OFFICIAL REPORT
AITHISG OIFIGEIL

DRAFT

Equalities, Human Rights and Civil Justice Committee

Tuesday 11 June 2024

The Scottish Parliament
Pàrlamaid na h-Alba

Session 6

Tuesday 11 June 2024

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EQUALITIES, HUMAN RIGHTS AND CIVIL JUSTICE COMMITTEE
15th Meeting 2024, Session 6

CONVENER

*Karen Adam (Banffshire and Buchan Coast) (SNP)

DEPUTY CONVENER

*Maggie Chapman (North East Scotland) (Green)

COMMITTEE MEMBERS

*Meghan Gallacher (Central Scotland) (Con)
*Marie McNair (Clydebank and Milngavie) (SNP)
*Paul O'Kane (West Scotland) (Lab)
*Evelyn Tweed (Stirling) (SNP)
Annie Wells (Glasgow) (Con)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Tressa Burke (Glasgow Disability Alliance)
Jamie Cooke (Enable)
Heather Fisken (Inclusion Scotland)
Suzi Martin (National Autistic Society Scotland)
Eddie McConnell (Scottish Commission for People with Learning Disabilities)
Jenny Miller (PAMIS-Promoting a More Inclusive Society)
Dr Pauline Nolan (Inclusion Scotland)
Lyn Pornaro (Disability Equality Scotland)
Alice Struthers (Neurological Alliance of Scotland)
Karen Wylie (Glasgow Disability Alliance)

CLERK TO THE COMMITTEE

Katrina Venters

LOCATION

The James Clerk Maxwell Room (CR4)

Scottish Parliament

Equalities, Human Rights and Civil Justice Committee

Tuesday 11 June 2024

[The Convener opened the meeting at 10:00]

Disability Commissioner (Scotland) Bill: Stage 1

The Convener (Karen Adam): Good morning, and welcome to the 15th meeting in 2024, in session 6, of the Equalities, Human Rights and Civil Justice Committee. We have received apologies from Annie Wells.

This morning, we will take evidence on the Disability Commissioner (Scotland) Bill from two panels of witnesses. I refer members to papers 1 and 2.

I welcome to the meeting our first panel. Lyn Pornaro is the chief executive officer of Disability Equality Scotland; Tressa Burke is the chief executive officer of Glasgow Disability Alliance; Karen Wylie is the policy and participation manager at Glasgow Disability Alliance; Heather Fisken, who is joining us remotely, is the chief executive of Inclusion Scotland; Dr Pauline Nolan is the head of policy and engagement at Inclusion Scotland; and Jenny Miller is the chief executive at PAMIS—Promoting a More Inclusive Society. I thank all of you for attending the meeting.

We are quite tight for time, so we will go straight to questions. I will ask the first questions. What are your thoughts on the bill? Do you agree with its general principles?

Heather Fisken (Inclusion Scotland): I apologise for not being with the committee in person. I was defeated by the M8 this morning and had to rush home. I appreciate the staff at the Parliament having managed to accommodate that so well.

We are a disabled persons membership organisation that is run by disabled people. We consulted our members on the bill and have recognised, through the results of that survey, that roughly 75 per cent are outright in favour of the bill and 25 per cent have raised concerns about it. Key concerns of both types of respondent were that the landscape is very crowded and that there is a potential lack of clout in the proposals in the bill that we consulted on.

I think that my DPO—disabled people's organisation—colleagues Lyn Pornaro and Tressa Burke will probably support what I am about to say. One of the reasons why there is so much support for the bill is that there is such great need and there has been so little change or positive movement in respect of disabled people's rights. We recognise that the bill lacks clout, in the sense that although an investigatory power is proposed, there is no enforcement action behind it.

I am happy to pass over to colleagues now; I recognise that we are short of time, with four organisations being represented here today.

Jenny Miller (PAMIS-Promoting a More Inclusive Society): I totally agree with Heather Fisken. I support families and carers of people who have profound learning and multiple complex disabilities. Although I think that our families recognise that there is an absolute need for something because they face so many issues at the moment, we are still really concerned about that very small niche group.

We were absolutely invisible during Covid, and we feel that we could be very invisible in a very crowded landscape. The commissioner remit is very broad. Additionally, I worry that we are having to look at all the commissioners because people are so unhappy with what they are receiving at the moment and feel that they have nowhere to go when things go wrong.

My concern, and PAMIS's concern, is what will happen and what clout the commissioner will have. There have been reviews that have been looked at and recommendations have been made, but there seems to be a real "So what?" factor. Who will have the clout to actually take forward future improvements?

Our other concern is the question about what best practice looks like for such a diverse group; it is so broad. An organisation would have to be pretty enormous to take on board all the best practice for all the different groups that it would be representing.

It is very sad that we have to think about having so many commissioners, because we are not getting it right within the services that we are providing.

Dr Pauline Nolan (Inclusion Scotland): I would say exactly the same things. When we consulted disabled people, the question was asked why money is being put into a commissioner when it could be spent on services. I am not suggesting that that is how funding works, but the bill raises that question at a time when so much improvement is required of services for disabled people across the board, but is not happening. For example, the Scottish Human Rights Commission is reviewing "Coming Home Implementation: A report from the working group on complex care and delayed discharge" at the moment. The "Coming Home" implementation plan was due to deliver from April this year, but it has not done so. The SHRC is looking through the lens of human rights at the plan and why it has not happened.

I go back to what Heather Fisken said about there being an already cluttered landscape, in which commissioners have responsibility—we do not want to lose that—but some might not be making the most of that responsibility. It is really difficult to come to a clear view on support for a disability commissioner when we know that a lot of disabled people want it, but that their wanting it is based on huge need.

Karen Wylie (Glasgow Disability Alliance): The GDA is a member-led organisation so, obviously, we consulted our members extensively on the issue. I would say that they are broadly supportive of having a disability commissioner. They appreciate that it would perhaps be very useful to have one individual—one champion—advocating and focusing very specifically on the rights of disabled people. Obviously, that could be valuable, but it must be caveated with many of the concerns that have already been raised.

The bill must absolutely have teeth. It must include real powers that could make real changes for disabled people, and that has to be properly resourced. Disabled people must be involved in the work of the commission, or commissioner, so the commission would have to be properly resourced to allow full and meaningful participation.

Also, our members are obviously aware of the Scottish Human Rights Commission and the Equality and Human Rights Commission, and they are aware that those bodies are monitoring and keeping an eye on human rights for all people, including disabled people. However, disabled people have been so deprioritised—in particular, through having been disproportionately impacted by Covid and by the cost of living crisis and 15 years of austerity. There is a feeling that we are not on a level playing field because disabled people's rights are so far back; we are not starting from the same point as other groups whose rights are being protected. What comes across really strongly from our members is that it is very important to have somebody who can be a champion for them because of how far back disabled people feel they are at the moment.

Tressa Burke (Glasgow Disability Alliance): I agree with everything that has been said so far about complexity and the cluttered landscape. In particular, to build on Karen Wylie's views, I agree that disabled people fared so badly during the pandemic. The highest number of people who died were disabled people. We surveyed our members; we spoke directly to more than 6,000 people who called us on a helpline, as well as phoning our members. More than 80 per cent did not know where to turn for support, despite all the wonderful community support that arose at the time; 60 per cent were digitally excluded; almost half were worried about money, which has got much worse; and 82 per cent were socially isolated and felt that loneliness was absolutely crushing. Those figures are from before the cost of living crisis kicked in.

Having thought long and hard about the issue and having spoken to members about it, I know that disabled people want a champion, an advocate and somebody who will defend and protect their rights, but—as Karen Wylie and others have said—the commissioner needs to have teeth.

I am aware of the fiscal situation and context, and I know that the Finance and Public Administration Committee is looking at the issue, but I suggest that the amounts of money and staff that are proposed in the financial memorandum would not be enough. If the commissioner is to have real weight, it will need people to work on participation, legal people and people who investigate. The cost of all that would be a drop in the ocean if we are trying to turn the tanker in relation to the inequality and discrimination that disabled people face in every part of their lives, including in delivery of public services. That will require a disability commissioner that has focus, that has a platform and a spotlight, and that has the ability to develop and promote good practice—I hope that they will do more than investigate and will take on legal cases. That work should be done, under a memorandum of understanding, with other human rights and equalities bodies.

Our members have extremely strong feelings. They are not fools—they know that there is a cluttered landscape and that there are financial constraints, but they are desperate, given dehumanisation, deprioritisation and the lack of political leadership in allocating resources that would change disabled people's lives. We are left asking this question: if we do not have a disability commissioner, what are we going to do and who will do that work?

All the commissions that gave evidence gave a great critique of why the proposal might not work, so I would like to meet them and all of you in a separate context to develop a plan for Scotland. For 16 months, we have been trying to work with the Government on what was an immediate priorities plan to address disabled people's poverty and inequality, but 16 months in we are still not near to publishing that plan, because no resources are being committed. We can get political leadership and buy-in—we were almost there, but there was a change of First Minister, so we now need to rebuild.

Disabled people have been dehumanised and deprioritised. A professor from Glasgow Caledonian University has written an anthology, taking us back to Plato and Aristotle, on the othering and dehumanising of disabled people throughout history. That is what is happening now.

We have a serious problem, and we need to do something about it, so members of the Glasgow Disability Alliance are willing to put their bet on a disability commissioner as a good way of making progress, because it would provide a spotlight and a focus.

