are requested democratically by the electorate. Most of the new laws etc that we get, the majority of the population do not want, therefore they are undemocratic. This survey is not democratic because it is very hard to find online and the majority of people do not know that it exists." (Helen Keith, response number 189, SS ID: 196956356)

## General

# Question 12. 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)?

Ninety-nine respondents (48% of the total) answered this question. There were no tick-box options for this question, the comments made by respondents are summarised below.

The majority of respondents who answered this question reiterated their support for the proposal or stated that they had no further comment to add. Other respondents spoke of their own personal experiences. Where points made in response to this question have been covered elsewhere in the document they are not repeated below. In addition, where comments relate to specific consultation questions, they have been included in that part of the summary, rather than set out below.

### The remit of the Commissioner

- the Commissioner must have clear, measurable objectives intended to bring change; (Anonymous, Response number 25, SS ID:191445769)
- it should be made clear to the public that the Commissioner could only be involved in matters that are devolved, and not to those that are reserved to the UK Government. (The ALLIANCE, Response number 171, SS ID: 196889077)
- the Children and Young People's Commissioner could be/is being used as a model for the Disability Commissioner with MND Scotland querying if there has been research into the effectiveness of that role. (Response number 178, SS ID: 196816851)
- focus should be given to specific areas, such as public transport (Kevin Robert McAndie, Response number 18, SS ID: 191281712), adapted housing and access to toilets. (Robert H. Dick, Response number 47, SS ID: 191856339)

## Interaction with current policy and legislation

- consideration should be given to initiatives that are already in place, such as the proposed Scottish Postural Care Strategy, and how this could tie in with the work of the Commissioner (Christina Poole, Response number 81, SS ID:193586999). Consideration should also be given to developments in legal and policy reform, relating to economic, social and cultural rights; (Susan Lee Kemp, Response number 66, SS ID:192514621)
- there is concern that the proposed UK Government Bill of Rights "would erode or negate the legislation and the role of the Commissioner" (Highland Home Carers, Response number 73, SS ID: 192573390)
- there is concern that the Scottish Government's final progress report on its strategy for disabled people, published in March 2021, contained no recommendations for next steps. (Cerebral Palsy Scotland, Response number 120, SS ID: 194641358)

## Criticism of the consultation

 that it is unsatisfactory that the consultation document is not in accessible format. (Anonymous, Response number 111, SS ID: 195011944)

## Section 4: Member's Commentary

Jeremy Balfour MSP has provided the following commentary on the results of the consultation, as summarised in sections 1-3 above.

I would like to start by taking this opportunity to thank all those who took the time to respond to my consultation on establishing a Disability Commissioner for Scotland. I welcomed hearing the views from a wide cross section of people. From disabled people keen to have their voices heard, families and carers of disabled people who can feel overwhelmed by their caring responsibilities, individuals who feel strongly about improving the rights of marginalised groups and to organisations who campaign tirelessly to work towards a society where all disabled people enjoy equality and fairness.

I would also like to express my gratitude to those behind the scenes who have guided me through this consultation process, including the Non-Government Bills Unit for their guidance, for Robert McGeachy in Camphill for his expertise and to my parliamentary team for handling the consultation process so efficiently.

The results of the consultation are clear; 90% of public individuals and organisations who responded support my proposals. I am buoyed by the many positive comments received in the consultation that indicate a Disability Commissioner for Scotland is needed, wanted and required. This is summarised well by comments such as those made by SPAEN (Scottish Personal Assistant Employers Network) which commented:

"SPAEN has long believed that a Commissioner for disability and disabled people in Scotland is required. We hope that such a Commissioner will advance the rights of disabled people in Scotland and that disabled people will have a single point of contact through whom they can raise issues rather than the current disjoined systems in place which often result in matters relevant to disabled people are lost." (Response number 4, SS ID:191207876)

and Disability Equality Scotland (who surveyed their over 1,400 members in order to respond to the consultation) which says:

"The majority of our members are supportive of the Bill and believed that the Disability Commissioner has the potential to address existing inequalities that prevent disabled people from being able to meaningfully participate in society. Existing inequalities experienced by disabled people have been exacerbated by the COVID-19 pandemic and the rising cost of living. Our members shared the barriers they face across all facets of society, including fair and equal access to housing, employment, transport and justice." (Non-smart survey response)

There are some key themes to have emerged from the consultation that I look forward to exploring further as this Bill progresses. Firstly, there seems a clear message that a Disability Commissioner should represent *all* disabilities, with 92% of respondents stating support of this key aim. This is something I feel strongly about, to ensure no-one is left behind and that the Commissioner is a uniting force in highlighting disparities and inequalities that affect all disabled people, whether they have a physical, hidden, learning difficulties or other disability.

