

Learning Disability, Autism and Neurodiversity Bill: Recruitment of Lived Experience Advisory Panel

December 2022

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Background

The Scottish Government has committed to introducing a Learning Disability, Autism and Neurodiversity Bill. This Bill will ensure that the rights of autistic people, people with ADHD, dyslexia, and other neurodivergent people are respected and protected. This Bill will also consider establishing a Commissioner to protect people's rights in practice.

A Bill is a potential new law. This Bill will be prepared by the Scottish Government and then considered by the Scottish Parliament. When a Bill has been passed by the Scottish Parliament, it becomes a part of Scots law as an Act.

The Scottish Government is working towards a human rights-based approach to ensure that the Bill is fully co-designed with people with lived experience, involving from the outset Disabled People-led Organisations and charities representing the views of a wide range of people.

Initial scoping work on the Bill took place between May and July 2022. As part of the scoping work, the Scottish Government ran a series of events with national charities, Disabled People-led Organisations, and other advocacy groups. We carried out 30 events with 18 different organisations. This gave us some helpful initial feedback and information about what is important to people and what we need to do further work on.

We are currently analysing what we learned from these events. We will prepare a report informed by this analysis which we will then share with stakeholders, and with the advisory panels.

We now want to establish a lived experience advisory panel to work with us throughout the Bill process. This is a really exciting opportunity to provide information about your views and experiences to Government to help us improve lives for people with learning disabilities, autistic people, and other neurodivergent people in the future.

The diagram below gives you some information about a Bill process in Scotland.

How Bills become Laws in Scotland

1. Pre-Legislative Consultation

The Scottish Government seeks the views of people across Scotland on a proposed piece of legislation.



2. Bill Introduced to Scottish Parliament

The Scottish Government presents a draft Bill to the Scottish Parliament, providing additional information on likely costs, the legal effect of the Bill, and why the Bill is being proposed



3. Parliamentary Stage 1 (General Principles)

The Bill is given to a lead committee. The lead committee is responsible for examining the Bill. It hears from experts, organisations, and members of the public about what the Bill would do. It then writes a report about what it has heard and giving its own view of the Bill. This Stage 1 report usually makes a recommendation about whether the Parliament should support the main purpose of the Bill.



4. Parliamentary Stage 2 (Amendments)

MSPs can propose changes to a Bill – these are called "amendments". Any MSP can suggest amendments. The amendments are debated and decided on at a meeting of the lead committee. Only the committee members can vote on amendments at this stage. If any amendments are agreed to at Stage 2, a new (amended) version of the Bill is published



5. Parliamentary Stage 3 (Amendments, Debate, and Final Vote)

MSPs can propose further amendments to the Bill. These are debated and decided on in the Debating Chamber, and at this stage all MSPs can vote on them. There is then a debate and vote on whether to pass the Bill. If the Bill is not passed, it falls and can't become law.



6. Royal Assent

If the Bill is passed, it is normally sent for Royal Assent after about 4 weeks. Royal Assent is when the Bill gets formal agreement by the monarch and becomes an Act of the Scottish Parliament.

What is the role of the panel?

Members of the lived experience panel will provide their views and information about their experiences to Scottish Government officials. Some key roles of people on the panel will be:

- To help us decide on the information we need to include in a consultation paper and the questions we need to ask – especially the impact on your life and the issues you want to see addressed by a Bill;
- To help us understand some of the advantages and disadvantages there might be around the potential establishment of a Commissioner so that we can include that in the consultation paper;
- To help us understand the best way to communicate with different groups of people of all ages and backgrounds who will be affected by the Bill;
- To help us reach the widest range of people of all ages and backgrounds who will be affected by the Bill;
- To assist us with commenting upon a research project on existing Commissions and Commissioners that the Scottish Government has commissioned; and
- After the public consultation, to provide your views on the key elements that need to be included in a Bill.

We would also look to continue the panel once the Bill goes into the Scottish Parliament for the “legislative stages” of the process. It is therefore our intention that you would get the opportunity to be involved in providing your views and information on your experiences during the whole process.

The panel will exist to complement the role that charities, Disabled People-led Organisations, and advocacy groups will continue to play in providing information and views to the Scottish Government Bill Team.

What will be the extent of the panel’s influence upon the Scottish Government?

The panel will be closely involved in the design of the consultation documents, helping civil servants to make decisions on drafts and final versions, with ultimate sign-off responsibility lying with the Scottish Government. You will help us communicate out with our wider stakeholder group who will also be given the opportunity to comment. You will help us to think through the options. You will help us to get our communications right and to think about how we promote the consultation as widely as possible in Scotland.

What is the composition of the panel likely to be?

The panel will consist of at least 12 and up to 20 members, and will include a mix of people with ADHD, dyslexia, and other neurodivergent people.

Our intention is to facilitate the panel in order to support commonly-agreed approaches and solutions. Previous initiatives that featured advisory groups, such as the Rome Review, have demonstrated how bringing people together in this way can achieve positive outcomes. There may be times when we adopt a flexible approach

to involvement, speaking with panel members on a meeting-by-meeting basis to put in place practical solutions to ensure that they can participate fully, and in ways that best suit them. This might, for example, involve breaking out into smaller groups during the body of a given meeting in order to discuss challenges and proposals, before coming back together at the conclusion of a session to present ideas and agree on the best way forward.

Where will panel meetings take place?

This depends on the preferences and views of the panel. However, we are happy to host virtual, in-person, and hybrid meetings depending on the desires and needs of the panel.

Should in-person meetings be selected and arranged, expenses for travel outside Edinburgh will be reimbursed to members.

What is the time commitment?

We anticipate that the advisory panel will be in place for over 1 year.