Lyn Pornaro (Disability Equality Scotland): Disability Equality Scotland is also a membership organisation and, similar to what my colleagues have said, the majority of our members are supportive of there being a disability commissioner because there is nowhere to turn. Although disabled people's organisations across Scotland advocate on behalf of our members to get their voices heard and to get them participating, there is closed door after closed door—or people say that there is an open door and say all the right words but there is no action. Our members want action. They want to participate in everyday life across Scotland and to have the same opportunities as others have, but they have been disregarded over and over again. Quite a lot of them have almost given up the fight. They say, "What's the point, any longer?" However, the proposal that there be a disability commissioner has reinvigorated them and they are thinking about whether that would make a difference.

As everybody else has said, proper financial resources will be needed, and the commissioner will need powers not only to investigate but to hold people to account and make changes. Otherwise, we will have another person standing up and talking for disabled people while nothing happens or changes.

Our members broadly support the proposal, but with those caveats. For example, they strongly believe that, if a disability commissioner is put in place, the commissioner must be a disabled person.

The Convener: Thank you.

10:15

Maggie Chapman (North East Scotland) (Green): Good morning and thank you for joining us this morning and for what you have said so far.

You have all talked about the cluttered landscape and the difficulties that disabled people might have in finding a route to the person who can help them. There is the potential for duplication of the powers and mandate of a disability commissioner and those of other commissioners or organisations. As we try to work through that, how do you see the proposal dealing not only with the cluttered landscape but with potential duplication and overlap of mandate and action, from the point of view of disabled people?

Lyn Pornaro: Disability is not in a silo—people have lots of additional responsibilities and intersected protected characteristics within themselves, as human beings Therefore, a disability commissioner would need to work closely with other commissioners. We need to stop working in silos so that we can see disabled people for the people they are rather than just saying "Oh, they're disabled", which we do not want. We want people to say, "That's Lyn" or "That's Maggie"; we do not want them to say, "Oh, that's Lyn, who is a disabled person, so we'll put her in that box."

A disability commissioner would be standing up for, promoting and—I hope—making changes to our human rights and the additional human rights that disabled people require in order to live a full life, but the disability commissioner will need to work alongside other commissioners and organisations that do the same work, because disability is not in a silo.

Maggie Chapman: Thanks, Lyn. That is very clear.

Tressa Burke spoke very powerfully and said that disabled people are betting on the commissioner. How do you see the potential overlap or duplication of effort, and the complication in respect of which route a disabled person who is looking for a remedy goes down? Would they go to the SHRC, the disability commissioner or the EHRC? Where would they go? How do you see all that working out?

Tressa Burke: The first thing to say is that accessibility is a major issue for disabled people, and being able to identify a champion—somebody who will take forward their issues—is really important. We have heard from the other commissions about limitations, whether in relation to areas of law or not having the resources or the power to do participation work. I presume that the commissioner will be able to do participation work, so disabled people would be able to approach them. The disability commissioner would be dealing with disabled people with all types of impairments and conditions, as well as with disabled people who experience marginalisation because of the way in which society responds to their protected characteristics. I am speaking about intersectionality; there are organisations that do brilliant intersectional work. If GDA can work intersectionally, then a disability commissioner definitely can.

What disabled people would be able to get from a commissioner is engagement and dialogue, but what we want in a commissioner more than the participation and investigation aspects is the ability to take cases and to make legal challenges. GDA members have been really clear that we want those additional things. They are fully supportive of the proposal, but with the caveat that the commissioner will need to have power. As I said earlier, from looking at the financial memorandum, I think at this point that the commissioner would not be properly resourced to do those things.

Finally, the commissioner would need a memorandum of understanding with the other commissions. Although the other commissions are doing wonderful work and do the best that they can within the limitations that they have, it is not the case that they are making a difference, after all these years, to the lives of disabled people. That is the challenge from our members—they want a disability commissioner because they want a commission that is able to intervene and to make a difference to and improve their lives.

Maggie Chapman: I would like to explore that point a bit further. You have all said that we are in the situation that we are in because disabled people have been failed by existing bodies and, probably, by every structure not delivering and not supporting them appropriately.

We have also heard your point about the need for the commissioner to have clout and teeth. If we get a disability commissioner with the clout, the teeth and the resources, how do you see that commissioner working with some of the other commissioners? You have mentioned memorandums of understanding, but given that the mandates of the SHRC and the EHRC are different, do you see there being any problem with the disability commissioner potentially having more powers than a national human rights institution, whether that is the SHRC or the EHRC? Tressa, do you have a view on that?

Tressa Burke: I have a really clear view on that. I have heard the argument about hierarchies of rights, but the proposal that we are discussing is about addressing a hierarchy of oppression and the fact that disabled people are the furthest removed from having the most basic human rights. We have members who did not have a shower for more than two years during the pandemic, and who have been told that they need to have only so many showers a year, once a month. Those are genuine stories that our members have told us about their lived experience.

When people do not have the basic choices or control over their lives, the country that we live in—a dignified, civilised country like Scotland, with the resources that we have—should be able to take action to address that. I am therefore not so worried about the arguments about hierarchies of rights. We should be looking to target and tackle the issues for those who have the least rights.

Maggie Chapman: That is very clear. Thank you. I will move on to Heather Fisken. I have a similar question for you, Heather, about the duplication and overlap of potential mandates and powers and how you see that working out.

Heather Fisken: Could I turn the question around? If the landscape is so busy, why has there been no change so far? Tressa Burke has answered that question, which is really good.

There is also the fact that we live in an information age. There is so much information out there that people simply do not know where to go any more. It is even harder for disabled people, because so much information is online. We have documented digital poverty. Even for people who have access to the digital world, so much of that information is inaccessible.

It is also worth saying that there is no bespoke focus on disabled people. We have already outlined how complex the issue is, given the intersectionality and the entrenchment of disabled people's lack of human rights.

I think that the commissions, which do a lot of good work within the capacities that they have, are alert to the complications. They will work with MOUs and recognise that. It is more a case of them bolstering and supporting one another. If we had a disability commissioner, that person would have a laser focus and would be able to assist the other commissions with the work that they do.

We have noticed that the bill does not include enforcement powers for the disability commissioner, alongside the investigative powers. However, the commissions can publicly name—they can name and shame, if you like—organisations that they have investigated that are failing. If the bill goes ahead and a disability commissioner is put in place, I hope that that is something that they will do to great effect, so that the lessons are learned across the wider sector and across society.

Yes, it will be a complicated landscape, and it is important that not just the commissions but people in Scotland have clarity on how to use that landscape. Again, that goes back to my point about the information age. If a disability commissioner came online, part of their role would be about how to make the wider commission landscape accessible and relevant to, and beneficial for, disabled people.

Maggie Chapman: Thank you—that was very clear.

Jenny, I am interested in the answer that you gave to the convener's earlier question on the breadth of the role that the commissioner could and, arguably, should cover. How would one organisation, or one commissioner with a commission behind them, deal with the complexities and the variation across the range of needs and requirements that disabled people have, given the overlaps in the landscape and the issues that we have touched on?

Jenny Miller: That is definitely an area of concern. From listening to colleagues, maybe we just have not got it right yet. Profound means deep, wise or expert, and people with a profound learning disability are the best educators that we have, because they cannot communicate in the ways that we normally do, so you have to use all your senses to listen to them. They teach us that nobody has the answer. Everybody needs to collaborate, and when we collaborate, we begin to get it right.

Maybe we need to take a lesson from people with learning disabilities and their family carers. Our family carers have been around all the commissioners trying to get support and have found that they do not have an answer because they do not have teeth. We might not have the answer, but if we collaborate and consider a commissioner model where we all learn to work together, perhaps we will come up with something that will work.

People who have a physical disability might also require the Mental Welfare Commission or have human rights issues that need to be met. Maybe we have not got it right yet, but we could look at commissioners working together across the whole spectrum, which would enable us to include everybody. We should listen with all our senses.

Maggie Chapman: It is easy to get channelled into a particular form of communication and to miss much of what else is going on.

I could go on, but I know that the convener wants to move on. Thank you all.

The Convener: We move on to questions from Paul O’Kane.

Paul O’Kane (West Scotland) (Lab): Good morning. I will expand on the theme of potential duplication and related issues. I am conscious that there is a proposal for a bill on learning disabilities, autism and neurodivergence. Related to that, there is a question about whether there should be a commissioner in that space. Many of the organisations that are represented here today support those proposals, although some have raised different views and concerns.

My first question is on the growing landscape of commissioners, which Jenny Miller touched on in one of her previous responses. I am keen to understand whether you are concerned that that landscape will begin to fragment within the wider disability sphere. Seeing as I mentioned her, I will start with Jenny.

Jenny Miller: I am concerned. I think that there is a real risk, particularly if we are setting up commissioners to compete with one another. However, I go back to the point that we need to reconsider that model and to think about how we can get people to work together and collaborate. All the commissions, including the Mental Welfare Commission, which I do quite a bit of work with, and the reference group there, talk about having more teeth and more power. There is probably a desire for people to do more and to make more of a difference, but I go back to the point that we do not have the right model.

We have put in a response on the LDAN bill. The concern there is that there is so much that is wrong that we have to do something to make it right. I know that people with disabilities and family carers are hanging on having a commissioner because they feel that it is the only route to making a difference.

The issue is about how, collectively, we work together to make sure that the landscape does not become fragmented. We all support one another in different ways. I know that if I am not at an organisation, people talk about the very tiny group of people with profound learning disabilities who are invisible. By working collaboratively, we will all be able to make a difference.

