OFFICIAL REPORT
AITHISG OIFIGEIL

Equalities, Human Rights and Civil Justice Committee

Tuesday 18 June 2024

Session 6

The Scottish Parliament
Pàrlamaid na h-Alba

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CONTENTS

EQUALITIES, HUMAN RIGHTS AND CIVIL JUSTICE COMMITTEE

16th Meeting 2024, Session 6

CONVENER

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

DEPUTY CONVENER

*Maggie Chapman (North East Scotland) (Green)

COMMITTEE MEMBERS

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

*attended

THE FOLLOWING ALSO PARTICIPATED:

Amy Dalrymple (Marie Curie Scotland)
Tomas Gerrard (Deaf Action)
Kirstie Henderson (RNIB Scotland)
Richard Meade (Carers Scotland and Carers Northern Ireland)

CLERK TO THE COMMITTEE

Katrina Venters

LOCATION

The James Clerk Maxwell Room (CR4)

Scottish Parliament

Equalities, Human Rights and Civil Justice Committee

Tuesday 18 June 2024

[The Convener opened the meeting at 10:01]

Disability Commissioner (Scotland) Bill: Stage 1

The Convener (Karen Adam): Good morning, and welcome to the 16th meeting in 2024 of the Equalities, Human Rights and Civil Justice Committee. We have apologies from Paul O'Kane and Meghan Gallacher.

Our first agenda item is an evidence session on the Disability Commissioner (Scotland) Bill. I invite Maggie Chapman to declare an interest.

Maggie Chapman (North East Scotland) (Green): Thank you, convener. I probably should have done this at the start of our evidence taking. Just so that folks are aware, I note that I used to work for a vision impairment organisation of which the Royal National Institute of Blind People Scotland was a member—the Scottish Council on Vision Impairment. That was about a decade ago.

The Convener: I refer members to papers 1 and 2 and welcome to the meeting our witnesses. We have with us Kirstie Henderson, who is a policy officer at RNIB Scotland; Amy Dalrymple, who is the associate director of policy and public affairs at Marie Curie Scotland; Tomas Gerrard, who is a bid writer at Deaf Action; and Richard Meade, who is the director of Carers Scotland and Carers Northern Ireland. You are all very welcome—thank you for attending.

There is an opportunity for brief opening statements before we move to questions from the committee. We start with Kirstie Henderson.

Kirstie Henderson (RNIB Scotland): Good morning, everyone. Unfortunately, James Adams is unable to be here, due to being unwell.

RNIB Scotland originally responded to Jeremy Balfour's bill proposal for a disability commissioner in 2022, and we recently submitted to the committee's call for views.

RNIB Scotland works on behalf of all people with sight loss in Scotland. We support them to live full and independent lives, we campaign for their rights, and we highlight the physical, emotional and financial challenges of living with a visual impairment.

We have been very supportive and are still supportive of the creation of a disability commissioner for Scotland. We obviously work closely with the sight loss sector in Scotland. We play a unique role in that sector to reflect the diverse needs of blind and partially sighted people, and we are interested to hear more about how the disability commissioner could represent the needs of people with visual impairments in Scotland.

Amy Dalrymple (Marie Curie Scotland): Thank you, convener and committee members, for inviting Marie Curie to give evidence.

Marie Curie is the largest charitable provider of palliative and end-of-life care for adults. We provide care for people across Scotland, and, last year, we cared for roughly 8,000 people in the last year of their lives.

Our interest in the bill is due to the fact that we know that too many people with a terminal illness are not able to access the care and support that they need at the end of their lives, and we welcome the intent of the proposal on the basis that it would create an accountability mechanism to ensure that people who are dying and their families get the care and support that they need. People with a terminal illness are defined as having a disability under the Equality Act 2010, so they would come within the scope of the disability commissioner.

At the moment, too many people who are dying do not get the care and support that they need. That leads to suffering for them and their families, and it leads to avoidable system pressure. Furthermore, unmet need for palliative care leads to significantly poorer physical and mental health and poorer financial outcomes.

We welcome the intent behind the proposal. We are interested in the discussion that the committee has had around where it fits, because we are interested in accountability and outcomes. It fits with our campaign for a right to palliative care as well. It is important to pin down and clarify how the rights landscape and the commissioner landscape interact with each other. People need clarity and coherence, and they need the ability to ensure that they can get the support and care that they should have and be able to participate in society.

Tomas Gerrard (Deaf Action): Hello. Thank you very much for inviting Deaf Action to the committee. I am a bid writer and am representing the organisation. I am a deaf British Sign Language user and my BSL interpreter is in the room with me.

Deaf Action is a charity for the deaf, and is based in Scotland and the south of England. We provide services across nearly all sectors, including health and social care. We also support education through our youth service, and through our cultural section, which runs Edinburgh deaf festival every year.

We recognise that deaf people face barriers every day, in all sectors, including in health and education, and in the social aspects of their lives. We are very interested to see how the disability commissioner will work in the current landscape. We have recently been involved with the BSL national plan as a key stakeholder, and we are interested in seeing how that role will provide intersectionality with that plan and across all the other organisations that are here with us today.

Richard Meade (Carers Scotland and Carers Northern Ireland): Good morning, and thank you for inviting Carers Scotland to give evidence. Carers Scotland is a charity that supports Scotland’s 800,000 unpaid carers, and we campaign and lobby for change, as well as providing direct support to carers. We are a membership organisation with nearly 3,000 unpaid carers who are members in Scotland.

We support the proposed legislation. We see a need for a disability commissioner in Scotland to ensure that disabled people are prioritised and put on a level playing field with the rest of the people of Scotland. Far too often, those living with disabilities do not get the support that they need to enjoy the same opportunities that are available to those without disabilities.