The time commitment will vary depending on the stage in the Bill process. During preparation and finalisation of the public consultation on the Bill, and during the public consultation period, we anticipate that the panel will meet at least once a month but we may need one or two additional meetings.

Scottish Government guidance estimates that it takes at least 2 months to prepare a public consultation, and that consultations themselves take at least 3 months to run. We would therefore seek to hold at least 5 sessions with the panel during this initial phase.

During analysis of the consultation responses, which can take up to 16 weeks depending on the volume of responses to the consultation, we expect that the panel would meet less often – perhaps twice over that period.

We would then look to revert back to a regular schedule of monthly meetings during the development of final policy options for the Bill, in order to help us understand how to make sure those options meet the needs of people with lived experience.

All of this will be discussed with the members of the panel and agreed as part of the first meeting. We will also co-create mechanisms for resolving disagreements between panel members during this meeting.

Who can apply?

We welcome applications from anyone who identifies as being learning disabled, autistic, and/or people with ADHD, dyslexia, and other neurodivergent people. You do not need a formal diagnosis to apply.

You will be representing yourself on the panel as an individual expert by experience, rather than representing the views of a specific organisation.

If you are an office-bearer (paid or unpaid) or paid staff member of an interest group that has a publicly-stated stance on the Bill or Commissioner, then you will not be able to apply for a role on this panel. Instead, we would ask that you contribute to the Bill's development via your organisation.

An office-bearer is anyone who plays a leadership role in running an organisation, such as a President, CEO, Secretary, Team Leader, etc.

If you are an unpaid volunteer or member of such an organisation who does not contribute to its day-to-day functions, you will still be free to apply to participate in this panel. This is in recognition of the fact that such persons do not usually play a key role in setting organisational direction or policy.

We have adopted this approach because we want to ensure that a diversity of voices is involved in the process of developing the Bill. As office-bearers of interest groups are already involved in our work as spokespersons of their organisations, and will continue to be so, we want to open this opportunity to more people across Scotland who we may not otherwise hear and learn from. We also want to complement the expert views offered on behalf of organisations by office-bearers with those expressed by experts, who may or may not have some involvement in those organisations, but who are not ultimately speaking on behalf of the organisation, but rather as individuals.

Payment arrangements

Panel participants will be paid an allowance to enable the participation of a broad spectrum of people from different socio economic groups. Participants will act as volunteers and will not be paid for their time preparing for or attending the panel. They will not be employees of the Scottish Government or any related organisation in relation to their participation in the panel.

The Scottish Government values participation from across the socio-economic spectrum and seeks to reduce barriers to it. Payment of an allowance to enable people with lived experience to provide their contribution to informing policy and decision-making making sure that the widest possible range of people with lived experience can participate.

We recognise that different payment arrangements may have different tax and benefits implications for panel members. Accordingly, we will agree payment arrangements with each panel member on an individual basis to account for their specific circumstances.

Payment can either be in the form of vouchers or cash, depending on the individual circumstances and choices of the participant. Participants can also choose to refuse payment if, for example, they would otherwise lose their benefits.

We will provide a written participation agreement and, where relevant, a letter addressed to relevant welfare agencies such as the Department for Work and Pensions. The participation agreement will ensure participants are aware of the

choice of payment type and the potential impacts on benefits and taxes, and will signpost them to expert advice, e.g. [Citizens Advice Scotland](#). The letter to welfare agencies will ensure that those agencies know that the participation is not employment and the reason for payment of an allowance.

What we expect from you

- Come to panel meetings prepared to discuss your thoughts and provide your views as an individual;
- Identify how plans proposed by the Scottish Government could be improved;
- Help the Scottish Government prepare information and questions for the public consultation on the Bill;
- Help the Scottish Government ensure that the public consultation is accessible to people with lived experience, and that it reaches as many people with lived experience across Scotland as possible;
- Prepare for panel meetings by reading, watching, and/or listening to any materials that we have prepared for the meetings;
- Treat others on the panel with respect.

What you can expect from us

- Organisation of meetings and provision of any material relevant to those meetings two weeks in advance;
- Arrangement and facilitation of any adjustment that you may need in order to involve yourself in the panel, such as accessible materials, interpreters, etc;
- Payment for your time. Whilst we cannot yet confirm a figure on this, we expect payment to be in the range of £75 and £150 per meeting.

We want to support you to take part so we will not ask you to talk about anything you are uncomfortable with or to talk about personal experiences unless you want to and feel it is relevant.

You don't have to have any special skills to be involved except to feel comfortable taking part in group meetings with the appropriate support.

We are interested in your knowledge from your own experiences as a neurodivergent person. If you have particular views on, for example, health and social care support or other experiences, you may find the panel a good way to contribute, discussing matters with a range of people from diverse backgrounds. We are also very interested in involvement from people who identify with groups that it can be more difficult to connect with including people who identify as LGBTQ+ and ethnic minority communities.

Process

We would ask you to take part in a simple process:

- Submission of the attached Expression of Interest form to the LDAN.Bill@gov.scot email address by 19/01/2023.
- Informal discussion with a Scottish Government official and an external interviewer from Scottish Commission for People with Learning Disabilities (SCLD) or Inspiring Scotland. We will ask you about why you want to participate in the panel and your experience, and what we can do to help you involve yourself with the panel.

We look forward to hearing from you.



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This publication is available at www.gov.scot

Any enquiries regarding this publication should be sent to us at

The Scottish Government
St Andrew's House
Edinburgh
EH1 3DG

ISBN: 978-1-80525-313-6 (web only)

Published by The Scottish Government, December 2022

Produced for The Scottish Government by APS Group Scotland, 21 Tennant Street, Edinburgh EH6 5NA
PPDAS1202222 (12/22)

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