Paul O’Kane: Would anyone like to give a broader view on the possibility of there being too many commissioners in the landscape?

10:30

Dr Nolan: We are a pan-impairment organisation, which means that we work with all disabled people. Because we describe ourselves as a disabled people’s organisation, people often think that that means people with physical impairments. However, we work with everyone, including people with addictions, people with mental health conditions, people with learning disabilities, autistic people and neurodivergent people.

Organisations for autistic people, organisations for disabled people and organisations for people with learning disabilities are members of our organisation. They have mixed views on a commissioner. They support the learning disabilities and neurodivergence bill to the extent that there is such great need. There are parallels with this bill to the extent that things such as education and access to justice are inaccessible for that group of people. However, that is the case across the board for all disabled people. It is therefore very difficult to come to a view.

That said, there are specific issues for which it might be necessary to have such a commissioner—for example, in relation to things such as coming home, although the SHRC is doing that work at the moment.

It is a really difficult question. We go by general comment 7 of the United Nations Convention on the Rights of Persons with Disabilities, which says that resources need to be provided for disabled people’s organisations that are diverse. Pan-disability organisations represent all disabled people, and we do our best to do that, including representing the so-called hardest to reach.

I will finish there, as someone else might have a view.

Karen Wylie: Glasgow Disability Alliance, too, is a pan-impairment organisation. For example, hundreds of our members have learning disabilities, so we support a commissioner specifically for that.

One of the questions in the consultation was about the definition of disability. At the moment, the Equality Act 2010 definition is used, and we are concerned that perhaps that takes things down the path of a more medical model of disability, whereas we would use a social model. Rather than a commissioner looking at people’s particular impairments or conditions, it would be a case of them looking more broadly at the barriers that people face.

That could go for other groups as well. As has been mentioned, GDA works in an intersectional way. We have black, Asian and minority ethnic disabled people, LGBT disabled people and disabled people of all ages and so on, so it is perhaps more a case of looking more at the barriers that are faced by people, rather than at individual conditions or impairments.

Tressa Burke: The reasoning behind why people are asking for an LDAN commissioner is sound. The stats on the life outcomes for people with learning difficulties and neurodiverse people are awful. However, rather than being a blunt tool—people are right in what they have said—a disability commissioner could look at the barriers through the lens of the social model of disability, as has been described.

For example, the shielding criteria missed people who had intersecting conditions that made them extremely vulnerable. We are in the same position here. Without a doubt, the LDAN bill is, in itself, a good thing, but, as long as the disability commissioner takes account of the additional disadvantage, stigma and oppression that people who have learning difficulties and neurodiverse people experience, just as other disabled people experience those things, that need can, I hope, be met through a disability commissioner. However, we would not dissent from supporting that bill, because we support the people.

It is a complicated situation, as you said. It is difficult to separate out the issues. We do not want to not support the LDAN bill, just in case the Disability Commissioner (Scotland) Bill does not go through. However, the disability commissioner bill, too, should be able to address that, because it should look at intersecting oppressions and intersectionality. If it does that right, it will cover the people in that group as well.

Paul O’Kane: We touched briefly on the role of the Mental Welfare Commission in some of those spaces; the Scottish Human Rights Commission has given evidence; and we have spoken more broadly about the need for that intersectionality as well as the need not to become too siloed but to work across that space. Is there a sense that those organisations need more resource or input from people who have a disability, is there more that we can do in the broader landscape without a commissioner or is it a bit of a mix of all those things? Going back to Jenny Miller’s original point, I think that, across the board, we need to improve what is on offer and what we are moving through. Do any members of the panel have a view on that?

Dr Nolan: This goes back to the laser focus that people have been talking about. What the other commissioners do can be quite good, although some are better than others.

The Equality Advisory and Support Service is an advisory service for the whole of the United Kingdom, and more than 70 per cent of the calls to that come from disabled people with inquiries about their rights and things such as poverty, social security and many other areas. Yet, in 2017, the UK’s Equality and Human Rights Commission disbanded its disability committee, which took away its focus on disabled people, despite them being one of the most oppressed groups across the board.

We absolutely support there being a place for the other commissioners to work with a disability commissioner to look at specific issues as they affect disabled people. However, they must not take that focus away, particularly where they are looking at the equalities impacts on multiple different groups and intersectional impacts. We require that laser focus.

The Convener: We have a supplementary question on this from Meghan Gallacher.

Meghan Gallacher (Central Scotland) (Con): Good morning. My question is on the point that Paul O’Kane raised in relation to other commissioners who should be carrying out work to help, support and promote the interests of people who are living with disabilities.

I was interested in the responses to the call for views. An Inclusion Scotland member stated:

> "We are very aware of the Children and Young People's Commissioner, the Scottish Human Rights Commission and the Equality and Human Rights Commission. All do work to promote and protect disabled children's and adults rights. However, all have wider responsibilities that sometimes mean that disabled people's rights are not their first priority."

Heather Fisken, even though the SHRC's and the EHRC's remits could be strengthened, do you still feel that there would be a gap for disabled people and, because of that, do you think that a disability commissioner is essential?

Heather Fisken: I think that it goes back to what we have all said in previous answers: it is about having a laser focus, developing understanding and having a direct connection with disabled people and disabled people's organisations.

I want to add the sidebar that it would be important for the commissioner to work with disabled people's organisations as well as disabled people. We already do a lot of work in this area, but we are few and far between and we are very stretched.

The issue is complex. Our staff and our board members are disabled people, so we get it. We do not require a long, drawn-out explanation every time that somebody says that something is happening to them, because we understand the situation. It takes quite a lot of time to develop that understanding. I cannot speak for every disabled person in Scotland as I do not have their exact lived experience. However, as organisations, we are inured to that lived experience.

I am sure that there will have been evidence to Scottish Parliament committees about the fact that, in the past, when people were applying for benefits, they had to tell their life story time and again to various officials. We need to get rid of the unnecessary burden of having to give that information to the many professionals that disabled people have in their lives. There needs to be a single point, with evolving and developing expertise. Of course, we have also made the point that the commissioner should be a disabled person.

Meghan Gallacher: The point about lived experience is important. I know that we use that phrase a lot in the committee, but what Heather Fisken said shows how important having lived experience within such organisations is in terms of the aims of the bill. Does anyone else want to respond to the question?

Tressa Burke: I want to build on what Heather Fisken said about the fact that the disability commissioner could or should be a disabled person. A 2017 study by What Works Scotland on engaging people who were previously considered to be hard to reach spoke about the know-how of skilled practitioners being required, which I think is what Heather is getting at.

On the question about whether the existing commissions could carry out the role, I would ask why they have not done so, because they have some powers, although I appreciate that there are limitations in the SHRC and the EHRC. We are not absolutely opposed to having a conversation about whether the SHRC could host something like a disability commissioner and related staff, but the important thing is that it is an area of expertise based on the lived experience of disabled people and their ideas and contributions about solutions.

Disabled people know best what will work, but we cannot do it on our own and just by talking to ourselves; we need to collaborate with other people, who I hope would be power holders, politicians, decision makers and the commissions. If the role was to be located in an existing commission, in order to save money and declutter the landscape to make it less complicated, we would need to be convinced that it would be sufficiently resourced and that the person would be able to become an expert in the issues. As I said, there would also need to be access to legal advice and investigators who understand the issues, rather than just generalists.

One thing that I picked up from Jan Savage's evidence, although I have possibly got this wrong, was that the SHRC has to work on all human rights, and that that is an important principle in human rights. That is fine and great, but we specifically want to target disabled people whose human rights are so far back and regressed. We know from the 2024 United Nations report that not only have the UK and the devolved nations not addressed the "grave and systematic violations" since 2017, but we have actually got worse. We really need to think about that, and we need skilled practitioners, wherever they are, to do that work.

The Convener: We will move on to questions from Marie McNair.

Marie McNair (Clydebank and Milngavie) (SNP): Good morning. The committee is looking for the panel members' thoughts on the financial and resource estimates in the financial memorandum. Tressa Burke, as you touched on the issue earlier, and I got the feeling that you had much more to say but that you felt that your time was constrained, and because it was your organisation that raised concerns that the funding that is required for the disability commissioner could be diverted away from other public policies that are aimed at disabled people, I will give you the opportunity to come in on that issue first.

Tressa Burke: I was particularly interested in the financial memorandum, as I run an organisation that engages and does highly participative work with disabled people every year and, although our budget will probably be down this year, in the past few years, it has been about £1.2 million. I noticed, for example, that there is a figure of up to £85,000 for what looks like marketing—people might not understand that, but it is about engagement and participation. Our budget for that, which is for Glasgow only, might be higher than that, which is for the whole of Scotland. I appreciate that we do community development work, so we are building people up and delivering services and supports, which is different. However, I felt strongly that that is an underestimation of the cost to do the work meaningfully and properly. Also, not all the staff who should be in the commission are included in the figures.

One thing that came out in the previous evidence from the commissions was about the SHRC not having the power of participation. With such a power comes a high degree of cost if you are going to do it right, which means including disabled people and across the length and breadth of Scotland, and ensuring that people have open access. You have to think about the channels that people will use to access the commissioner, which can involve quite simple things. For example, many wonderful anti-poverty organisations are doing great campaigns and have online tools to help people who are living in poverty to vote, but our full-scale mail-out to almost 6,000 people cost upwards of five grand. You might think of 85 grand is a lot but it may not be so much, especially as there are other costs that have also not been taken into account.

