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Equalities, Human Rights and Civil Justice Committee

Tuesday 26 November 2024



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EQUALITIES, HUMAN RIGHTS AND CIVIL JUSTICE COMMITTEE 26th Meeting 2024, Session 6

CONVENER

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

DEPUTY CONVENER

*Maggie Chapman (North East Scotland) (Green)

COMMITTEE MEMBERS

*Pam Gosal (West Scotland) (Con)

*Marie McNair (Clydebank and Milngavie) (SNP)

*Paul O'Kane (West Scotland) (Lab)

Evelyn Tweed (Stirling) (SNP)

*Tess White (North East Scotland) (Con)

THE FOLLOWING ALSO PARTICIPATED:

Susan Burt (People First (Scotland))
Jamie Cooke (Enable)
Gregor Hardie (People First (Scotland))
Joe Long (Scottish Autism)
Suzi Martin (National Autistic Society Scotland)
Jenny Miller (PAMIS, Promoting a More Inclusive Society)
Dr Simon Webster (Scottish Commission for People with Learning Disabilities)

CLERK TO THE COMMITTEE

Katrina Venters

LOCATION

The James Clerk Maxwell Room (CR4)

^{*}attended

Scottish Parliament

Equalities, Human Rights and Civil Justice Committee

Tuesday 26 November 2024

[The Convener opened the meeting at 10:01]

Decision on Taking Business in Private

The Convener (Karen Adam): Good morning, and welcome to the 26th meeting in 2024, in session 6, of the Equalities, Human Rights and Civil Justice Committee. We have apologies from Evelyn Tweed.

Our first agenda item is a decision on taking in private item 3, which is consideration of today's evidence on the proposed learning disabilities, autism and neurodivergence bill. Do members agree to take that item in private?

Members indicated agreement.

Learning Disabilities, Autism and Neurodivergence Bill

10:01

The Convener: Our second agenda item is an evidence session on the pause to the introduction of the proposed learning disabilities, autism and neurodivergence bill.

This morning, we will hear from a panel of witnesses that is made up of member representatives and others representing people with learning disabilities, neurodivergent people and autistic people. I welcome to the meeting Gregor Hardie and Susan Burt, who are member representatives from People First (Scotland); Jamie Cooke, who is the head of policy at Enable; Suzi Martin, who is the external affairs manager at the National Autistic Society Scotland; Jenny Miller, who is the chief executive of PAMIS, Promoting a More Inclusive Society, and who joins us remotely; Joe Long, who is the director of practice and innovation at Scottish Autism; and Dr Simon Webster, who is the chief executive of the Scottish Commission for People with Learning Disabilities. You are all very welcome. Thank you for attending.

We have a larger number of witnesses than usual today, but we have plenty of time, so I will take things steadily. I refer members to papers 1 and 2. I begin by asking our witnesses for brief opening statements.

Gregor Hardie (People First (Scotland)): Good morning. I represent the powerful voice of citizens with a learning disability in Scotland. I have the privilege of doing that because I am a director and member of People First (Scotland), which is the disabled people's user-led organisation for learning disability.

The Equalities, Human Rights and Civil Justice Committee has invited us to bring our expertise and to give evidence a few times over recent years. We welcome the opportunity as a rare example of meaningful citizenship that recognises us as humans and as experts on our lives.

When we gave evidence previously, that happened through our partnership with the Fraser of Allander Institute. It followed research by the institute that focused on the life experience of citizens with a learning disability and described Scotland's failure to realise our human rights. The institute's latest research states that

"while employers have a desire to recruit people with learning disabilities, they are lacking an understanding of how to do so."

The research revealed five key themes that are holding employers back, which are

"lack of knowledge leading to prejudice, lack of prioritisation, lack of intention and knowledge about how to recruit, not knowing where to start, and a perceived cost barrier."

In fact, those things apply to every aspect of our lives, and their impact reinforces the low expectations that Scotland has for us.

Susan Burt and I will offer a number of examples in our evidence today. The proposed LDAN bill has ideas in it that hold the potential for change. We were hopeful that some of the changes that People First (Scotland) has campaigned for over more than 35 years might finally move ahead, but we remain unheard. Action, not words, is required. Without legislation that is specific to us, Scotland will continue to fail us as humans with rights.

Please look at our website and take time to watch the film that tells you why legislation in Scotland that is not specific to us will continue to fail us.

I will now hand over to Susan.

Susan Burt (People First (Scotland)): Thank you, Gregor.

I also represent the powerful voice of citizens with a learning disability in Scotland. Like Greg, I have the privilege of doing this because I am a director and a member of People First (Scotland). My networking with partner organisations includes the equally safe project's development and a wide range of issues around women's health, women's rights and gender-based violence.

I represent People First (Scotland) on the adult support and protection committee in Fife. I bring our collective learning disability life experience to areas of policy development, governance and decision making.

Some of the life examples illustrate the five themes holding Scotland back from employing us, which Greg mentioned, including research about employment. We agree that employment is one part of life where we are failed, but the failure touches every part of our lives.

Overall, the lack of knowledge of our lives that leads to prejudice is made worse when we are not seen. Some of us are still locked away in hospitals. The policy says that that should not happen, but it still does.

Many of us live in streets and have tenancies and might be part of local life, but we still experience incidents of hate daily, which also results in us being invisible. Our members say that verbal abuse is a daily misery, being called things such as "mongo" and "Down's syndrome" while we are travelling or when we are shopping. One woman has spoken about not opening the curtains or going near the windows, because if she was

seen, the local youths gathered opposite and would start shouting and making offensive gestures.

Lack of knowledge can also impact our lives even before we or our children are born. Parents who have a learning disability are not supported in private or family life. Society does not see us as sexual beings or humans who are entitled to live lives like others, whether with partners or alone. Social workers act to remove our children, rather than to support us on our journey as parents. Many of our members still find that they are given no option other than to live with others. That happens for young people as well as for those who are older. We keep hearing that support for choice and independent living costs too much, unless we are grouped together. Legislation uses words like "dignity", but where is that for us? After all, other citizens choose who they live with and

We are not a priority for Scotland. We will say more about that in our answers to the committee's questions.

We have two people we employ who will support us while we give evidence today: Franck David is the national development worker and Rhona Neill is the service manager. Gregor and I might speak to them or ask them to remind us which of the notes that we have we should use for our answers. Thank you for giving us a little time to do that, if we choose to do so, during today's session.

Jamie Cooke (Enable): I am the head of policy at Enable, which is one of Scotland's largest social care charities. We were set up 70 years ago by a group of parents who were looking to create better opportunities for their children with learning disabilities, which were not offered in society at the time, and we have been working ever since to try to make those opportunities a reality.

Working with our members and supporters across Scotland, we were very encouraged by the proposed bill as a real commitment, because, as we have heard powerfully from our colleagues, the rights of the people for whom we work are not being delivered day to day. Those rights exist—people have them—but, all too often, there is no accountability, no follow-up and no opportunity to take them forward.

We welcomed the proposal, so we have been disappointed by the lack of progress with the bill. This is a chance for Scotland to be a world leader: our challenge is whether we will be a world leader in rhetoric or a world leader in reality. I hope that we can explore that in more detail today. There has been an effort across sectors and organisations to drive progress collaboratively,

and I hope that there is still a chance for us to do that as we move forward.

Suzi Martin (National Autistic Society Scotland): I will keep my comments brief, so that we can get on to questions.

I am the external affairs manager for the National Autistic Society Scotland. We are part of the United Kingdom-wide National Autistic Society, which is a charity that seeks to create a society that works for autistic people. We provide support to autistic people and their families, and we seek, by influencing policy and legislation and campaigning for change, to improve outcomes for them and address the systemic injustices that they face.

We were deeply disappointed by the delay to the bill, which has the potential to be transformative for autistic people and their families. There was an opportunity for Scotland to lead the way, but Scotland now risks falling behind. It is already falling behind England, where the Autism Act 2009 has been in place for a number of years, where there is mandatory training for health and social care professionals and where data on waiting times is collected, disaggregated and published.

I look forward to exploring the issues more with the committee, including why autistic people and their families feel, at best, let down and, at worst, abandoned, at the moment.

Jenny Miller (PAMIS, Promoting a More Inclusive Society): PAMIS is a charity that promotes a more inclusive society, and it supports children, young people and adults who have profound and multiple learning disabilities, as well as their families, to lead healthy, valued and inclusive lives. That group of people and their families continue to be some of the most marginalised and isolated people in their communities and suffer huge inequalities in health and social care.

Before Covid, the group's circumstances were difficult, and their circumstances have been exacerbated since the pandemic. Unlike the rest of society, the group has remained in crisis. That community is at the back of the queue and continues to be forgotten, undervalued and let down.

The promises that were made throughout the pandemic have been broken. The return of services, respite and health interventions, as well as relief from 24/7 caring roles, have not been realised. Instead, families are left to battle. The proposed LDAN bill, equalities and human rights legislation and the proposed national care service were rays of hope, and the community embraced those ideas, innovations and solutions. The halt of those proposals greatly impacts the community, as

the current situation in which they find themselves is not sustainable, so urgent action is needed.

However, the community never ceases to amaze and inspire. Although I have painted a dark picture of the current situation, there are real solutions and suggestions.

We highlight "profound" as meaning "deep, wise and expert", and as ever, the group teaches us to work collaboratively and to use our collective wisdom to develop different approaches to solve the problems that we are encountering.