The issue of independence was also highlighted as important in the consultation, for example in responses sent in by Epilepsy Scotland, #MEAction and Royal Pharmaceutical Society amongst others, with strong, overall support for the Commissioner to be autonomous to allow them to use powers of investigation (83% in favour of powers of investigations for both Scottish Public Bodies and service providers) in an impartial and unbiased way. As a member of Enable, part of one of the country's largest care charities states in response to the consultation:

"This post MUST be a genuinely independent "voice of disabled people" with respect to the Government but MUST only be influenced and moderated by disabled groups and disabled individuals." (nonsmart survey response)

This independence would allow them to hold the Scottish Government to account in all aspects of policy and legislation that could impact disabled people and to provide robust scrutiny to new policies being created and challenge inequalities in existing legislation. There were comments from some organisations regarding cross over and/or duplication of powers with existing bodies and asking for more details on how investigations would be carried out, so I have held several constructive meetings with organisations including The Equality and Human Rights Commission and the Law Society of Scotland since the consultation closed and look forward to continued co-operation and discussion with them and other organisations as the Bill progresses.

Overall, I believe this consultation has set out the clear need for a Disability Commissioner for Scotland; someone who is independent, who can be an advocate for all disabled people and have appropriate legal powers of investigation to ensure they can champion disabled rights. I hope to be able to pursue this Bill over the coming months, seeking cross party support from my MSP colleagues in the Scottish Parliament, to ensure this becomes legislation and a ground breaking force for disabled people of Scotland.

Jeremy Balfour MSP December 2022

# Annexe

# Organisations –Smart Survey responses

Name of organisation	Response number	Smart Survey ID
Aberdeen Independent Multiple Sclerosis	136	196129000
ALLIANCE (the Health and Social Care	171	196889077
Alliance Scotland)		
Anonymous	42	19179392
Anonymous	186	19694440
ASK Autism North East	94	194256187
Camphill School Aberdeen	115	195443177
Camphill Scotland	179	196280242
Cerebral Palsy Scotland	120	194641358
Deaf Links	55	192373167
Down's Syndrome Scotland	184	196921375
Drake Music School	13	191237986
Dyslexia Scotland	121	195817827
Edinburgh Access Panel	22	191428695
Epilepsy Scotland	116	195519501
Guide Dogs Scotland	160	196642935
Highland Home Carers	73	192573390
Inclusion Scotland	164	196790626
Independent Living Fund	191	196937504
Lead Scotland	192	196956699
Mobility and Access Committee Scotland	106	193927925
#MeAction Scotland	175	196910891
ME Association	158	196623337
MND Scotland	178	196816851
Muscular Dystrophy UK	56	192443488
National Deaf Children's Society	190	196935165
Neurological Alliance of Scotland	156	196556828
Renfrewshire Access Panel	7	191208545
Royal Pharmaceutical Society	163	196788596
Scottish Association of Social Work (SASW)	170	194922236
Scottish Borders Council	154	196529298
Scottish Disability Sport	78	193226454
Sight Scotland and Sight Scotland Veterans	159	193726472
SignHealth	169	196792899
Skye and Lochalsh Access Panel	114	195370596
Scottish Personal Assistants Employers Network (SPAEN)	4	191207876
Tiphereth Print Studio	40	191717306

# Organisations - Non-Smart Survey responses

Name of organisation/individual		
Carers Scotland		
Disability Equality Scotland		
Equalities and Human Rights Commission		
Enable Scotland		
Law Society of Scotland		
Mobility and Access Commitee Scotland (additional		
submission)		
MS Society Scotland		
National Autistic Society Scotland		
RNIB Scotland		
RNID Scotland		
Scottish Commission for People with Learning		
Disabilities Scotland (SCLD)		
Scottish Dementia Working Group (SDWG) and the		
National Dementia Carers Action Network (NDCAN)		
Volunteer Scotland		