10:45

Marie McNair: It feels as if good work is constrained by finance.

Does anyone else want to come in and share their views?

Karen Wylie: I know that your question is specifically about finance, but it is also important to think about other resources such as the time, capacity and energy that would go into setting up a disability commissioner. Our members are concerned that that might be seen as an easy win or as something that could be done quickly to give us a figurehead, but that it would actually take time and energy away from other areas that we have touched on, such as the disability and equality strategy that is meant to be getting worked on, or the immediate priorities plan that is now the initial action plan. There is a bigger picture, beyond the financial resources, and that should be considered.

Jenny Miller: There is a breadth of individuals involved. It takes time to get to know a group of people who have profound learning disabilities. Engaging with them takes even longer and having meaningful conversation also takes time and a huge breadth of skill. You will need to have a diverse group of people working within the organisation if you are to engage with the breadth of people who have disabilities.

Dr Nolan: Tressa Burke touched on the issue of how to go out to people in remote rural places and engage with them to get feedback. One part of Skye might have a community centre that has no access, whereas another community might have access but it might be impossible to get there on public transport. You might have to do things in a hybrid form or ensure that you offer bespoke engagement.

There are costs to ensuring accessibility. Scotland has a communications accessibility standard, which absolutely must be kept to, so there is no question but that you have to cost that and budget for it. However, there is insufficient funding in the financial memorandum for the engagement support that people will require.

Marie McNair: Thank you; that is really helpful.

Heather Fisken: I back up what others have said about the cost of engagement. They have given good answers. That cost should never be underestimated. One thing in the financial memorandum that struck me was the amount of money allocated to publicity and promotion. That will cost money, but will it have an impact? The financial memorandum refers to a “short-term advertising campaign”, but that kind of thing can have a very short-term impact, so that is something that the commissioner, if they are in place, should look at carefully.

I am also concerned about the issue that was alluded to about money possibly being diverted from other work. We have spoken about the challenges. I am sure that you will be aware of the challenges that are faced by the wider third sector as well as those faced by disabled people’s organisations. The costs of supplies, communications and personal assistance are all going up, as is the cost of venues in the hospitality industry, particularly the accessible ones that we would agree to use.

Disabled people’s organisations work to build capacity so that disabled people can have an influence and be decision makers. I hope that, if we were at the decision-making table and were taking part in that work, we would not see a depreciation of the equality and human rights fund that we rely on to continue our work with the disabled people who form our board and our membership.

The Convener: We move to questions from Evelyn Tweed.

Evelyn Tweed (Stirling) (SNP): Good morning, panel, and thanks for all your answers so far; they have been illuminating.

I will play devil's advocate. You have said that, generally, a disability commissioner is needed: a figurehead and a champion, with laser-like focus. However, your answers suggest that there will be a lot on such a person's shoulders. You are looking for them to deliver a lot and when I look at the provisions in the bill, I wonder whether it is too much. Is everything that is set out in the bill too much for one commissioner to deal with?

There may also be fiscal challenges. The Scottish Government has set aside £1 million in the first year; other people have said that that will not touch what is needed. Is one way to look at the situation to agree that we need a commissioner to be the figurehead and to do the overarching work, while considering that some of the work could go elsewhere, to some of the organisations that already exist. A bigger role for the SHRC has already been discussed.

Lyn Pornaro: The commissioner's role is big, but one in five of us in Scotland is disabled: there are a lot of us. The reason why our members and others are pinning their hopes on a new commissioner is that, so far, we do not have anybody fighting for us in the manner that we need. The Equality Act 2010 has failed disabled people across the UK. The human rights organisations do amazing work, but disabled people are put to the side, with that disability protected characteristic. If the existing organisations and commissioners and the Scottish Government were all fighting for and speaking up for disabled people regularly, there would be a focus on that. Organisations would not be saying, "We'll do this and we'll do that," and only asking, "Oh, but what about disabled people?" right at the end. That is what happens. We see that in our roles day in, day out. Whether it is in public services, in local government or in local shops on the high street, there is an attitude of, "Oh, well, we can't really do that, so we'll just concentrate on the majority." At what point do we have to get disabled people to be classed as the majority? We are the biggest minority group in the UK and within Scotland, yet we are ignored over and over again.

That has been happening not just during the pandemic or the cost of living crisis; we are going back years, decades and decades. As Tressa Burke said, it goes way, way back. When the Disability Discrimination Act 1995 came in, it was a win for disabled people and there was a hope then that it would move things forward and that the focus would not be siloed into disabled people and non-disabled people. We thought that we would come together at that point, but it has not happened and it continues to not happen.

Disabled people are dying because there is not that focus. A human rights bill is being discussed just now—not to divert away from the Disability Commissioner (Scotland) Bill. We have heard the contention that the Scottish Government is fighting for the rights of all people, but it has already committed to agreeing with the United Nations Convention on the Rights of Persons with Disabilities. Yet we are told, "We can't do that." We know that there is all the legal stuff around that, and we are told, "Okay: we'll maybe get there later on." We would say, "Fight for us now." Yet again, we are being ignored on that point. Considering all the stories that we all know about people's human rights being degraded and ignored, with discrimination happening—despite all the dignity, choice and control that disabled people are meant to have in their lives, as non-disabled people do—we find that we are just being ignored, that there is no control, there is no choice and, at times, no dignity.

Do we need a figurehead? We should not really need one at all. Our First Minister, his Cabinet and our elected officials should be our figureheads for shining a light on disabled people. If they shone a light on disabled people, other organisations that are there to do the work would have that light shone on them as well.

Jenny Miller: It is a really interesting question. I totally agree with what you say, but I think that there are all sorts of resources out there, the provision of which we would be able to enforce if we had a disability commissioner. Although we have standards up the ying-yang, which are set and developed by a range of organisations, they are still not delivered.

I think that you are talking about putting a spotlight on what we already have. If we had a commissioner, I would hope that we would not reinvent the wheel but would look at what we already have and ensure that those things are enacted. That is the big issue that we have.

What has happened with the deaths review is absolutely amazing. After many decades of never reviewing the deaths of children with a profound learning disability, we now review their deaths. We have always been expecting them to die, which is why we have had no progress and why we do not plan for life. We had a review that did not go as well as it should have done, because although we have the most amazing standards and resources, nobody was able to force each local authority to use the tools that it was given. As a result of that, harm was done, because a family was contacted without the right process being gone through. We approached Healthcare Improvement Scotland and said, "Look. You've got a standard there and you've developed the resources. You need to enforce that."

Nobody seems to feel that they have the power to enforce best practice. I think that we are looking for someone who can look at all the resources that we have and make sure that those things get enacted. If they do not get enacted, there needs to be some recourse, because we spend millions of pounds developing fantastic practice in Scotland, but sometimes we do not have the impetus to implement it. Our hope would be that a commissioner—an LDAN commissioner or a physical disability commissioner—would be able to make sure that those things were enforced and that they would be given the authority to ask, "Why not?" and "What are you going to do?" We need to make sure that things that should be there, are there.

The Convener: Heather, would you like to come in?

Heather Fisken: I am sorry—I was just waiting for my captions.

I agree with what Lyn Pornaro said, and I will not repeat it. As far as the idea that the role is too big is concerned, yes, it is massive. I think that we have said that quite clearly.

However, there is another angle that I want to add. Over the past decade, we have had some very sudden pressures that have had a massive impact on disabled people and that have meant that our DPOs have had to change tack suddenly and drastically. We had Covid and then the cost of living crisis. That changed everything. We had to react so quickly. A commissioner is going to have to do the same.

That goes back to the point that I made earlier about working with disabled people's organisations and recognising the UN definition of what a disabled people's organisation is, which is set out in general comment 7 of the UNCRPD. To summarise, that definition is massive—it covers every aspect of life. Of course, disabled people are not a homogeneous group. We have spoken about intersectional barriers, socioeconomic issues and the fact that we have the Equality Act 2010 and are considering an incorporation act for human rights in Scotland. Unfortunately, however, the UNCRPD will not be fully incorporated into Scots law through those proposals. There will be a requirement only to give due regard to it, which really is not strong enough. However, that is a different conversation.

It is a really big ask to ask one person to act as a champion. Disabled people are their own champions. We do not need somebody to inspire other people. The law is there. We have our rights. We just need our rights to be delivered in a way that ensures that we have the choice, control, dignity and freedom to exercise our right to independent living in society in Scotland.

11:00

Karen Wylie: I will come in as well. In her question, Ms Tweed said that it would be an awful lot for one person to take on the role of disability commissioner—it would be a huge amount for one individual—so perhaps the SHRC would consider whether it needed to step in more.

The evidence that the committee heard last week said that the Finance and Public Administration Committee was conducting a review of the role of commissioners. The SHRC had suggested that it saw deficiencies in its powers and the roles that it can take on, particularly on participation. Therefore, perhaps it is too much to expect it to take on a stronger role in focusing on disabled people until there is legislative change to achieve that. That will take time, so, again, it is perhaps just a case of us being told, "Bide your time. We are not going to have a disability commissioner. We do not have the strength and remit that we need to have a stronger focus on disability at the moment, but that will come." As Lyn Pornaro said, there is almost a sense of people saying, "When is it going to be? If not now, when?"

Tressa Burke: I will add to that, too. Ms Tweed used the term "figurehead". I want to be really clear that we do not want a tokenistic figurehead; we want a champion. This is not about just one person but about having a team. I really do not mind whether that team is part of the SHRC or would be better on its own—all that needs to be worked out—but it needs to be a team of skilled people, with the right powers, so that not everything falls on one person. It will already be set up to fail if everything is put on the shoulders of one person. The approach needs to be about systemic change that is driven by a team, but it also needs to be better resourced than the financial memorandum suggests.