We welcome being part of the committee's discussion today and on an on-going basis, and being part of the solution. We highlight that that will require different ways of working and different ways of listening with all our senses to the various groups of people that the proposed LDAN bill seeks to support.

10:15

Joe Long (Scottish Autism): I am the director of practice and innovation at the charity Scottish Autism, which is Scotland's largest provider of autism-specific services. We are also advocates for change and good practice everywhere.

Every day, on our advice line, in our family support services and in our social care and education services, we hear from autistic people and families who have to fight for the support that they deserve. They do not receive the understanding and accommodations to which they are entitled, and we know that autistic people are disproportionately excluded from education, both formally and informally, that they have difficulty accessing health and public services of various kinds, and that they continually have that fight on their hands.

After a lot of well-meaning legislation, multiple reviews and a 10-year strategy, a lot of hope has been invested in the proposed bill to provide the mechanisms that will finally deliver people's rights and the mechanisms for the changes that need to happen for services to be received. People have not just invested hope: they have also invested a lot of their time and they have given of themselves and told their stories—often quite traumatic ones—in the hope that, this time, we might see real change.

If the proposed bill is effected and has the right provisions, it can make real change for people's lives. We must not miss the opportunity. Our community is telling us that loudly and clearly everyday.

Dr Simon Webster (Scottish Commission for People with Learning Disabilities): Good morning. I have been the chief executive of SCLD

for roughly four weeks, but I am well briefed and come from a relevant background.

The commission hopes that the bill will be the framework that ensures that people with learning disabilities have access to well-resourced support from all professionals, in whatever areas of life it might be required, and that they have equal access to all areas of Scottish society. More fundamentally, the bill needs to redefine people with learning disabilities as equal citizens who, without exception, are equally valuable members of our society.

Scotland's understanding of people with learning disabilities is shaped by a history that segregation, institutionalisation and includes dehumanisation. In 2024, the legacy of institutions continues to provide context for the work, and our law has been shaped by that legacy. In practice, the shift away from long-term detention of people with learning disabilities is not complete. Our understanding is still shaped by a view that learning disability is primarily a health concern. From that perspective, social and economic problems for the community were seen as the inevitable consequences of a condition, but those problems are not inevitable consequences. Rather, social and economic problems are barriers that disable the community.

Our society's understanding of learning disability has shifted, but the barriers continue to exist, at least in part because Scotland's perspective does not fully recognise people with learning disabilities as equals in all areas of life. The bill is our main opportunity to accept how people with learning disabilities see themselves, to reflect that to our society, and to define people with learning disabilities primarily as people and as equal citizens, and not as patients first. The Scottish Commission for People with Learning Disabilities looks forward to the transformational change that the bill can help to effect.

The Convener: Thank you for your contributions so far. We will now move to questions from members. What has your involvement been with the development of the bill?

Susan Burt: For months, our groups and members looked at different parts of the consultation. Sometimes, we had to choose groups different experts from our memberships to look at different parts, because there were so many questions. We are still speaking about all those things, because we always do. Even though the consultation has come to an end, we talk about our lives and the future and the lack of change all the time. We continue to fight until we are heard. The LDAN bill and what was proposed after the consultation period was never enough.

Gregor Hardie: The whole idea of the LDAN bill was not a fit for People First (Scotland). Although we work in positive and respectful partnership, and always have done, we have said all along that a law that is about only learning disability is what Scotland needs. That would be meaningful for us. It could offer us dignity as humans with rights.

The proposed LDAN bill had ideas within it that members of People First (Scotland) thought had potential, but People First (Scotland) has, for 35 years, described clearly, and as experts, the changes required. At the top of the list is for us to be recognised as human rights holders, with experience that is unique. We ask for legislation that sees us that way and does not group us with others.

Although there is a plan to go ahead with actions on LDAN, we still hope that the expert message that we bring will be respected, heard and acted on. We need actions, not words. Please look at our website and take the time to watch the film that tells you why legislation that is not specific to us in Scotland will continue to fail us.

Jamie Cooke: First and foremost, our engagement has come through working with our members and the people we represent to see what they need and what they are looking for. It is very much about accountability for the rights that already exist for them, but which far too often—as colleagues have covered—are denied them.

From there, we worked closely with other organisations, particularly with Scottish Autism and the National Autistic Society Scotland, around campaigning on the bill and how it could take shape. We have also engaged in activity across Scotland with our members. We have run a large number of events in different parts of the country to ensure that as many voices as possible within our community could be heard, as well as, finally, being part of the stakeholder group that was brought together to work through the process of the bill.

Throughout the process, we have been driven by our members and their needs, but we have also seen how, collaboratively, we can have a greater impact on the bill rather than simply driving it as a single organisation.

Suzi Martin: To understand our involvement in the development of the bill, we have to go back to 2011 and the publication of the "Scottish strategy for autism", which was a 10-year strategy that came to an end in 2021.

The independent evaluation of that strategy found that it had failed to create the systemic and sustained change that was needed to improve outcomes and address the systemic injustices that autistic people face. A review by the cross-party group on autism found the same thing. In fact, it

found that, at the end of the strategy, 72 per cent of people still did not have enough support to meet their needs, and 78 per cent felt that support was still too difficult to access in their local area.

That led us to acknowledge that there was what we termed an accountability gap—which is sometimes called an implementation gap. It is a gap between the support that people should receive, which is outlined in policy and strategies—and sometimes that they are entitled to in law—and what they receive in reality.

We then worked with Scottish Autism and Enable in the run-up to the 2021 Holyrood election on a campaign to have a commissioner for autistic people and people with learning disabilities as a means to address that accountability gap. It was called the our voice our rights campaign. We were delighted that a commitment to legislate was made in several party manifestos and that the commitment to legislate and to establish a commissioner was also published in the Scottish Government's programme for government in 2021. That triggered a process that you are all very familiar with. We were involved in the scoping exercise. We helped to facilitate engagement with autistic people through that exercise. We were a member of the stakeholder panel, along with other organisations here today, and we worked collaboratively with them throughout the process. There were two other panels and I want to quickly say that we think that the lived experience advisory panel that the Scottish Government established was excellent. It did great work on advising the Scottish Government and drove the delivery of the proposals for and the publication of the public consultation on the bill. We have been involved from the outset, along with colleagues on this panel, and we hope to continue to work with the Scottish Government and colleagues.

Jenny Miller: As Suzi said, we have been involved and we were part of the stakeholder group. We ensured that we sought the views of the community that we support.

We recognised that a lot of the things that were being talked about and asked for had been on the cards in our community for the last 32 years. We therefore spent quite a bit of time going back over what families had been asking for and what people with profound learning and multiple disability were requiring. We then cross-checked that with the community to check that what we were saying in the consultation was still current. Very sadly, there has been 32 years of limited progress, which is why the bill is so important.

Our community has been created and it is innovative, solution-focused and trying to think about ideas to support a more inclusive and equitable world where we are all valued. It has been quite an overwhelming process, but we

sought to be as inclusive as possible. As a small organisation, we were very grateful for the support from the organisations that the committee is meeting with today.

Joe Long: Suzi and Jenny have given a picture of the long-term forces that led to our involvement. We campaigned ahead of the 2021 election for legislation. We placed particular focus on accountability, as we felt that a lot of good legislation frameworks were in place, but we needed to see some mechanism for accountability. That was a big focus of our campaign.

It is also worth adding into the picture that the Rome review, which reported in 2020, said that autism and learning disability should be taken out of the Mental Health (Care and Treatment) (Scotland) Act 2003, and also made a recommendation for a commissioner for autistic people and people with learning disabilities. We welcomed that report, and it gave us a bit of an impetus to campaign for accountability and a potential commissioner role.

We were also part of the stakeholder panel that the Scottish Government team convened around the development of the bill.

I want to emphasise what others have alluded to. Organisations such as ours did an awful lot of work to engage people in the consultation that went into this bill. Autistic people who might have diverse communication styles or additional learning disabilities may have found it difficult to respond directly to the public consultation. The consultation report and the process of it, which was provided in the briefing for today's meeting, show the number of responses, and it is worth saying that some of those single responses represent organisations that engaged with tens or hundreds of people who may have found it difficult to engage themselves.

Organisations such as ours did a lot of legwork in engaging people, and in passing on the message from the Scottish Government that it wanted to hear their stories and their experiences. That was another big factor in our involvement in the development of the bill.

Dr Webster: The LDAN bill consultation was the main focus of the commission's work this year. Following on from what others have said, I confirm that it has been a huge undertaking and has resulted in some amazing contributions from people with learning disabilities and the wider community. However, we found that there was not anything like the time that was needed for people with learning disabilities to be fully engaged across all areas of the consultation.

The commission contributed to the accessibility of the process for people with learning disabilities

across Scotland, for example by creating animations on how laws are made and on how to respond to a consultation, through accessible briefings, through supporting wider engagement with around 180 people, by presenting on the consultation to around 250 people and by supporting four of our own programmes and networks to respond. We also submitted our own response, which ran to around 80 pages.

The Convener: What difference would the bill make to people with learning disabilities and neurodivergent people in Scotland? I will ask Gregor Hardie and Susan Burt to respond first.

Susan Burt: As we said in answer to the first question, changes resulting from a bill that is not focused on or is not about only the lives of citizens with a learning disability will be too weak. The inclusion of other groups always leaves us last and at the bottom of the list.