# Individual responses

Name of individual	Response number	Smart Survey ID
Alan Lockhart	98	194677848
Andrew Love	149	19634866698
Anonymous	1	191171340
Anonymous	2	191194084
Anonymous	12	191227105
Anonymous	15	191222608
Anonymous	16	191258104
Anonymous	17	191259442
Anonymous	20	191396599
Anonymous	23	191448548
Anonymous	25	191445769
Anonymous	26	191481716
Anonymous	28	191510643
Anonymous	31	191553171
Anonymous	34	191570083
Anonymous	36	191619350
Anonymous	44	191817455
Anonymous	48	191904775
Anonymous	52	192172548
Anonymous	59	192460289
Anonymous	60	192508322

Anonymous	64	192512475
Anonymous	65	192514164
, menymous		102011101
Anonymous	67	192522197
Anonymous	68	192522496
Anonymous	72	192536750
Anonymous	76	192850828
Anonymous	77	193099048
	79	193099048
Anonymous Anonymous	80	193465094
,	82	193757872
Anonymous	84	193861681
Anonymous	85	193914914
Anonymous	91	193836082
Anonymous		
Anonymous	96	194277460 194796767
Anonymous	103	
Anonymous	110	194974782
Anonymous	111	195011944
Anonymous	113	195312298
Anonymous	123	195909002
Anonymous	125	195920052
Anonymous	128	196065312
Anonymous	131	196114467
Anonymous	133	196118546
Anonymous	135	196124212
Anonymous	138	196144320
Anonymous	148	196264075
Anonymous	150	196362477
Anonymous	152	196415099
Anonymous	153	196418065
Anonymous	167	196378904
Anonymous	174	196909102
Anonymous	177	196924086
Anonymous	188	196949829
Anonymous	500	N/A
Barbara Graham	99	194684850
Benjamin Woods	117	195532880
Betty Marx	118	195547807
Carey J. Leslie	27	191510714
Christina Poole	81	193586999
Clare Arron	6	191207558
Dahlia Somerville	157	196607716
Daniel Taggart	129	196069698
Dave M Hunter	75	192720471
David Renton	162	196758368
Douglas Peddie	46	191822622
Elizabeth Richardson	185	196924275
Eric Holford	168	196839843

Erika Martin	41	191777014
Faith Ougham	161	196723846
Fiona Rogan	13	191568487
Fulton Hunter	49	191906247
Geoff Orry	57	192440293
Graham Brown	37	191642341
Graham Monteith	86	193985031
Gwyneth McBride	193	196965146
Helen Keith	189	
	39	196956356
Henry Knowles	100	191658339
Ian Campbell		194737959
Iris Dewar	53 5	192222665
Isla Scott		191206820
James Irvine	107	194936834
James McCall	187	196949605
Jane Carmichael	137	196130775
Jane Edwards	112	195188856
Jill Bannister	61	192508995
Jim Ewing	95	194275193
Jo Smith	194	196976938
Jocelyn Hammer	63	192509995
John Green	83	193818967
John McGovern	8	191210342
John Morton Ballantine	14	191239376
Johnny Timpson OBE	19	191303959
Jordon Anderson	151	196375664
Julie Kelly	134	196121958
Karen Procek	165	196819777
Kevin Robert McAndie	18	191281712
Kim Kemp	38	191642387
Kris Procek	166	196837170
Laura Rutherford	58	192451483
Leon Cameron	54	192329620
Linda Bamford	43	191812333
Linda Campbell	101	194785517
Lindsay Buchan	62	192509968
Lynn Murray	180	196928192
Lynne Buchan	127	196039451
Margarita Sweeney-Baird BEM	74	192661659
Marjan Sikkel	92	194129250
Martin Alfred	97	194550985
Maureen McAllister	70	192534245
Miss Hilary M Rae	102	194792157
Mr.Tom Scott	172	196902256
Nichola Brown	147	196230570
Parent	132	196117293
Pat Graham	71	192535996
Patricia Hewitt	173	196903743
	1	. 500007 10

Peter Beaven	29	191525541
Phil Rogers	51	192167499
Robert H Dick	47	191856339
Robert McInytre	3	191202884
Rosa Hardt	21	191410043
Scott Wilson	32	191564597
Shirley Todd	88	194019120
Susan Ashton	89	194042196
Susan Lee Kemp	66	192514621
Sylvia Mendham	104	194815396
Terry Robinson	50	194815396
Thomas K Kelly	93	194227228
Ying lei lee	11	191225935