Evelyn Tweed: At one point you mentioned thinking, "What if this fails? What if it does not happen?" How would we fill in the gaps that you have told us about? How could we strengthen the powers of other organisations?

Tressa Burke: If the proposal for a commissioner fails?

Evelyn Tweed: If this does not happen.

Tressa Burke: We need full-scale systemic change across society. We are talking about transformational change. We would need to properly implement and deliver public sector reform. We need better collaboration, with a focus on prevention, we need to implement the Christie commission's principles and we need to fully resource DPOs. I feel very strongly, as do representatives of other DPOs, that we need the incorporation to include a duty to comply with disabled people's human rights as they are outlined in the UNCRPD. There is not a quick fix for this; it will take time. Disabled people are impatient to see progress made, but they are not unrealistically thinking that it will all happen overnight. We need a plan, with timescales, and we need politicians, the Scottish Cabinet and all the institutions to work together to prioritise disabled people's rights, because they are so far removed from other people's rights.

Jenny Miller: We definitely need a power shift. Without wishing to be politically incorrect, our organisation finds the extent of the power that the Convention of Scottish Local Authorities has in the process incredibly difficult. Having a decision about enacting something that saves people's lives come down to whether parties agreed on some point is frustrating. For example, it once said, about a proposal to introduce health checks, "We would need to check what our members think." Surely, if the evidence tells you that a measure saves lives, you need to enact it.

We need to ensure that the power lies with all of us and that we all have a right to make suggestions. The group of people we support need to plan for life and they need to be expected to live. They have now hit adulthood, but there are no services for them because everybody expected that they would die. Everyone accepted that the mortality rates were shocking and that is what people expected. We need to change that power shift so that we can use the evidence and hold people to account when they do not adopt best practice.

The Convener: We are running very short of time, but I would like to ask for our witnesses' thoughts on the bill's provision on inclusive communication. I put that first to Heather Fisken.

Heather Fisken: It is incredibly important. There is no doubt about that. Having that in the bill will be incredibly important for not just deaf people or people who are visually impaired but people who have a speech impairment. There is a whole range of communication issues. That is not to put those particular issues on a higher plinth than the barriers that other people face.

One of the most important things is that communication is not one way but two way. I saw that in the policy memorandum, and that is welcomed. To look back to what was said about capacity building, it is not just the physical act of making yourself understood but people's understanding of the issue in hand. For example, not everybody who comes to our member webinars has a policy background, so there is a capacity building issue.

Another thing to say is that there is an absolute dearth of supply in Scotland of communication support of particular types. Potentially, that, too, needs to be addressed. The will may be there to supply communication support, but it is not available to provide.

Another thing—which is an experience of all our DPOs—is that, sometimes, when the Scottish Government issues a consultation or a paper, we have to go back and say, hold on, we need this in EasyRead at the same time. Otherwise, it is not inclusive.

That is a very quick answer, taking account of the time.

Lyn Pornaro: I agree with Heather Fisken. We need to think about that two-way approach. We can be really good at putting out inclusive communication in order to include people, but we are not so good when we get it back in again. We need to look at inclusive communication—as in the principles that the Scottish Government has adopted—and enforce that. We need to be able to say how that communication comes back from disabled people, DPOs and other organisations. When reports are done, that is great and wonderful, but they are not inclusive, because of the way in which they are written—often, in a researchy manner. That is not necessarily what disabled people want. A lot of people are excluded if they are told that they have to go online to do something and they are uncomfortable doing that or do not have the facility to do it. Where is the phone number to get the information? I am talking about services. Often, people call a number and are told, just go online and do that. The reason why they are calling is because they cannot access it online or it is complicated.

Often, given different impairments across individuals, when they are faced with something that causes a barrier, they do not know how to react. They do not know what kind of response they will get, so they just turn around and walk away. Their voice is not shared. They do not get on that bus. They do not go into that building. They do not make an appointment. They do not fill a form in. It is just too complicated.

For example, sometimes the information that comes out for applying for benefits is long and long and long. With the coming of Social Security Scotland, that has changed slightly, but it is still a long process for somebody to go through in that way. Often, the information that is given and the questions that are asked are confusing.

We want to make it as inclusive as possible, but we need people's responses to come back. That involves attitudes as well as the physical ability to pass information back.

We support the six principles that the Scottish Government has set out, and we follow those in all our work. We want to make sure that a disability commissioner—or whatever—does so too. Hopefully, that would have a butterfly effect on the other commissioners that they work alongside, and on other organisations as well.

Jenny Miller: As Tressa Burke mentioned, disabled people are often the ones who come up with the solutions. Family carers tell us how to make things more accessible. Having that involvement and making it a two-way process supports that.

The Convener: Since no other member wishes to come in on that question, that brings us to the conclusion of our first panel. I thank you all very much for your testimonies. I suspend the meeting briefly until we go to our second panel.

11:09

Meeting suspended.

11:16

On resuming—

The Convener: We will now take evidence from our second panel. I welcome to the meeting Jamie Cooke, who is head of policy and communications at Enable; Suzi Martin, who is external affairs manager at the National Autistic Society Scotland; Alice Struthers, who is programme director at the Neurological Alliance of Scotland; and Eddie McConnell, who is the chair of the Scottish Commission for People with Learning Disabilities. You are all very welcome, and thank you for attending this morning.

We are tight for time, so we will move straight to questions. I will kick off by asking what your views are on the bill and whether you support its general principles.

Jamie Cooke (Enable): Enable supports the intention and view of the bill. We definitely see the need for further support and for enhancing and delivering on the rights that people with disabilities have and should have in Scotland, so we strongly support the bill.

As we work particularly with people with learning disabilities, we recognise that that community is quite often further excluded—indeed, statistics show that levels of premature death and exclusion from the workplace and universities are much higher.

We recognise that the learning disability, autism and neurodivergence bill is also being considered. We see the need for ensuring the development of further support for that part of the community through any of the work that is taken forward, and for that community to not simply be taken for granted in the wider setting.

Suzi Martin (National Autistic Society Scotland): Thank you for the opportunity to speak to the committee. We also agree with the principles and the intent of the bill. We understand why Jeremy Balfour has introduced it and pay tribute to the work that he has done, and continues to do, for disabled people during his time in Parliament. A lot of work has gone into the bill, so we pay tribute to that work and to Mr Balfour’s staff.

Although we agree with the principles and the intent of the bill, we think that further work is needed to protect and promote the rights of all disabled people. As you will be aware, the learning disability, autism and neurodivergence bill has been consulted on, and there was a proposal in the consultation for a commission or commissioner for people with learning disabilities, autistic people and neurodivergent people.

Similarly to Jamie Cooke, we believe that there is good reason to have a specific commissioner for autistic people, people with learning disabilities and neurodivergent people. Often, those individuals can be overlooked when a more generalist, pan-disability approach is taken—the outcomes speak to that—so there is a real need for a focus on that specific community. However, we agree with the intention and the principles of the bill, and we understand why Jeremy Balfour has introduced it.

Alice Struthers (Neurological Alliance of Scotland): The Neurological Alliance of Scotland is a membership organisation with 55 charity members. We fully support the call for a disability commissioner in Scotland. We believe that the need for a dedicated disability commissioner is shown by the lack of care that people with disabilities currently get from authorities. Essentially, people feel that their individual and collective voices are simply being ignored at the moment. That is why we fully support that call for a commissioner. We are worried about the cluttered landscape—I know that that has come up quite a lot—and we worry slightly that the remit lacks teeth, but we stand by the principle that a disability commissioner is needed in Scotland.

Eddie McConnell (Scottish Commission for People with Learning Disabilities): Good morning, everyone. Thank you for the opportunity to speak to the committee about the bill.

The Scottish Commission for People with Learning Disabilities supports the policy intent of the bill. People with learning disabilities tell us on a daily basis that the status quo is not acceptable and that their lived experience of abuse, discrimination and continual injustice has to end. To be brief, I will simply say that I support the comments that my colleagues on the panel have made.

The Convener: Okay. Thank you. We will now move on to questions from Maggie Chapman.

Maggie Chapman: Good morning and thank you all for joining us and for your comments so far.

Alice Struthers talked about the cluttered landscape and the potential confusion for people, which we have heard about in previous sessions. If a disabled person is not able to realise their rights and wants to go to somebody to seek redress, would they go to the Scottish Human Rights Commission, the Equality and Human Rights Commission or the disability commissioner? What are your views on that cluttered landscape and the different commissioners potentially working alongside one another, with overlapping or maybe duplicated mandates? How do you see that working out?

Alice Struthers: We agree that we are edging towards a cluttered and expensive commissioner landscape. In fact, there is no evidence to demonstrate the efficacy of having commissioners in terms of whether they work for everyone, and there is a real risk of overlap.

I know that the EHRC and the SHRC currently have responsibility for reviewing legislation that impacts on disabled people. However, we support the idea of introducing a disability commissioner because they will have responsibility for all disabilities without a focus on any single condition. A condition-agnostic disability commissioner who can pull together evidence across a whole spectrum of long-term conditions would be able to see the bigger picture in relation to what is going wrong.