10:30

Gregor Hardie: We have been at the bottom of Scotland's list for ever. We are invisible in society and in communities. Some of us remain hidden and locked up in hospital. Promises—for example, on the deadline for the coming home work—are broken. The Scottish Government promised to significantly reduce long hospital stays and out-of-area residential placements for people with learning disabilities or complex needs by March 2024. We set a countdown clock running on our website when that was said, and the deadline has been and gone without the commitment being met. You can see the image on the cards that are being handed out to you.

We are disappointed by the lack of progress and we call on national and local Government to act now. The clock hit zero in March, but change has not taken place at all for many people. The change will be good enough only when no one has hospital as their home. People First (Scotland)'s founding members first said that at our founding conference in 1989, and we continue to say it. Although we welcome some of the ideas in the LDAN bill proposals, they are simply not enough.

Jamie Cooke: Our drive at Enable is to ensure that everyone has the chance to live full and active lives in the communities of their choice. For us, the LDAN bill is the chance to ensure that rights that already exist on a legislative footing meet the accountability gap that Suzi Martin touched on. It would make a massive difference to the people whom we work for, as it would not only give recognition of the challenges and exclusions that they face, but give them the mechanisms that were touched on earlier to drive things where they are not being met, to ensure that authorities and others are held accountable where they fall short,

and to ensure that we support the sharing of best practice and approaches in different places. For us, that is essential if we are to have that sense of progress. Several colleagues have already touched on how long this has taken. This is not a new process, and we need some sense of change and for real embedding to happen in a way that cannot be overturned too quickly.

There are real positives with the legislation being approached through a human rights focus. For a start, it gives a sense of inclusion. The LEAP has been highlighted as a fantastic example of bringing people with experience to the forefront of policy design. However, although it is fantastic, if this does not go anywhere, there might be negative implications with regard to the next steps.

As I touched on earlier, and as others have said, this is a world-leading opportunity. We are finding huge interest in what is happening here in Scotland from colleagues across Europe and beyond. Earlier this year, we hosted for the first time in Scotland the Europe in action conference, which is a large international gathering of 450 practitioners and self-advocates from across Europe, and they were looking to Scotland not just to learn from our deinstitutionalisation journey, but to see how we were trying to bring human rightsembedded practice and law into reality.

Another fantastic chance that we have is with the people whom we work for seeing an opportunity to ensure that their experience shapes changes across the world. The legislation gives a chance for that to be embedded, but of course, if it is not taken forward, there is also the chance that the approach will be quite significantly undermined.

Suzi Martin: The bill has the potential to be transformative for autistic people and their families. I cannot emphasise this enough: there is an urgent need to legislate, as is evident from the outcomes that autistic people face.

Autistic children and young people, along with others with additional support for learning needs, are five times more likely to be excluded from education than their peers. That does not include informal and internal exclusions, of which there is an epidemic in this country. Only 29 per cent of autistic people are thought to be in employment in the UK, and it is thought that the figure could be even lower in Scotland.

Autistic people face much poorer health than non-autistic people, especially poor mental health, and are likely to die younger than neurotypical people.

As has already been mentioned, hundreds of people with learning disabilities, many of whom are also autistic, are still living in hospitals and other institutional settings.

The outcomes speak for themselves and to the urgent need to legislate. The bill would definitely have the potential to be transformative in nature.

In our view, three particular proposed provisions in the bill would have had a significant impact. Those were statutory strategies, mandatory training in the public sector and, as Jamie Cooke alluded to, an accountability mechanism to ensure that local government, service providers and national Government are delivering for autistic people and people with learning disabilities.

In our view, the bill would be crucial to improving outcomes and addressing the systemic injustices that autistic people face today in Scotland.

Jenny Miller: I echo many of Suzi Martin's well-articulated responses. Our hope was that the bill would raise the profile and rights of people with a learning disability and neurodivergent people in line with other groups within our society, that it would enable them to live healthy, valued and inclusive lives, and that it would combat many of the issues that Suzi has just highlighted, which have been on-going for decades.

Currently, all of those groups experience discriminatory practices and a lack of understanding of the value that they can offer to our country. Their and our voices are not visible enough in decisions that are made and, if we reflect on the evidence that is currently being gathered within the Covid inquiry, we see what happens when a group or groups of people are not separately considered.

As Suzi Martin and Jamie Cooke highlighted, there appear to be no repercussions when policies and guidance are not taken forward. It was hoped that the bill would absolutely change that and put people with a learning disability and neurodivergent people centre stage instead of on the sidelines.

Joe Long: The difference that the bill would make would depend on the content of the bill, and we have yet to see draft provisions. If the Scottish Government gets the bill right, people would get the support that they need when they need it. They would be included and feel included, whether that is in education, work or leisure activities, and we would be in a world where people are not just not in crisis, but flourish and contribute to the best of their potential.

However, we need a clear picture of how that happens. We need accountability mechanisms for delivery, join-up between different service areas, and an end to crisis-led commissioning of services, so that people get timely support and do not have to fight for it. We need greater professional skills and understanding, so that there is greater access and accommodation within healthcare, school and community services. We

want people to have a better sense of wellbeing and a greater chance at finding a meaningful vocation, whether that is employment or other means of occupation and vocation.

It is worth taking a moment to think about how the bill would intersect with other bits of policy work that are going on at the moment. At the moment, autistic people and people with learning disabilities can be detained under the Mental Health (Care and Treatment) (Scotland) Act 2003, not on account of mental illness but on account of their neurodevelopmental profile. Organisations such as ours want to see an end to that kind of discrimination in the system. The argument that is often made against that is that, often, if someone is in crisis or needs urgent support, the only lever that people have is health, hospitalisation and, in some cases, detention.

If the bill gets it right and provides the right mechanisms to support people and uphold the rights of autistic people and people with learning disabilities, that argument should go away. We should see mechanisms to support people in their communities at the right time and an end to detention under the 2003 act as a lever to support people and make them safe. I wanted to give a nod to the other pieces of legislation and processes that we want the bill to aid.

Dr Webster: First, the proposed bill could redefine people with learning disabilities as people first—as equal citizens. For people with learning disabilities who the commission worked with on the consultation, the proposal is massively significant. Its symbolism is huge. Those individuals felt that they were being seen as a priority.

Second, in practical terms, the bill would be our opportunity collectively to work out how we complete and fully implement the cultural change that began with deinstitutionalisation.

The United Nations Convention on the Rights of Persons with Disabilities states:

"disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others".

It can be technically complex and politically difficult to shift society towards that understanding of disability, but Scotland has begun to do that—we have begun to remove barriers that disable people. We could say that the bill would be Scotland's main vehicle for removing barriers from society that disable people with learning disabilities—for example, barriers to employment, autonomous decision making and physical health.

Third, the bill would perhaps also be the main vehicle for ensuring that there was, as others said, specific and effective accountability for the removal of systemic barriers. The clear priority for the bill that we hear from people with learning disabilities and from carers is about strengthening accountability when publicly funded services are not provided or do not meet requirements. People with learning disabilities continue to have poorer outcomes than other marginalised communities across a range of domains. Therefore, the bill would need to provide for strategic planning with effective accountability.

Fourth, in the process of developing the bill, we need to determine how law reform would ensure the ending of inappropriate restraint, seclusion and related practices against people with learning disabilities of all ages. We need to determine what law reform will end the institutionalisation of people with learning disabilities in Scotland by ensuring that support needs are met in the community and by ending long-term detention on health grounds.

Marie McNair (Clydebank and Milngavie) (SNP): Good morning to our witnesses. I appreciate your time.

The consultation had 61 questions with a range of proposals and various options. What are your views on how it was designed and undertaken?

I will start with Susan Burt.

Susan Burt: People First absolutely welcomes the change over recent years that the Scottish Government and other bodies have put in place to accessible summary documents make consultations. That never used to happen. We had to fight for that. When it is done well, it feels meaningful and respectful. However, there is still information missing or things that are lost in translation. We still promote the idea that if you start with clear, easy-read instructions or information, things are understandable. Producing something else with further technical or complicated information for those who want it can also be of use, but please start with the one that works best for everyone.

Gregor Hardie: One of the things that made the consultation so complex was the point that we refer to in all our answers: grouping citizens with learning disabilities with others is not what is required. Even when people have lived experience that includes barriers that we face too, their life experience is different. Learning disability is unique. A law that supports our lives as humans is needed.

Jamie Cooke: It was certainly a huge and complex consultation. There were many questions and there was a lot of information to explore. For us, that meant having to break it down into numerous smaller pieces to work with our members in a number of different settings, which was time intensive. We tried to engage as many

different people in as many different parts of the country as possible. That meant that we had to put a lot of effort into ensuring that we gave people different spaces and different materials, as was touched on, to ensure that they had that chance.

To go back to Joe Long's earlier point, that makes for a strong reflection, which we will hear from everybody on the panel, about how committed and invested not only we as organisations but the people we represent were in the bill proposal.

People gave up their time, energy, ideas and efforts to feed into the process to ensure that the response on their behalf, through Enable and others, really started to capture the importance of the issue for them. It is important not to lose that in this process. A huge amount of effort was put into the process because we believe that it is so important for the people we work for and with. Ensuring that that is continued as we move forward—harnessing that without it being burnt out—will be one of our big challenges. However, that shows that that undercurrent of support is very much in place across the country and certainly among the people we were working with.

10:45

Suzi Martin: First of all, it is important to acknowledge the fact that the Scottish Government worked very hard to put lived experience at the centre of the pre-legislative process, the development of the proposed provisions and the public consultation. The lived experience advisory panel was very effective.