For us, it is about focusing on the barriers that impact on disabled people, and looking across all disabilities would be a way of doing that successfully. There is a cluttered landscape—there is no doubt about that—and I know that more commissioners are in the pipeline. Looking at the roles and remits and making sure that there are memorandums of understanding and so on is very important, and that has to be factored in right at the beginning rather than carving things up later and trying to work out who does what. There is a risk of more time being spent on working out who has responsibility within the commissions as opposed to time being spent on the people who have disabilities and who want to seek help. You are absolutely right—I agree that the landscape is cluttered.

Maggie Chapman: You mentioned people working together across commissions and sharing information. Do you see any potential issue with different commissioners having different levels of authority or different levels of power? For instance, under its current mandate, the SHRC cannot take enforcement action.

As you have said, there are proposals for different commissioners. We could argue that that means that the powers that the existing commissioners have are not sufficient or that all the powers that they have are not being used effectively. What are your thoughts on potential differences of authority or mandate across different commissioners?

Alice Struthers: It is important that there is not a hierarchy of commissioners and commissions. The remits of the commissioners must be very well understood and clear, but the work should be collaborative. It should involve working together intersectionally and understanding where things meet and where they need support from each other. We heard from the earlier panel of witnesses about the importance of joint work and collaboration and about whether the commissioner model may not be the right one at all.

In essence, disabled people need to have a commissioner. At the Neurological Alliance, there is no doubt in our minds that that is the case. However, on how they work that out—it is complicated.

Maggie Chapman: Thanks. Eddie McConnell, I will come to you with the same kind of question. How do we deal with the potential problems and confusions around that duplication of work and mandate and the overlap that might result if the decision is made to go ahead with a disability commissioner?

Eddie McConnell: It is a fair question. I would view it slightly differently, because the daily experience of people with learning disabilities and their families is complexity and a complex landscape that is not user friendly for them. They know about complexity and they unfortunately spend most of their lives fighting that complexity and struggling to get their human rights recognised and respected.

My view and that of SCLD is that a disability commissioner could actually cut through that, and I invite the committee to think of that as a possibility. It does not necessarily need to be the case that a disability commissioner would add to the complexity. If the office is properly framed and actively involves people with learning disabilities, it could use that experience to cut through the complexity. It could actually be a beacon in what is undoubtedly a challenging landscape at the moment.

Maggie Chapman: That is interesting. You have all described and the committee heard earlier this morning and previously the failures of commissioners, other structures, support organisations and Governments to deal with some of the inequalities—you talked about the abuse, discrimination and continued injustices that disabled people face. Given all that, you therefore think that this focus—this office, person or resource—would be really instrumental in transforming that.

Eddie McConnell: SCLD believes that, for the community that it represents and listens to—people with learning disabilities—anything like a disability commissioner that places a sharp focus on their needs and injustices and human rights can only be a good thing. We are concerned that, for the particular community that we are involved with—people with learning disabilities—a pan-disability approach, as is advocated by this bill, could mean that we are at the back of the queue again. That has often been the experience of people with learning disabilities. We often find ourselves at the back of the queue. Therefore, there is more to be done in this bill to articulate how that would be avoided and how people with learning disabilities would be seen as equal to all disabled people and advance, probably, at a faster rate, because they are undoubtedly the group, within a pan-disability environment, whose rights are most at risk.

Maggie Chapman: Thanks—that is helpful. Suzi, you were nodding as Eddie was talking. What are your thoughts on this?

Suzi Martin: I will touch on a couple of things. You have raised some really interesting issues. First, I want to touch on the idea that it is a confusing landscape. Eddie McConnell's point that disabled people, and in particular autistic people and people with learning disabilities, deal with complexity every day is a really good one.

The idea that people will be confused by introducing something that is specifically for them in name is a bit bizarre to me, to be honest. Also, if, in the future, an autistic person goes to what I hope will be a learning disability, autism and neurodivergence commissioner and it turns out that the Children and Young People's Commissioner Scotland is maybe better placed to deal with, or is already working on, that particular issue, I would hope that it would not be beyond the wit of our existing commissioner landscape to make a referral happen behind the scenes and for that person to then be given the appropriate advice and guidance, for action to be taken quickly and for them to be put in touch with the right commissioner or the right body. I would hope that that is not beyond the wit of the existing commissioner landscape.

I would push back on the idea that something specifically for autistic people and disabled people would somehow increase complexity. Were such a commissioner to be established, there would need to be memorandums of understanding. Having those is really important. That is the first point.

11:30

On duplication, different mandates and potential hierarchies, I would say that, certainly from the perspective of autistic people, if we were to have a commissioner for autistic people and people with learning disabilities, there would be no duplication, because the existing bodies that we are talking about are not really doing any focused work on this community. Where they have done focused work, they have maybe done one report in a period of 10 years.

If you look at the current strategy for the Scottish Human Rights Commission, I think that there is one mention of autism or autistic people. I do not believe that autism or autistic children and young people are mentioned at all in the Children and Young People's Commissioner Scotland's strategy. That is not a direct criticism. Those bodies are set up to deal with all people in Scotland, in the case of the SHRC, or all children and young people, in the case of the Children and Young People's Commissioner Scotland. They have to deal with those whole groups of populations. However, that puts people with learning disabilities and autistic people at a disadvantage, and it always has done. That is our concern.

On different mandates, we have seen when that has worked really effectively. Again, I would push back on the idea that that is inherently a bad thing. The Children and Young People's Commissioner Scotland worked with the Equality and Human Rights Commission on restraint. They pulled the different levers that they have to achieve change and to get the ball rolling on what will eventually be, I hope, a legal framework on the use of restraint and seclusion. Therefore, I would push back a bit on the idea that having commissioners with different mandates is inherently a bad thing. However, it is important that there is collaboration as opposed to duplication.

The last thing that I want to talk about is the idea that there is a lack of evidence on commissioners being effective. Things are happening at a macro level that commissioners cannot hope to influence. It is really important that we understand that having a commissioner does not equal immediate change. Commissioners are there to leverage change, and they will always be a few steps back from the change that happens; we need to understand that.

I can see from looking at recent evidence sessions in other committees that the commissioners have had a grilling, but it is important that we understand that they are doing really good work that is often under the surface and behind the scenes. Often, that work is strategic litigation, where they are testing the law, but they also provide advice and guidance to families and individuals.

Those are the main points that I wanted to make.

Maggie Chapman: That is really helpful. You mentioned that a disabled person might also be a young person or an older person. That is what I interpret as intersectionality and an understanding of the multiple identities that any one person can hold. Is the way to deal with those intersectional issues and have internal referral processes—if I can use "internal" in that way—by having a very clear framework or structure, however it is designed, of collaboration and communication? Would taking that intersectional approach deal with some questions or potential problems, but would we then miss a vital need elsewhere, because we are looking at a different picture?

Suzi Martin: Yes, I think so. It is about complementarity and addressing the gaps as opposed to necessarily overly worrying about overlap. For our communities, it is about the gaping holes in the system; that there is a slight overlap in a certain place is not the problem.

What is really interesting about the intersectionality issue is that what you have described addresses that in part. However, we must understand that, when specifically thinking about autism, there is widespread misunderstanding of what autism is and what it means to be autistic, although there is also increasing awareness. That is leading to a lot of really big issues and big problems. What we are seeing at the moment is autistic people doing the work of training professionals and educating the public. That should not be their role, and the public sector and public bodies need to step up in that respect.

For us, then, intersectionality is important, because it is about addressing those gaps, and there is a big, big gap when it comes to autism understanding and acceptance. Nothing is filling that gap at the moment, because the bodies that we have often take a generalist approach to human rights. As Eddie McConnell has described, people with learning disabilities and autistic people often end up at the back of that queue.

Maggie Chapman: Thanks, Suzi. Jamie, perhaps I can ask you the same question. How do you view the potential for dealing with overlap and duplication, notwithstanding what Suzi Martin has said about the gaping holes in provision?

Jamie Cooke: The issues have already been set out very eloquently by my colleagues on the panel and I agree with what has been said.

For me, though, there are a few key points. First, I do not think that we get a cluttered landscape if there is clarity. If each commission that we have, in whatever shape or sense, is very clear about its own role and how it interacts with others, that will start to reduce the clutter. After all, we do not get clutter if we have the correct number of different agencies and commissions producing things; the clutter comes when we create silos.

My concern—and, indeed Enable's concern—about having a specific commissioner is that they just get put in the corner as, say, the learning disability, autism and neurodivergence person and get talked to only when such issues come up. As we have all touched on, intersectionality and the impact with regard to social deprivation, education, health and so many different areas means that they have to be part of all those conversations.

As for the hierarchy of commissioners, which you touched on, some of the commissioners that we are talking about could, together, play a role in keeping not only Government, politicians and society itself honest, but other commissioners honest, too. That, I think, would give us a chance to enhance the role of the commissions and commissioners that are already in place, because it would help to expand their impact. As has been touched on, when we deal with human rights in their entirety—and, indeed, children and young people in their entirety—we are talking about a huge, broad section of society and we need to be able to focus specifically on those people who are being left behind just now.

Moreover, although the commissioner role is important, we should not be focusing solely on an individual. After all, we are not, as has been said, talking about some person who is just going to come in and magically fix everything; instead, they will be building into an existing ecosystem that you are already hearing support for and evidence from. There is an environment out there that will support and contribute to the commissioner's work, and this is about their providing a focal point to take some of that work forward.

Finally, I would build on that by saying that this is also an evolutionary process. We are not discussing the introduction of something that will never be looked at again; indeed, we are already reviewing the impact and the current status of commissioners and commissions. Ideally—this was covered in the previous panel—we should not need commissioners, because these ideas would be championed in every piece of work. Having them might well drive that change and lead to our not having commissioners in future, so we should be reviewing on an on-going basis how they are interacting and functioning with each other.

Maggie Chapman: Thank you—that was really helpful. I will leave it there, convener.

The Convener: We will now have questions from Paul O'Kane.

Paul O'Kane: Before I ask my questions, convener, I will just say that it was remiss of me earlier not to declare or draw attention to my entry in the register of members' interests as having been employed by Enable Scotland until 2021.

I am keen to expand on the previous discussion. Obviously, your organisations have been across the detail of or have been involved in the campaign for a learning disabilities, autism and neurodivergence bill and, potentially, the establishment of a commissioner as part of that process. Building on what has been said about the interaction of commissioners, what are your views on how a disability commissioner and a potential LDAN commissioner might interact? Do you have concerns about siloed working, which I think has been referred to, or about things becoming so broad that we do not have the specialism that is required?

I do not know who wants to respond to that large question. Suzi?

Suzi Martin: Yes, I am happy to respond.

As I have said, we understand why this bill has been brought forward, and we agree with its principles and intent. As we have said in our written submission, if there were to be a disability commissioner and an LDAN commissioner, we would expect there to be a memorandum of understanding.

For us, it is about addressing a gap. As has already been said, we have concerns that autistic people's rights would not be sufficiently focused on or addressed and that sufficient resource would not be put behind promoting and protecting autistic people's rights within a more generalist or pan-disability context. In considering the outcomes, we therefore feel that there is a really good argument for having a specific LDAN commissioner.

If there are to be two commissioners, there will have to be close collaboration, close working and an understanding—particularly when consultation has taken place and strategies are being drafted and published—of what each commissioner is planning and what their key priorities are over a certain period of time in order to ensure that they do not duplicate but complement one another, and potentially work with one another to achieve positive social change where they can.

I think that that answers part of your question, Paul.

Paul O'Kane: Does anyone else want to comment?

Eddie McConnell: SCLD's first priority is to support the Government's stated aim of introducing a learning disabilities, autism and neurodivergence bill, but we do not have the detail of that in front of us. The consultation process has only recently been completed. It will be interesting to see what comes forward in the draft bill in due course.

However, at SCLD, we talk more about the need for accountability measures. We emphasise those, more than whether there should be a commissioner under the LDAN bill. From talking to people with learning disabilities and their families, we are clear that their single greatest frustration is that people, organisations and public authorities appear not to be held to account for the absolute dereliction of their duties in upholding those people's human rights. It is imperative that new accountability measures come forward so that people's rights are amplified as well as protected and safeguarded.

In a scenario where an LDAN commissioner was created as well as a disability commissioner, it would be imperative that there was close co-operation and dialogue. I could not envisage a situation where either commissioner would fulfil their remit without that close and really tight collaboration.

This is a bit speculative because we do not have the detail of the proposals in the LDAN bill or the ideas around a commissioner, but our fundamental point is that we have to deliver greater accountability for the continuing injustices that people in our community—people with learning disabilities and disabled people more generally—continue to live with day in, day out. Some form of accountability measure needs to be properly introduced.

In that regard, the Disability Commissioner (Scotland) Bill, which is the focus of our discussion today, probably needs to go further in holding people to account, with provisions that go beyond just carrying out an investigation or an inquiry to ensure that any recommendations and proposals from such inquiries are enacted. That would feel like full accountability rather than partial accountability.

Paul O'Kane: PAMIS raised concerns in its evidence that the Disability Commissioner (Scotland) Bill could jeopardise the LDAN bill, or its success. Do you share that view or do you not see that risk?

Suzi Martin: I do not necessarily see the Disability Commissioner (Scotland) Bill as posing a risk to the proposals for a learning disabilities, autism and neurodivergence commissioner. As the Parliament has recognised—we know that the Finance and Public Administration Committee is looking at this—there are multiple calls across various sectors for commissioners, which speaks to what we have termed the accountability gap and some have termed an implementation gap. Those calls are coming from potentially similar places, which is, again, why we understand and agree with the intent and principle of the bill. We would not necessarily see it as a risk, because we have very strong evidence about the outcomes of autistic people and people with learning disabilities.

11:45

It is also worth emphasising that a lot of work has been done, over a number of years—since 2021—on the LDAN bill and, specifically, looking at the possibility of a commissioner. As you will know very well, Paul, we campaigned for that in the run-up to the 2021 election, and a proposed commissioner appeared in several party manifestos and ended up in the Scottish Government's programme for government in 2021.

Since then, there has been a large-scale scoping exercise, in which autistic people and people with learning disabilities were consulted, and there has been a lived experience advisory panel, which agreed that accountability is really important. It was at the top of the panel's list of things that the bill really needed to address. There has also been a very large public consultation, and we are waiting on the analysis of the responses to that.

It is worth mentioning that context: that the bill, which includes proposals for a commission or a commissioner, has had a lot of work go into it. We have heard from autistic people and people with learning disabilities and we are going to hear more from them through that consultation process. It is really important that the Parliament listens to what autistic people and people with learning disabilities say that they want the bill to achieve and what they want from a commissioner. For me, it is really important that we recognise all that work and the fact that we have gotten this far.

Our research, by the National Autistic Society Scotland and Scottish Autism, indicated that, out of more than 1,000 autistic people, family members and professionals, 96 per cent supported the concept of a specific commissioner. We know that there is really strong support out there. We also have the key foundation that builds the argument, which is that outcomes for autistic people and people with learning disabilities are very poor. They are five times more likely to be excluded from school, fewer than one in five autistic people are in employment, they are more likely to die earlier from preventable illnesses and the mental health of autistic people is very poor. We also know that there are more than 300 people in institutional settings who are either experiencing delayed discharge or should not be in those settings, so the outcomes speak for themselves.

Paul O'Kane: Would Eddie McConnell like to add something?

Eddie McConnell: Thank you, Paul, for the question. If I recollect it correctly, you were asking whether we had a view on the view expressed by PAMIS, with which we work very closely. As I said in my earlier remarks, SCLD supports any initiative that will throw a greater spotlight on improving the rights of disabled people in general and, in particular, our community of people with learning disabilities.

We know, and it is self-evident, that disabled people are not a homogeneous group. Within that, we recognise that people with learning disabilities often find themselves very much a marginalised group within the broader disability population. That is where our concern comes from, in that the Disability Commissioner (Scotland) Bill does not, at the moment, address the issue of how people with learning disabilities would be particularly protected and prioritised.

In that sense, in the absence of that specificity and clarity in the bill, the SCLD would share the concerns that a pan-disability approach might result in people with learning disabilities finding themselves once again at the back of the queue. We would argue, strongly and robustly, that all of the evidence, over many years, and the lived experience of people with learning disabilities, is that they are the people—the particularly marginalised group—whose rights are most at risk.

It seems to us that, if you wish to address a marginalised group whose rights are at risk, you have to put unequal effort into that group to bring them from a page called inequality to a page called equality. It requires unequal effort, and that is probably where we differ slightly from the view offered by the Scottish Human Rights Commission in its universal argument for all people. We know that the very marginalised group of people with learning disabilities, and, even within that group, people with profound and multiple learning disabilities and people with Down syndrome, have particular needs and require particular support. We cannot adopt a homogeneous approach. If we are truly in the business of addressing people's human rights, we need to understand the complexity of the population that we are dealing with.

Meghan Gallacher: I would like to touch on what you said about the powers of the Scottish Human Rights Commission in response to Paul O'Kane's question. We heard from the previous panel concerns about the commission not having sufficient powers and about disabled people always feeling as though they are at the back of the queue, given that that overarching commission deals with a lot of various issues and groups. Why do disabled people feel as though they are not being represented? Even if the SHRC's role was strengthened, would there still be a black hole, with disabled people not fitting in? Is that why it is important to have a disability commissioner?

Eddie McConnell: Part of my response will be based on my experience as the father of a young man with a learning disability, which I bring into play every day in my role as the chair of the SCLD. From my experience, I am fairly clear that my son will not be put further up the queue; he will always find himself right at the back of it.

There is a need to focus on marginalised groups and to understand their needs. Their needs are complex, but that should not mean that we push back from dealing with them. In fact, we should be more inquisitive and more determined to understand that complexity, because, as I said earlier, if we understood that complexity, we could cut through the unintended clutter and complexity elsewhere.

People with learning disabilities have not experienced their rights being advanced as a consequence of the SHRC and other such organisations or commissions with existing powers. I am not suggesting that there is a lack of interest—those organisations do very good work—but they take a universal approach. The SHRC has set out that its approach is to address the human rights of the general population. We argue that a universal approach will serve only to continue to keep people with learning disabilities further back, without their rights being properly addressed.

A disability commissioner—or, indeed, an LDAN commissioner, which might emerge in due course—cannot do all this work alone. Given the sheer complexity and demand of the work involved, as well as the sheer history of abuse and discrimination, a sector-wide and society-wide approach is required. I cannot imagine a situation in which a disability commissioner, working with and for disabled people—or an LDAN commissioner, working for that particular community—could move the agenda forward without really close collaboration with the Scottish Human Rights Commission.

The SHRC might well be better placed to advance certain elements, but, in its work, it would really value the expertise and specific knowledge of the learning disability community. I see the relationship as reinforcing; it is not a case of either/or. I would much prefer us to view this as an opportunity to shift the dial for disabled people in Scotland by understanding the disability commissioner's role in the context of the current provisions, standards and work, because we need to drive all of that forward in a powerful and collaborative way.