On the public consultation, our understanding was that the Scottish Government wanted to put as much as it could on the table for people to give their views on. That speaks to the fact that the challenges and systemic injustices that autistic people face are things that they experience throughout their whole lives and cross many areas of Government policy. It was important to put as much of that on the table as possible so that people could express their views. Inevitably, that meant that the process was extensive and complex.

I will leave it to colleagues to comment on the easy-read versions of the consultation. However, I will say that, although we always seek autistic people's views before responding to a consultation, it was more incumbent on us to do that this time because of the complex and extensive nature of the consultation. We encouraged people to submit individual responses in addition to telling us their views, but we knew that many of the autistic people we support and their families would not be able to engage with the public consultation as individuals. Therefore, it

was very important that we sought their views and represented them in our response to the public consultation. As Jamie Cooke alluded to, we were very committed to that process and to ensuring that as many people as possible responded to the consultation. Therefore, yes, it was extensive and complex, but it was important that the public consultation put as much as possible on the table for people to give their views on.

Jenny Miller: The process was extensive and enormous and it took up a huge amount of time. As Suzi Martin said, the consultation was that size because it needed to be-because there are so many areas that need to be addressed. At times. the process became overwhelming. For families that are very much engaged in an intensive caring role, it was probably difficult to respond to the consultation as individuals. However, as Jamie Cooke said, like all the organisations, we attempted to gather thoughts from across our community. We looked back over the past 32 years, which provided us with an opportunity to gather a host of past and current information. It was also an opportunity to engage with our community, to hear people's views and to think about the current issues. We have been able to use that piece of work in other areas, too.

The size of the consultation probably put many people off completing it as individuals, which is why the role of organisations such as ours and the others that are gathered here today was so important. It enabled people to give their views and to ensure that everybody's voices were heard.

Like Suzi Martin, I applaud the Government for the fact that so much thought was put into how the engagement took place. As a group of organisations, we tried to work together to ensure that there was a strong enough response to all the proposals. It was difficult for us not to comment on them all. I think that I will shut up at this point.

Marie McNair: Thank you, Jenny. Joe, do you have any comments?

Joe Long: Like colleagues, we commend the team at the Scottish Government for the inclusive way in which they went about the pre-consultation work. The lived experience advisory panel and the stakeholder panels were great to be involved in and very productive.

We ended up with a very long and complicated document, as colleagues have alluded to. On that, I would say that the fact that it had so many subsections—on transport, social care, education and so on—probably speaks to the number of fronts on which autistic people and people with learning disabilities have to fight every day. That fragmented and often-siloed policy landscape just shows how many fronts people have to fight on. In a way, the consultation reflected that.

We were interested in the cross-cutting, overarching themes of accountability, knowledge and understanding, and of access. That is where we have some hope for legislation. Instead of reproducing many policy silos, we would like to see legislation, or a body or a system of accountability, that looks across all those different areas, identifies those themes and works to join up people's experience, so that they do not have to keep recounting their trauma to numerous professionals in different contexts. In a way, the complexity of the consultation document is quite telling of people's experiences of the system that they have to navigate.

The other point to make is that we were a bit disappointed that autistic people specifically were not mentioned more in the consultation. At Scottish Autism, we absolutely subscribe to the vision of a neuro-affirmative and neuro-inclusive society in which people of every neurotype and supported and accommodated. However, we recognise that there are specific forms of exclusion that autistic people face, and our feeling is that, to have a neuro-inclusive and neurodiversity-affirmative society, we need to meet the specific needs of particular groups. I do not know whether that has come through in the form that the consultation took, or in the report that has come from it. That note of caution comes from what we felt when we read the consultation and the responses to it.

Dr Webster: To agree with colleagues, we felt that the Scottish Government had carefully considered the accessibility of the consultation and that the consultation was particularly complex, perhaps of necessity. I understand that 12 weeks were allowed for the consultation from the end of 2023, and there was a large amount of evidence in the consultation document, as others have said. That made it a difficult process. We found that people with learning disabilities were enthusiastic and very engaged in the consultation work, but were often exhausted by it. It took several months of intensive group and individual work through the commission to respond to just a few of the 22 areas that were in the consultation. The scale of what is required for accessibility in a consultation of this nature is quite considerable.

To come back to the main point, however, accessibility was considered and efforts were made, and I am sure that further developments can be made, too.

Marie McNair: Thanks for your responses.

The Convener: We move to questions from Pam Gosal.

Pam Gosal (West Scotland) (Con): Good morning to the witnesses. What are your views on the Scottish Government's reasons for not

introducing the bill during this parliamentary year? Do you think that other pressures may have also played a role?

Susan Burt: People First mentioned the lack of priority that citizens with a learning disability experience in all the work that we do. That prejudice exists throughout Scottish society at every level, so there are always other reasons why action does not take place.

That happens in social care. Eligibility criteria are applied to decisions, and our support is cut. Many members now have no social care support in life at all.

At our audit meeting a few weeks ago, our board set five priorities for our work over the coming three years. One of them is as follows:

"we will work with partners, but celebrate our powerful, expert voice."

We will do that because grouping us with others means that everyone has to compete.

The other pressures are just that we do not come high on the list. We have campaigned as experts for a law that is about us—just us. As we lead, we say loudly in all that we do that Scotland should do nothing about us without us.

Gregor Hardie: As Susan said, reasons for things not happening often stem from the prejudice that Scotland has against us. We should be removed from the definition of mental disorder, and a system of supported decision making should be established. Scotland has a chance to be a world leader and make significant change.

Our responses to consultations, including on the LDAN bill, are informed by lives lost as well as still lived. The serious case review into the life and murder of Margaret Fleming gives even more evidence that things must be completely different.

Inside the consultation document that has now been published on a strategy to mainstream human rights, we read these words:

"We want to have ... laws that support Scotland to be a world leader in equality and human rights."

What an excellent ambition—and the chance is still there. However, with respect, going ahead with the plans for the LDAN bill will not achieve it.

We ask Scotland to pause and do what is required to secure our rights. Scotland can lead the world by creating a system of supported decision making, and it can remove learning disability from the definition of mental disorder.

Scotland can act effectively on the United Nations Convention on the Rights of Persons with Disabilities. Sir Robert Martin, who was the only person with a learning disability to ever sit as a UN committee member, invited Scotland to do so at

every one of the sessions at which he spoke to Scotland and the United Kingdom. Unfortunately, he died early this year, having asked again in March. Like that of many of our members, his life was spent seeking the changes that People First (Scotland) seek. His voice is now powerfully and loudly shared by us.

Jamie Cooke: I start by acknowledging, from our experience, the commitment to and support for the bill that the minister and her team showed, which was clear throughout. They were accessible and supportive from start to finish, and Maree Todd showed a personal commitment to it. However, it cannot be seen as anything other than profoundly disappointing for the bill not to proceed. To echo our colleagues, it was simply not viewed as important enough to be put on the agenda.

As Suzi Martin mentioned, several manifestos included a commitment to the legislation, which had broad cross-party support. There was a real opportunity for it to be taken forward at a time when, frankly, we do not often see a huge amount of cross-party collaboration in the Parliament. It is difficult to see the bill being dropped from the legislative programme as anything other than that it was simply not of importance to the Government and the Parliament to take it forward. That is profoundly disappointing, given the amount of effort that has been put into it, which we have touched on already.

The fact that the bills that would have been alongside it, such as the National Care Service (Scotland) Bill—which was more controversial, although it would have linked in for many of the people we serve—and the human rights bill, were dropped, too, gives an overall sense that the priorities of the Government are not sitting with the people we serve, which has a huge impact on their sense of importance and their ability to contribute, to be listened to and to see progress take place.

With regard to other pressures, I know that some of the feedback was that there might be complex interactions between the LDAN bill and human rights legislation. If that is the case, we clearly need a pathway towards a resolution of that issue through collaboration with the UK Government or elsewhere to try to overcome it, otherwise it runs the risk of simply being an excuse rather than a justifiable explanation.

I reiterate that we saw some real commitment to taking the bill forward. However, there is huge disappointment that it was put aside as not being a priority at this point.

11:00

Suzi Martin: I reiterate that it was clear to us that the minister was personally committed to the proposed legislation, as was her team, which

worked extremely hard on it. We, along with autistic people and their families, are deeply disappointed by the delay. Our understanding from the correspondence that we received from the minister is that the reason for the delay is that there remains diversity among views, but we disagree with that. There is very strong support for the legislation and for most of the proposed provisions in the public consultation. That is evident from the analysis of the consultation responses, which was published in September.

On the three areas that we considered to be particularly transformative, there was strong support for statutory strategies; there was significant support for mandatory training in the public sector; and, in relation to accountability, 65 per cent of respondents who answered that question were supportive of a commission or commissioner model. Therefore, we do not agree that there is diversity among views. There was also strong support for a commission or commissioner model in our "Closing the Accountability Gap" report, which showed that 96 per cent of respondents were supportive, including 93 per cent of autistic respondents.

We recognise that things still needed to be worked through in relation to the bill, which was by no means completely tied up and ready to be introduced in Parliament. However, the Scottish Government could have worked with the three panels to work through those things, which certainly should not have been a reason for delaying the legislation indefinitely. The bill would have gone through a process of parliamentary scrutiny, which would inevitably have resulted in further changes, as parliamentarians had their say on it. It is safe to say that we were very surprised that, after three years of robust consultation, that was the main reason that was given for the delay.

Jenny Miller: I agree with Suzi Martin. I guess that there was an incredibly busy landscape—the amount of proposals in all sorts of Government areas was pretty overwhelming—but we feel that the voices of people with learning disabilities and neurodivergent people were at the bottom of the pile, as People First eloquently said. That was a powerful and emotionally charged answer, which made the hairs on the back of my neck stand up.

In relation to the finances, a bit like with the national care service, the voices of very dominant stakeholders, particularly those in the public sector, might have provided a conflicting view, and it is a worry that those voices have been allowed to be heard over the voices of those with lived experience, given the absolute need for the bill.

Joe Long: Scottish Autism also acknowledges all the work that the minister and her team in the Scottish Government did on the bill—in particular,

to get the consultation completed by the end of the summer.

We were led to believe that the bill was a priority, as the 2021 programme for government said that work on it would begin. It is for the Scottish Government to say whether priorities have changed or what pressures might have led to the delay.

It is worth repeating what Jamie Cooke said. Over the course of this parliamentary session, third sector organisations, including all of ours, have put an awful lot into consultations, including those on the national care service, the proposed learning disabilities, autism and neurodivergence bill and the proposed human rights bill.

The pausing of those three things, or their being left to the point at which it is unlikely that we will see them in this parliamentary session, really represents a tranche of disappointment—and not just disappointment. There is a fatigue that comes with giving a lot to consultations and putting a lot into getting our communities to engage with them, and it is frustrating that we will not see the real changes that we had hoped for in all those areas.

I would echo Suzi Martin's comments. We hear a lot about the need to establish consensus around some of the measures that might be in the proposed bill. There was really clear majority support for some of the measures around accountability, for example. Consensus is not the same as unanimity, but I think that there is a groundswell of support for the bill and for measures that lead to better accountability. At this point, we just need some leadership to decide what will to go into the bill and to take it forward.

Dr Webster: We would generally agree with what has been said. We are very disappointed with the delay. The commission's priority now is to reach the best possible legislative solution with people with learning disabilities and the whole learning disability community in Scotland, which is a difficult task and will take time.

Pam Gosal: Thank you.

The Convener: We will move to questions from Maggie Chapman.

Maggie Chapman (North East Scotland) (Green): Good morning, and thank you for being here this morning.

What impact has the Scottish Government's decision had on your organisation and the people whom you represent and work with? Susan, do you want to start?

Susan Burt: There has been some impact. We might well have chosen to use some of the time over recent months in a different way. We are always so very busy, but nothing is wasted when

we complete our work as experts in our lives. We really hope that the chance will be embraced to bring about meaningful and genuine change.

As we have said in all of our answers, the proposals for the bill were not enough. There is more work to do, and we are looking forward to completing that work in partnership.

Maggie Chapman: Jamie, can I come to you?

Jamie Cooke: As has been touched on, there is huge disappointment about this. Our annual general meeting is coming up on Friday, and we have also had the recent meeting of the crossparty group on learning disabilities; I think that the disappointment, the frustration and the anger are certainly clear when you talk to people.

There is a real risk when a sense of resignation starts to come in, and people start to think, "What's the point of engaging if that engagement is not going to go anywhere?" However, I would highlight—I think that Jenny Miller touched on this particularly eloquently—people's creativity, innovation and passion. The fact is that this is not an optional extra—it is essential. People have been living with the situation for decades, and I hope that that means that any sense of resignation will be kept on the angry side and used to fuel new activity. However, that sense of resignation presents a real risk, and we cannot understate it.

Joe Long touched on the sense of fatigue that people feel, having put a lot of effort and a lot of themselves into this, and there is a real risk in that respect. We as organisations have a role to play in supporting the people whom we represent with that, but I think that this should also be passed back to Government, to Parliament and to wider society to give us something to work with in order to show that progress is happening.

What I hope—and what I think that we are seeing-is that that anger and the sense of this being something that is necessary will drive the next stages. We are already talking about collaborative opportunities. How do we continue this fight and take things forward? Simply giving up is not an option for us, but that sense of real frustration and anger has to be heard and acknowledged and it must be realised that it just not from—to be frank—the disappointment with regard to the bill as it stands, but from decades and decades of disappointment that people have experienced.

Suzi Martin: Thank you for the question. "Disappointing" is the word of the day. Obviously, we are deeply disappointed, and it is deeply disappointing for the hundreds, if not thousands, of autistic people and people with learning disabilities and their families who engaged in the consultation process. However, the biggest impact is

undoubtedly on those who are desperately waiting for change.

As I said, many autistic people feel, at best, let down and, at worst, abandoned as a result of the delay. The longer the bill is delayed, the longer people wait for the support that they need and the more they are driven into crisis, and the longer people go without education and without employment and experience underemployment, the more they end up in poor and declining health, and in institutional care instead of living in their own homes in the community.

It is not necessarily us as an organisation that is impacted but autistic people and their families. The status quo is driving people into crisis, which has an immeasurable human cost; it is also unsustainably expensive to the public purse. Therefore, the delay will also have an impact on the public purse and the public sector.

Maggie Chapman: That is a well-made point. Jenny Miller, would you like to come in? [*Interruption*.] Can we have Jenny's microphone on?

Jenny Miller: Sorry about that. That was probably me—I was trying to do two things at once.

I, too, feel disappointment. There is a real sense that a lack of value is being placed on lives, and a worry that lives will continue to be lost due to the inequitable access, particularly to health screening and interventions, and a lack of will to progress with practice that makes a difference.

I again highlight that the mortality rates for people with a learning disability are just unacceptable. Dying from avoidable and preventable causes is unacceptable, but that has gone unaddressed for decades. Not investing in a bill makes our community feel even more invisible, forgotten and not cared about.

I will build on what Jamie Cooke said. Families are used to thinking about alternative solutions and innovations, and the lack of a bill is driving families and all of our organisations to consider what we can do now. I realise that that is another question.

Joe Long: The immediate effect, which everyone has spoken about, is disappointment, disillusionment, demoralisation, a loss of trust in the system, again, and people facing the question of whether they want to go another round of consultation and input if that will not lead to effective change.

However, the more profound effect is the lack of systemic change that we desperately need. People are still excluded from education, from work, from community, from health services and so on. People are still fighting every day for the

services to which they are entitled, and that carries on. That is the real effect of the lack of momentum.

Dr Webster: We are also deeply disappointed that a bill will not be taken forward in this session of Parliament. The commission's advisers with learning disabilities told us:

"It feels like we are hidden again";

"I'm really, really angry";

"Actions speak louder than words";

and

"We haven't got anything else left in the tank".

The development of a bill is still an opportunity to ensure that the human rights of people with learning disabilities are respected, protected and fulfilled, but that opportunity is now at risk. In particular, significant effort will be needed to rebuild the trust and confidence of people with learning disabilities. So many people are upset and disappointed that the time and energy that they put into responding to the consultation has not resulted in the bill being included in the programme for government. However, we remain committed to working to progress a bill and to deliver change for people with learning disabilities.

Maggie Chapman: If I can move on to my next question—

The Convener: I am sorry to interrupt, Maggie Chapman, but we have a supplementary from Tess White on the previous issue. I suggest that we suspend briefly at this point, for about five minutes, just to have a bit of a break. When we come back, Tess White can ask her question.

11:14

Meeting suspended.

11:27

On resuming—

The Convener: Welcome back. Before we move on with the rest of the session, I suggest that we include Susan Burt and Gregor Hardie in all of our questions—that is, all the main questions, not necessarily the supplementaries. Other members of the panel may come in if they have something different to add.

As time is pressing, I want to ensure that we get through as many questions as possible. Therefore, I would appreciate it if people could keep their answers succinct.

I now bring in Tess White.

Tess White (North East Scotland) (Con): I will put this question first to Jenny Miller, then to

Simon Webster and Susan Burt. MSPs are currently marking—

The Convener: Pardon me, but once you have asked your question, we will go to Susan first.

Tess White: Good—I will go to Susan first. Thank you, convener.

MSPs are currently marking the 16 days of activism against gender-based violence campaign. I understand that 90 per cent of women with learning disabilities have been subjected to sexual abuse, with 68 per cent experiencing sexual abuse before turning 18. Those are horrifying statistics. What changes need to be made to protect women with learning disabilities from sexual abuse?

Susan Burt: Society does not see us as sexual beings or humans who are entitled to live lives like others, whether with partners or alone. Social workers act to remove our children rather than supporting us in our journey as parents.

Lack of knowledge can also impact our lives, even before we or our children are born. Parents who have a learning disability are not supported in private or family life. My networking with partner organisations includes the equally safe project development and a wide range of issues around women's health, women's rights and gender-based violence.

As Tess White has said, all the statistics horrify us. Scotland and the world move on quickly from the horror regarding our lives. The whole world has always failed to prioritise us. We have spoken about a number of changes that would be meaningful.

I now hand over to Gregor.

11:30

Gregor Hardie: As I have said, the proposed LDAN bill has ideas in it that hold the potential for change. We were hopeful that some of the changes that People First (Scotland) has campaigned for more than 35 years might finally move ahead, but we remain unheard. Action, not words, is required.

Without legislation that is specific to us in Scotland, we will continue to be failed as humans with rights. Please look at our website and take time to watch the film that tells you why legislation that is not specific to us in Scotland will continue to fail us.