Alice Struthers: I agree with everything that Eddie McConnell has said.

There are an estimated 600 different neurological conditions. You would not necessarily say that someone has a disability just because they have a neurological condition, but neurological conditions in and of themselves can be very disabling.One of the problems that we have is around people recognising where to go for help. If they do not recognise themselves to be disabled or as having a disability, where do they go for help?

The benefit of having a disability commissioner role would be to have a champion and a clearly defined figurehead. There are obviously advantages and disadvantages to a pan-disability role; we stated our thoughts about that in our written evidence with regard to needing someone who understands the nuances of each condition and how not to apply personal experience to their understanding of someone else's disability.

For us, it is about having that focus, and having a champion. There is an element to do with the Equality Act 2010, as well. As I said, the ableist world that we live in is part of the problem, so it is not enough to depend on the definition in the 2010 act with regard to the ability to investigate and put things forward.

We feel that, even if the SHRC's powers were to be opened up, having a disability commissioner would still be of value.

Meghan Gallacher: Does Jamie Cooke want to come in on that?

Jamie Cooke: I think that you will hear a lot of agreement across this subject. We recognise that all our organisations work from a basis of human rights, so we are all firmly committed to, and we contribute to, the development of that approach. Having a commissioner is about the additionality that a specific focus can bring.

It is not to be expected that the SHRC as it stands, or even with enhanced powers, could fully cover that entire scope and environment. We have laws and rights in place, but we need to see accountability and follow-up. It is about delivery and accountability and how we deal with things when they go wrong.

Having that specific focus would feed into and—as Eddie McConnell said—enhance the impact of the SHRC. It would provide a space for, and provide overarching recognition of, the human rights-based approach that we want to see across society, and it would ensure that our communities are not left out as a result of the sheer scope of the population that is being dealt with.

An LDAN commissioner and a disability commissioner would offer an enhancement of the work that the SHRC could do in delivering through specialist knowledge and follow-up.

Meghan Gallacher: Does Suzi Martin want to come in on that?

Suzi Martin: Yes—I will try to be brief. We would not say no to the SHRC having more, and enhanced, powers; that would be a good thing. However, we would have concerns about a potential lack of focus on autistic people and people with learning disabilities. For us, an important benefit of having a specific commissioner is that that would be on the statute book—it would be set down in law that there is a commissioner for that specific group of individuals.

I know that the SHRC has talked about legislative change to enable it to have internal commissioners and rapporteurs who are specific to different populations, but I imagine that that legislation would not specifically refer to autistic people and people with learning disabilities. It would still be an internal decision as to how much focus, resource and time is given to that population of individuals.

For autistic people and their families, it is really important that that body is there and that there is a legal duty for it to consult them and to protect and promote their rights.

The Convener: We now have questions from Marie McNair.

Marie McNair: Good morning, panel members. You will know from sitting in during the previous evidence session that we are looking to hear your thoughts about the financial and resource estimates that are attached to the financial memorandum. I got a sense from the earlier session that the figure of £1 million is a huge underestimate; I pop that out there for your thoughts. Perhaps Eddie McConnell can start.

Eddie McConnell: I think—if I am allowed to say so—that the estimates are probably conservative. I listened to the previous witnesses, and I will not repeat too much, but the particular concern that the SCLD would offer to the committee is about the cost of ensuring meaningful participation, particularly by people with learning disabilities, in the work of the proposed disability commissioner. That requires a substantial investment of resources, and of time and skills, to ensure that people are properly and meaningfully involved. We have a particular concern that insufficient resource is allocated to that area.

12:00

On the broader issue of resources, notwithstanding my general observation that the figure is probably light, we would prefer the various collaborations to be tested to see where resources are levered from other places, too. Resources are already targeted in this area, and we know that existing standards are not being implemented. There is already quite a lot of resource. It would be fantastic to have a disability commissioner or LDAN commissioner with a focused role who can lever those resources in the best interests of disabled people in general, and people with learning disabilities in particular.

Suzi Martin: I agree with Eddie McConnell that the estimate is conservative. I echo what the previous panellists said about the need to ensure that there are appropriate resources for engaging individuals meaningfully.

I want to flag up what we want from a commissioner. The role should be to consult autistic people, people with learning disabilities and their families; to protect and promote their human rights; to conduct investigations and compel bodies to give evidence; and, ideally, to compel them to follow through with recommendations, so that there is that enforcement aspect, as well. The role should also be to promote good practice. It is important that all the functions of a proposed commissioner are appropriately and adequately resourced.

I recognise that there is an on-going inquiry by the Finance and Public Administration Committee into the current landscape and costs. The Scottish Government estimates that issues related to autism cost the Scottish economy £2.3 billion. That includes services as well as lost productivity due to unemployment and underemployment. Although there will be running costs and an additional outlay for a commissioner, it is worth flagging that we see that as a very good investment and as part of an ecosystem that is designed to leverage change and funding where it is needed most in order to save money further down the line.

Especially given the misunderstanding around autism that I talked about, autistic people regularly end up in crisis and a lot of money is spent on dealing with crisis situations—there is an increasing awareness of that. That has an untenable human cost, but also an unsustainable economic cost. We need to shift that balance, and we would see the investment in a commissioner as very positive. I just wanted to flag that.

Jamie Cooke: I agree. The language of investment and the recognition that it is not just a cost are important. Financials are of course critically important, but it is also about what that investment will do—what it will bring to and change in people's lives. It is also about resource that goes beyond purely the financial. There is the resource of time and space for the commissioner to work and deliver. We should not expect that, because we have funded the commissioner for a year, everything will somehow change tomorrow. We are talking about long-standing barriers to participation in society, which will take time to change. We need the resource of time and space to give the ability to make a difference.

With some of the functions, we need to consider what the wider set-up and team look like. As I said, there is often an automatic focus on the person who is the commissioner, whereas the impact for children and young people through the children's commissioner is through the wider team. The resource around research, enforcement and legal awareness is critical to taking forward that work. We need a sense of the resources in their entirety within that longer timescale to see the impact that they can drive, and we need to look at it as an evolutionary process that can be reviewed as it goes forward.

Alice Struthers: I just wanted to come in to agree that it is an investment. I am interested to hear Suzi Martin's statistics for the cost of autism. The estimated cost of neurological conditions across the UK is £96 billion, and that is just for 10 different neurological conditions. Roughly half of that is lost productivity in the workplace and the impact on carers, who might not be able to work full-time.

I share my colleague's concerns about the proposed costs of setting up the office, the budget and the staffing levels, and that, as they stand, the office might have minimal impact for disabled people. Setting it up without participation staff or legal staff and all those things will hold back the commissioner's ability to fulfil their role and make a real difference to people with disabilities. Generally speaking, the estimate for the disability commissioner's office is very conservative and, as has been said in this session and in the earlier session, it cannot just be a tick-box exercise. The set-up has to be committed to and desired if it is to make a profound difference to people. At the moment, as it stands, it feels as though it might not achieve that.

Marie McNair: Thank you for your comments.

The Convener: We now have questions from Evelyn Tweed.

Evelyn Tweed: Good afternoon, panel members, and thank you for your answers so far. What are your views on using the Equality Act 2010 disability definition in the bill?

Jamie Cooke: The Enable perspective is that using language that is already recognised helps to ensure, on one level at least, that the people whom we serve will be considered. However, we also recognise that the language that is used around impairment is not the language that the people whom we work with would recognise or wish to be used. Given that within the current work on the LDAN bill there has been recognition and clarity around using the language that people themselves wish to use and recognise, it is vitally important that that is incorporated. Although it is important to use the legally recognised language, if it disconnects the people whom we serve from that work, we are already running into the isolation and exclusion troubles that we have touched on so often already.

Suzi Martin: I agree with what Jamie Cooke said. Similarly, autistic individuals do not necessarily see themselves reflected in the language that is used in the Equality Act 2010. Many autistic people do not identify as disabled or having a disability. That poses a problem in that it could isolate autistic people from a body that would be designed to serve them or to protect and promote their rights. How the bill as it is currently drafted would capture and serve all autistic people is a concern for us, so we share the concerns that Jamie has outlined.

Evelyn Tweed: Does anyone else want to come in?

Alice Struthers: I am in agreement with my colleagues. It is generally a great starting point, but we would prefer there to be a more inclusive definition of disability. An approach of a more social model of disability would be useful for a disability commissioner.

Eddie McConnell: The SCLD is very uncomfortable with the use of the 2010 act definition in the proposed bill. We see it as a deficit-based definition that relies heavily on a medical model of disability. We advocate that that should be challenged, and we would propose a much broader and more inclusive definition that is aligned with the United Nations Convention on the Rights of Persons with Disabilities. We certainly advocate that as a much more appropriate and inclusive approach than the deficit-based model that we believe that the 2010 act definition perpetuates.

The Convener: As there are no more questions, that brings us to the end of the session. Thank you for your participation. We will pause while we move into private session.

12:09

Meeting continued in private until 12:22.

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Official Report
Room T2.20
Scottish Parliament
Edinburgh
EH99 1SP

Email: official.report@parliament.scot
Telephone: 0131 348 5447
Fax: 0131 348 5423

The deadline for corrections to this edition is:

Wednesday 10 July 2024

Published in Edinburgh by the Scottish Parliamentary Corporate Body, the Scottish Parliament, Edinburgh, EH99 1SP

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