Scotland can lead the world by creating a system of supported decision making. It can remove learning disability from the definition of mental disorder. Scotland can act effectively on the Convention on the Rights of Persons with Disabilities. Sir Robert Martin, the only person with a learning disability ever to sit as a member of the

United Nations Committee on the Rights of Persons with Disabilities, invited Scotland to do that at every one of the sessions at which he spoke to Scotland and the United Kingdom. Unfortunately, as I said earlier, he died earlier this year, having made the ask again in March.

Sir Robert's strongest message was that we should have a system of supported decision making. He made a very strong point that something has to be done about that.

Tess White: Thank you.

Would the LDAN bill be the right vehicle for tackling the issue? I will put that to Simon, and then to Jenny.

Dr Webster: I think that the LDAN bill would potentially have a role to play in that respect. You asked what changes are required to address the horrific statistics in relation to the situation that we face as a society, and I would say that an element of cultural change is required in attitudes towards persons with disabilities. The statistics reflect an interaction between those attitudes and cultural attitudes towards women and girls.

At least to the extent that the LDAN bill would be a vehicle for cultural change, there is potentially space for it to address the issue. In relation to systemic change, the work that is currently ongoing includes work that People First (Scotland) has referred to and which we are working with it on. Alongside the work that is being done to embed the equally safe strategy and the steering group for that, a specific project is under way, which, in our case, involves developing a tool for self-audit within services.

Personally, I imagine there being a place in legislation to deal with such a specific and pernicious issue. A lot of the issues that we are talking about in the context of the development of the bill are issues that affect not only people with learning disabilities but the community as a whole, but they specifically affect that community to an even greater extent. In that sense, I imagine there being a place for provisions in the bill to address that issue.

Tess White: Thank you, Simon. A bill could take years, but given how horrific the statistics that I mentioned are, we should be taking action now, instead of waiting years for a bill. Is a bill the right vehicle here? Should we not be doing things now?

Dr Webster: I am sorry—I might have misunderstood the question. I entirely agree that now is the time for action. I was not suggesting that any action should be delayed in order to allow for the bill development process. I understood you to be asking whether it would be worth including the issue in the bill, to which the answer could be yes.

Tess White: So prioritising the issue will help, but action should be taken now.

Jenny, what do you think?

Jenny Miller: I absolutely think that action needs to be taken now, particularly in relation to training and workforce development. It is terrible to say this, but folk talk about their families as sitting ducks, because people do not recognise what they are communicating when they highlight the things that have happened to them. We should be building on developing the workforce, and on learning and development.

Unfortunately, though, if you make that just an option and do not legislate for it, there are organisations and staff who will not always undertake that or think about how to put it into practice. This is about ensuring that people report on what they are doing with their learning and development and how they are utilising it, particularly for people whose voices are difficult to understand and where reasonable adjustments are not being made to ensure that those people are being listened to.

There is probably huge underreporting of these cases and abuse in the community that we support, which is terrifying to even think about. Action needs to happen now, but we need to ensure that legislation enforces it in practice.

Tess White: Suzi, I see you nodding your head. Is there anything that you would like to add?

Suzi Martin: I do not think that I have anything to add. I would vociferously agree with my colleagues that we should not delay any action, just because it has been decided that the legislation will not be introduced before the election. We might come on to this if we have time, but there are undoubtedly things that the Scottish Government can do outwith legislation. I think that all of us would urge the Scottish Government to take action on this issue and others, especially with regard to serious human rights violations and abuses of this kind. However, as Simon Webster has alluded to, the LDAN bill would have a place in shifting attitudes and culture, which is an important aspect of all this.

The Convener: I call Maggie Chapman.

Maggie Chapman: Is it possible that the proposals for the bill were too ambitious, or are they achievable? I know that we have covered some of that already. Susan or Gregor, do you want to pick that up first?

Gregor Hardie: As we have said, the proposals were not ambitious enough for us.

Susan Burt: As Tess White said, the statistics are horrifying. Scotland and the world move on quickly from the horror regarding our lives.

Maggie Chapman: Jamie, can I come to you?

Jamie Cooke: The proposals are absolutely not too ambitious and are absolutely achievable. As we keep touching on, these rights exist—the issue is accountability and the delivery of those rights.

Maggie Chapman: Does anybody else on the panel want to add anything?

Joe Long: The legislation is absolutely achievable and, particularly given its key overarching themes, is not overambitious.

We are not moving from a standing start; we have had 10-year strategies in the autism and learning disability worlds. We have piloted a lot of things in that time, and we have tried different service models and different ways of supporting the development of professional skills. There have been an awful lot of pilots, trials and reviews. If part of this legislation were to be another strategy, we would not need to spend the first three or four years on consultation. We have piloted things; we have tried things; and what we need is a clear theory of change, a clear set of outcomes that we want to achieve and the means to achieve them. That seems to me to be entirely doable.

Tess White: I have a quick supplementary question for Jamie Cooke, if I may. Integration joint boards are on their knees; councils are having to make swingeing cuts to budgets; self-directed support is, as we know, plagued with problems; and social care is in limbo because of the deeply flawed NCS bill, which has now been shelved. Given what would have been the wideranging nature and importance of the bill, do you believe that the infrastructure is in place to deliver on what the LDAN bill might have sought to achieve? There is an aspiration but, bearing in mind that other basics have just not been put in place—I have talked about IJBs and social care—is the infrastructure in place?

Jamie Cooke: There is no doubt that, as we see daily, social care is in huge crisis. Addressing that will require a huge amount of work across all parties in Parliament and beyond.

For far too long, social care as a sector and profession has been undervalued and underinvested in. We do not recognise the critical role that it plays across society. Until we address that, we will fundamentally continue to fail so many people in society, not only within the communities that we are representing today but more widely. As a number of the proposed LDAN provisions are not specifically tied to social care delivery, I think that we would still be able to take forward and deliver some aspects of LDAN with a lot of the infrastructure that we have.

There is no doubt that increasing accountability would have pushback into social care, too, as we

would be looking at accountability with regard to people being failed by service providers, IJBs and local authorities. Quite often, that failure will lie with the provision of the social care services that people are entitled to, but which they do not receive. For example, you touched on SDS. Far too often, people are not given information about the options that should exist for them and which they could take up.

All of these things are definitely interconnected—there is no doubting that. Obviously, as a social care organisation, we would obviously see the bill as a key priority. However, that does not take away from the fact that, when it comes LDAN itself, a lot could be achieved already. As I have said, the rights already exist; it is all about having that accountability and that pushback. They would provide some benefits for social care, without solving the crisis that we face at this point.

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

Paul O'Kane (West Scotland) (Lab): I refer members to my entry in the register of members' interests. I am a member of Enable Scotland and was previously employed by it.

How, and when, was the decision to delay the bill communicated to your organisation?

I will start with Susan.

Susan Burt: The decision was communicated promptly and directly by the minister and the Scottish Government team to our executive committee, which was welcome.

Paul O'Kane: I appreciate that we may all have realised at the same time. I can see nodding. I wonder whether, in the interests of time, anyone else needs to come in. Jamie, do you want to say more?

Jamie Cooke: Yes, I want to add a couple of quick things.

Certainly, we also had prompt communication, which was very welcome. I will add that we were delighted that Jacqueline Campbell from the Scottish Government team came to speak to the cross-party group on learning disabilities, which Paul O'Kane chairs. That was very welcome. I know that there will be an outreach to ministers.

As a slight piece of feedback from Enable, it was notable that the initial feedback we were given was in a session with the minister, which was very welcome. There was a session for learning disability groups and then there was a separate session for groups working with autistic people. If we are trying to create a collaborative bill, that perhaps felt a little bit siloed, but that is maybe just a personal reflection.

Paul O'Kane: Does anyone else want to add anything further?

Suzi Martin: I think that we probably all received very similar correspondence. Organisations on the stakeholder panel received a letter on 4 September, which was the same day that the programme for government was published, notifying us that the bill would not feature in the list of legislation for the year.

There was then a round of engagement with the minister, and we subsequently received an email from the learning disability, autism and neurodivergence team on 11 October to confirm that the bill would not be introduced before the 2026 Holyrood election.

We advised the minister and her team that it felt like there was a little bit of a vacuum in relation to communication, in that stakeholder organisations had been told, but the decision had not really been communicated to the public, so we were having to go out and tell the people that we support and represent.

The Convener: Jenny Miller would like to come in.

Jenny Miller: I want to add that it was a very heartfelt and personalised letter, which I think was quite unique. I do not know whether we have had that before. It highlighted that our response had been read and acknowledged and, given all the work that we have all talked about putting in, that actually meant something at the time.

The Convener: We will now move to questions from Pam Gosal.

Pam Gosal: What are your views on how the Scottish Government proposes to work with stakeholders and people with lived experience on developing draft bill provisions?

Gregor Hardie: As we have said, we hope that there will be different action that is more in line with realising our human rights. Of course, we always work in partnership.

11:45

Pam Gosal: Jamie Cooke, you mentioned the amount of consultation that you have been doing, and it is sad to see that the bill has not come forward after all the work that you have done. Does anyone want to add to that?

Suzi Martin: We do not think that there is a need to consult further. As I said, there were three years of consultation, what with the scoping exercise, the panels and the four-month public consultation, which received more than 800 responses. Many of those responses included the views of tens, if not hundreds, of individuals, because they were the views of organisations

such as ours. It is important for the Scottish Government to recognise that the starting point for any further consultation on bill provisions is that people feel let down and that some people feel abandoned. People have been asked for their views, not just through the public consultation but over many years, and they are being asked for their views again. Ultimately, we know what the issues, the systemic injustices and the challenges are, and, actually, we also know what some of the solutions are.

We are not saying that the bill is a panacea or a magic bullet by any means, but many of the provisions that were included in the public consultation would go a long way towards addressing some of the systemic injustices. We know all that, so the Scottish Government needs to be very sensitive to that context. Any further consultation process on bill provisions must demonstrate progress and would have to be very focused. It would have to focus on the wording of the bill and what the bill will actually contain because we have had a very broad consultation process. The process was very welcome, but we need to demonstrate that things are moving forward.

Tess White: The committee recently considered the Disability Commissioner (Scotland) Bill and heard views about the proposals for a learning disabilities, autism and neurodivergence commissioner. The Scottish Parliament agreed to a moratorium on new commissioners until a review is completed, by June 2025. What are your views on the need for a learning disabilities, autism and neurodivergence commissioner?

Susan Burt: When a commissioner was proposed, People First clearly said that that was not a top priority because action is needed on other things. Those other things are the changes that we have spoken about today, so, once again, we must say that the law for us and about us is a priority. A commissioner is less of a focus for us.

Joe Long: It is always worth revisiting why a commissioner was sought. We read the Finance and Public Administration Committee's report. which asserted that MSPs and committees such as this one are a means of accountability. We recognise that and give full respect to such committees. It is worth while to refer to my earlier comments that committees, like Government, represent particular subject areas and particular foci. We have always sought a commissioner, a commission or some kind of dedicated bodywhatever form that might take-because we want someone to take a whole-life view of the needs of autistic people and people with learning disabilities and a whole-system view, rather than replicating policy or service silos. Therefore, that is what we have been seeking with regard to accountability

and advocacy. Specific marginalised groups might need their own dedicated body to take a whole-life and whole-system view, to ensure that proper data is available and that there is direct consultation with the communities that are involved and to hold Government and services to account. We have supported the idea of a commissioner, or a commission, but it is worth stating why that is—why we want that accountability and the ability to take a whole-life, whole-system view. That is what we are seeking, and we need the bill to provide us with that.

Tess White: But can that not just happen without those things? It is so obvious that the culture needs to change. Why does it need a commissioner to actually get things done?

Joe Long: It needs a catalyst, because the status quo is failing so many people. We need something different—we need some accountability in the system that is not currently there. People are fighting every day for the services that they need, and they are let down. Something needs to change. If the system was working, we would not be asking for something different.

The Convener: We move to questions from Marie McNair.

Marie McNair: What advice do you have for the Scottish Government as it develops the draft LDAN bill for consultation?

Gregor Hardie: We advise the Scottish Government to act differently and see it from our expert perspective. There is still a chance to make real and secure change in our lives as humans. Although our life expectancy is 20 years lower than it is for others, the information to enable us to manage health conditions, to book and attend appointments and to order medicines to maintain better health is provided in ways that fail to include us. Our members have described digital systems, appointment letters, leaflets about risks and side effects and advice on the self-management of long-term conditions on websites that they cannot access.

Social care is reduced and in crisis, so we do not have support to attend, to understand or to benefit. Annual health checks were promised, but are not happening. As expert witnesses, we advise the Scottish Government to be brave and make change. We say, "Do not wait—do not, in another five or 10 years, apologise and act to try to explain or make redress for more failure. Make change now."

Marie McNair: Does anyone else want to comment?

Suzi, I think that you have already expressed your view.

Does Jamie Cooke want to come in?

Jamie Cooke: I think—

Marie McNair: Sorry, I see that Susan Burt wants to come in. Sorry, Susan.

Susan Burt: We ask the Scottish Government to abolish substitute decision making and establish supported decision making across Scotland; to realise and respect our human rights to independent and family life in the community; and to see us and celebrate with us as citizens with rights.

Marie McNair: Thank you for that, Susan—I appreciate that.

Jamie, do you want to come in?

Jamie Cooke: To echo the call, we need to see action-we cannot just use these processes as ways of constantly kicking things into the long grass. We need to see honesty and realism, so the fact that the bill is not in the programme for government this year makes it highly unlikely that it will be deliverable before the 2026 elections. I understand why the team is still working on that basis and I support and have a lot of empathy with them, but it is important to ensure that whatever is captured at this stage is not lost. The worst possible outcome, in many ways, would be to head into a new session of Parliament and have to start the process all over again. We need to ensure that we have the processes in place to really build on what has been happening for decades, in particular through the process of developing the proposed bill, given the incredible wealth of information and creativity that we have captured so far.

Marie McNair: Does anyone else want to come in?

Dr Webster: On a related point, people with learning disabilities who responded to the consultation have told us that there is an element of trust, which depends on how the Scottish Government uses their consultation responses to date. Government will need to show people with learning disabilities where it has used what they have said to inform draft provisions, and then allow for detailed scrutiny of what comes out.

Joe Long: We would ask for the Government to communicate regularly and clearly what is happening and what it means for people who are now deeply invested in the process. The term "draft provision" is a technical term, and not everyone understands what it means and what that will look like, so that needs to be unpacked and made clear to everybody.

We want to see a recognition of the level of consistent consensus that already exists—to go back to my previous comments—around what is

needed; of the urgency and the hunger for change that people feel around the process; and of the fact that we now sit here with no strategy. The 10-year strategy is finished; we are not sure what is coming next, and legislation has been delayed, so our communities need cause for hope, rather than despair, at this point.

Marie McNair: Absolutely. We are as disappointed as you are. Jenny Miller, do you have any other comments? I do not want to leave you out.

Jenny Miller: There is a real opportunity for collaboration and agile working. You are interviewing the third sector. We have an important role and I think that Government civil servants have recognised that, but we need to build on that and be equal partners. We must all get into the room together to talk about how we progress things, make changes and work in a more agile and collaborative way, but the third sector must be not a third party but an equal partner in that, because we have the voices of people who can make a difference. We are forever inspired by family carers who come up with ideas and solutions. In all that evidence, there was a wealth of ideas about how things could be different. We must harness that and take it forward.

The Convener: That brings us to the end of our pre-prepared questions. I recognise that some organisations may not have had time to think about the following questions, but if they want to respond in writing, that is perfectly fine. If you wish to speak, please indicate by raising your hand. We move to a question from Maggie Chapman.

Maggie Chapman: Thank you all for your answers so far. Some of you have hinted at some of this already but, given that the bill has been delayed, what outcomes could be achieved without legislation? I come to Suzi Martin first.

Suzi Martin: That is an important question. First, I reiterate the urgent need to legislate. I do not want to underplay that. The three things that have the potential to be really transformative, which I have mentioned—statutory strategies, mandatory training in the public sector, and some kind of accountability mechanism—all require legislation in order to be effective.

That being said, there are a couple of areas on which the Scottish Government can work without legislation. The first of those is diagnosis, which did not appear in the public consultation. Access to autism assessment and diagnosis is extremely difficult in Scotland. I do not think that the Government needs to legislate in order to improve that situation. It should work on that at pace. We welcome some of the work that it has done, but it needs to pick up the pace.

The Scottish Government needs to prioritise an understanding of the scale of exclusion from education. In this country, we record absences and formal exclusions, but not the use of part-time timetables, informal exclusions or internal exclusions. I have described the situation as an epidemic—which it is. The Scottish Government does not understand the scale of the problem; until it does, it cannot hope to tackle it.

Finally, as Jenny Miller alluded to, work can be done on training, especially to tackle some of the most serious human rights violations and abuses. The Scottish Government can take some of that forward. However, as Jenny alluded to, unless that training is mandatory, it will always be piecemeal, and the kind of support that people get and the service that they can expect from the public sector will always be a postcode lottery. Those are areas in which work could happen now.

Maggie Chapman: Thanks, Suzi, that is helpful. Jamie Cooke, do you want to come in on outcomes?

Jamie Cooke: Yes. I agree with everything that Suzi Martin has just said. I will expand a little on data. Being relatively new to the sector, I was struck by how difficult it often is to find data—in particular, up-to-date data. Often, data is several years out of date. A lot of the stats that we have talked about today are the most recent ones that we could access. There is something about how the Government could support greater collation of the data that will exist out there but is currently difficult to access. That would be huge for decision makers and for organisations when it comes to how we best support the people whom we serve.

Pieces can also be done on inclusive communications. I know that work was being undertaken on a statutory requirement for inclusive communications, which has been dropped, just now, for various reasons. However, pieces could definitely be rolled out. A lot of organisations, such as SCLD, already do fantastic work on that, but how could that be supported to at least break down some of the initial barriers to accessing support?

However, I agree with Suzi Martin and reemphasise what she said: legislation is also required to provide a backbone and a way of delivering on a lot of this, certainly in the longer term.

12:00

Joe Long: I echo the point about data, which is something that we would like to see. There is certainly no equivalent for the autistic community of something like the Scottish Learning Disabilities Observatory in Glasgow, for example.

Going back to Suzi Martin's point about training and learning, I think that we need investment in training that goes beyond one-and-done autism awareness courses. We need proper attention to be given to skills and inclusivity measures that can be learned.

We also need to be wary of the erosion of specialism that we have seen in the education and, indeed, adult support sectors. We need people with proper specialist skills to support people with specific needs in all our sectors, and attention needs to be given to that in professional education.

We have talked a little bit about social care. We need sustainable investment in those community-based services that often prevent people from ending up in crisis, because those kinds of proactive support services—post-diagnostic support for families, advice for individuals, peer support programmes run by, say, autistic people's organisations and services of the kind that Scottish Autism provides through our one-stop shop, our advice line and our online groups—are the services that have the least sustainable funding. They are the first to be cut, even though they prevent the human cost of crisis.

Maggie Chapman: We have been talking about things that have been in process for a long time, and I think that the Christie principles on prevention can be included in that, can they not?

Jenny, I know that you want to come in on this as well—go for it.

Jenny Miller: Thanks—[Inaudible.]—with colleagues. I wonder whether it would be possible to review our workforce. The group of people we support have profound and complex needs, and very often we put the least supported, the least supervised and the least qualified into managing the most complex people in our communities. Therefore, I wonder whether we can begin to think about reviewing the workforce, its payment and the support and supervision that it receives. Certainly, we in the third sector are already talking among ourselves about how we support each other to develop a workforce that is fit and ableand supported and enabled—to work with really complex people.

Education and training are therefore paramount, and we need to start them at undergraduate level and build on models that are already working. Hundreds of students come through our doors and, once they do so, their attitude and culture change. Those things will absolutely need legislation later on down the line, but we need to build on what we are already doing.

The other thing that frustrates me is that we have tonnes and tonnes of research. The Scottish Learning Disabilities Observatory, which we have

already talked about, is looking at how to implement the evidence and turn it into practice. That is essential, and we all need to commit to thinking about how we put that evidence and best practice actually into practice and stop reinventing and re-researching things when we absolutely know what works.

Data is incredibly important. I hope that, with our health checks, we will get more of it, but we need data to highlight those with very complex needs who seem to be just in the midst of things. We are not expecting them to live, but we need to plan for their lives and ensure that we build services around them.

There is tonnes that we can do, but we just need to be supported and co-ordinated in taking that work forward.

Maggie Chapman: Thanks, Jenny. That was really helpful.

Dr Webster: We think that progress on policy implementation across a range of areas is possible for people with learning disabilities, in addition to the need for legislation to be developed, but that will depend on continued and increased investment in a range of areas. I would highlight, for example, the coming home programme, which seeks to significantly reduce delayed discharges and inappropriate out-of-area placements, as well as the misuse of restrictive practices. Progress could also be made with, say, the roll-out of annual health checks, good practice in supported parenting, improving support for employment and participation in the community, improving access to supported decision making and, more generally, increasing access to accountability mechanisms, including judicial remedies. It goes across the board.

Maggie Chapman: Thanks, Simon.

Gregor Hardie: Because we are a collective, we would welcome the chance to come back in writing after we have had time to consider the matter.

Maggie Chapman: Of course. Thank you, Gregor.

Paul O'Kane: Following Maggie Chapman's contribution, I am interested in what outcomes we would like to see. If we think about the particular challenges with other aspects of policy, there are concerns that non-residential care charges will not end by the end of the parliamentary session. We know that not everyone with a learning disability is receiving annual health checks, and that the human rights bill that would have helped to address some of those things is not going to progress during this session. What outcomes will we achieve, and what is your view on that? I appreciate that it is a big question.

Suzi Martin: I am happy to have a go.

Commitments have been made, not just to the learning disabilities, autism and neurodivergence bill. As you have alluded to, there are other things that we are all hoping would have happened, some of which are still being worked on. In the absence of the bill being lodged before the election, it is more incumbent on the Government to deliver on its other commitments. I urge the Scottish Government to look at what it has said it is going to do for autistic people and people with learning disabilities that does not rely on the bill. That includes ending non-residential care charges, and ensuring that the additional support for learning action plan delivers and is impactful, which I am doubtful of. The Government needs to focus on those things and redouble its efforts to achieve them before the next election.

I want to touch on the idea of barriers to achieving outcomes. As I mentioned, because of implementation or accountability whatever term you would like to use, people are continually being driven into crisis situations. It is important for the Government to recognise that that is unsustainably expensive and for it to acknowledge that there is a return on investment from preventative spend. We are not seeing that recognition at the moment. Preventative spend can be many things, such as the provision of more support in schools, which young people are already entitled to but are not receiving; more comprehensive social care packages in the community; improved access to diagnosis and follow-on support; and being a model employer of autistic people. The accountability gap is a massive barrier. We do not see the Government recognising that that is perpetuating crisis situations and that preventative spend is a positive way to spend money.

Jamie Cooke: It goes back to this process not feeling as though it is wasted work and effort. It is a chance for the Government to recognise its disappointment, which we have all touched on. Jenny Miller rightly noted that the responses that have reflected disappointment have been very personal. It is a chance for the Government to ensure that the work is taken forward, whatever outcomes may be in place in the future, and to ensure that all the responses and evidence that have been collected so far are seen as being part of an on-going process. There is disappointment that the bill has not been delivered now, as it should have been, but we need to think about how we ensure that something continues, even if it goes beyond the length of the parliamentary term. For the Government to reach out to others, such as the third sector as equal partners, as well as those across party boundaries, could be quite a powerful stance for it to take. That would allow all

of us to ensure that we are working effectively as we move into next year and beyond.

Jenny Miller: I agree with everything that everyone has said, but for us, we want there to be a decrease in mortality rates. We have evidence and research on that, and we have an idea for a profound and multiple learning disabilities hub that would bring together experts so that we do not lose all their knowledge when people move from children to adult services. There are solutions, but what we really want is a decrease in people dying from avoidable and preventable deaths. If we all work collectively, I think that there are opportunities to do that. I flag the work of the family carers PMLD hub. There are a lot of answers within that, which I am happy to share at another time.

Joe Long: We rightly talk about preventative spend and, as I have said many times, we want to stop the crisis. However, we also need to recognise that, with the right support, people can flourish, contribute and thrive. We should not always think of the role of social care as being somehow to protect the national health service or the role of community services as being to prevent a bad outcome down the line. They can provide good, positive and meaningful lives to people now if the right sustainable spend is in place.

Sometimes we need to change the narrative. I prefer to talk about proactive services, but we absolutely need to invest in those if we want different outcomes.

Dr Webster: If we have an end goal of reaching full inclusion, in which all people with learning disabilities in Scottish society are equal with all other citizens, a key outcome might be to ensure progress and continue to shift society's perspective and expectations about the lives that people with learning disabilities can and do live, so that we fully value the lives of all people. There is potential to develop work in many areas on that.

Related to that, on the Government side, we probably need to establish highly effective cross-directorate working as a norm. The Scottish Government as a whole has the opportunity to take strategic leadership on policy across directorates by continuing to encourage and facilitate work across different policy areas and areas of spending, as well as by co-producing solutions with people with learning disabilities and the whole learning disability community.

Gregor Hardie: We have described the outcomes that are always needed for our lives. The outcome that we need is to be heard on that.

The Convener: What can the Scottish Government and public services do now to help support people with learning disabilities and neurodivergent people?

Suzi Martin: I will reiterate the point that I made in response to Paul O'Kane's question. We need local and national Government to prioritise positive, preventative and proactive spend when it comes to supporting individuals. That does not require legislation, but legislation cannot affect it directly. In many ways, the Government should start doing that now.

We want to see that shift so that individuals are not driven into crisis and can get the support that they need when they need it. Statutory strategies, mandatory training and accountability are all key, but that shift can start to happen now. I urge local and national Government to do that now.

Jenny Miller: We need to become an "us" rather than a "them and us". I feel defensive about how we work with the public sector. We have to have honesty, transparency and the collective wisdom to come together to consider solutions. At the moment, it is a battleground. I understand how awful it must be to be in the public sector, but the loss of empathy and the dwindling capacity to work together put everybody under pressure. We need to think about how we create a level playing field and how we listen and learn. We need to listen with all our senses to ensure that we do things together but, if we cannot do things, we just have to be honest.

I am of an age that means that I appreciate having a letter that says, "We noted that you put a lot of effort into that and we really appreciate it." We do not appreciate each other frequently but it is important. All that our families want to know is what is possible and, if something is not possible, what we might be able to do together. There seems to be a lack of honesty, particularly at a local level, that we need to combat.

Joe Long: I have mentioned before the idea of a whole-life and whole-system approach. We need to start thinking outside of silos—health in one silo and education in the other—so that people do not fall through the cracks when they transition to adulthood or, if they are autistic and do not have a learning disability or already have a long-term mental health problem, there is a clear pathway for support. We need to join the system up so that we take that whole-life, whole-system view and ensure that people are included and that their needs are met across the system.

Jamie Cooke: I echo everything that has been said. The pathways of how people get support are critical and we can improve them now, regardless of the legislation.

We have touched on the success of the lived experience panel. There is an opportunity for that to be utilised more widely, rather than just being brought in when we talk about learning disabilities, autism and neurodivergence. How do we engage

people across all the policies that will impact on their lives, not just put them in a silo for specific pieces? That could be explored more widely.

Dr Webster: I agree with what has been said. There could also be work towards updated national guidance for health and social care partnerships and local authorities on developing local learning disability strategies. We have been involved in that work in the past. It might be useful to identify contributions that each of the existing scrutiny bodies can already make to upholding the rights of people with learning disabilities.

The Convener: I ask members whether they are content with everything that they have asked and our witnesses whether they would like to add anything that they feel they have not been able to get across. If everyone is content, that is a good sign.

That concludes our business in public. I thank the witnesses for attending. We expect to take evidence from Maree Todd, the Minister for Social Care, Mental Wellbeing and Sport, on the proposed bill at our meeting next week. The witnesses' evidence has been very helpful in informing that session.

We move into private to discuss the final items on our agenda.

12:16

Meeting continued in private until 12:36.

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