However, we believe that the commissioner role should have a supplementary remit in relation to unpaid carers. An unpaid carer is a family member, partner, friend or neighbour who helps a person with daily activities that they would not be able to manage if they did not have that help. That could be a partner, a family member or friend who has a long-term or terminal illness, or it could be someone who is disabled, has a mental health condition, is affected by addiction or is in need of extra help as they grow older.

As I said, around 800,000 people in Scotland provide such unpaid care. The Scottish Government has estimated that it would cost £13.1 billion to replace the care that they currently provide. Many of those people living with disabilities are supported by unpaid carers. That support is crucial and can often be the difference between a person being able to stay at home rather than in another care setting, and it is crucial in supporting people to live as independently as possible.

The lives of disabled people and unpaid carers are often closely linked. Decisions made by public bodies and service providers on a range of issues that affect disabled people can often have a direct impact on the lives of carers and, indeed, vice versa. In order to support the cared-for person, it is crucial to ensure that unpaid carers are also supported. By extension, a proposed disability commissioner should have a remit that considers unpaid carers and how to promote and safeguard their rights, as, if unmet, they often have a direct consequence on the person whom they care for and on people with disabilities.

Take the right to be involved in the discharge planning of a person from hospital, for example. Sixty per cent of unpaid carers told us that they were not informed and not involved in decisions about discharge, yet, under the requirements of the Carers (Scotland) Act 2016, they should be. When that does not happen, it can have huge consequences for the person whom they are caring for and for their ability to be at home or in the community, often leading to readmissions or a person being moved to another care setting, such as a care home.

Many unpaid carers also have a disability in their own right. However, that can often be hidden from sight, as the focus of services, society and, indeed, the unpaid carers themselves, remains on the person for whom they are caring. Last year, more than 1,700 carers in Scotland participated in our state of caring survey, which found that 29 per cent of unpaid carers also consider themselves to have a disability. That is slightly higher than the average in the rest of the United Kingdom. If the proposed commissioner has a specific remit for unpaid carers, we hope that there will be greater opportunities for unpaid carers who have disabilities to access services and, perhaps, to help them to realise that they are carers and to get the support that they need.

Ultimately, we believe that a disability commissioner that has a remit that includes unpaid care would play an important role in exposing bad practice and a failure to access rights and services, would shine a light on those on-going challenges and would, we hope, lead to positive change. People are tired of failing to get the support that they need and that they deserve because they have a right to it. They are tired of being marginalised, they are fed up with feeling as though they have been left behind, which so many do, and they feel forgotten about. We should support any steps that might improve their experience.

The Convener: We will move on to questions from members of the committee. I will kick off. I will ask my question in sign language and then I will speak in English. My first question is on what you think about the bill and its main points. I ask Tomas Gerrard to respond first.

Tomas Gerrard: Deaf Action supports the bill as we are keen for there to be a voice for disabled people, people with mental health issues and other issues. From our experience of working with the Scottish Government on the BSL national plan, we feel that there is a systemic issue in policy making in that there are no true representatives of the voices of people who the policies and bills affect. For example, a hearing person might be dictating education policies for a deaf person, about which they may have no lived experience. They will be operating on the basis of numbers and statistics on a page, which may or may not be the right thing. However, as we all know, what is on paper does not reflect what happens in everyday life. We feel that the Disability Commissioner (Scotland) Bill is a real step forward in having a voice that is present in the room that is truly reflective of the deaf community's experiences.

The Convener: Thank you, Tomas. I spoke and signed a bit there, but, for clarity for others, I will ask again: what are your views on the bill? Do you support its general principles?

Amy Dalrymple: If the commissioner does not happen, then something else needs to happen in order to realise the intent that is behind the proposal. From our point of view, disabled people are marginalised across health and social care, in education, in access to justice and their inability to participate socially. If you walk around Edinburgh, you will see how inaccessible it is for people who have a physical disability. We can tell from our work with Marie Curie that people who have a learning disability experience huge barriers in trying to get the care that they need. That is also true of people who have a cognitive disability and who have additional problems with trying to get that recognised as a comorbidity or a disability, which means there are challenges with accessing the care that they need when they need it, and with being able to advocate for their rights. We absolutely recognise the need for the bill and why a disability commissioner is being proposed. We support the proposal that is on the table.

The only other option would be to take a very comprehensive look at the commissioner landscape—as I know is being done by parliamentary committees at the moment—to make sure that the existing commissioners, or a rejigged structure of commissioners, are specifically championing the rights of people with disabilities. There is a need for that voice and champion for disabled people, with a focus on disabled people, due to how marginalised they are from so many aspects of life in Scotland.

10:15

Kirstie Henderson: RNIB Scotland supports the bill and the proposals, including the ability for the commissioner to be a champion for disabled people. We note that there is quite a bit of detail in the bill on investigatory powers, where the commissioner could potentially take on individual as well as general investigations. We believe that the disability commissioner would have an important role in unifying the voice of disabled people from various impairment groups, alongside the important role that disabled people's organisations play in protecting and raising awareness of the rights of disabled people.

Our concern is that—as has been raised in evidence by previous panels—the current landscape is cluttered. More commissioners are potentially going to be created in the political landscape in Scotland, which could create quite a complex and cluttered landscape for individual disabled people to try to navigate.

From our point of view, representing blind and partially sighted people, we are already aware of the barriers that they face in many aspects of day-to-day life. One crucial barrier is around accessible information and their not being able to access information in a format that is accessible to them.

I am not sure whether I am jumping ahead to questions that might come later, but one challenge for the disability commissioner will be justifying what matters it takes on and what matters it does not. Building trust among disabled people is crucial in order for it to realise its role representing the diverse needs of disabled people. It will be important for it to justify whether it steps in or not and to have accountability mechanisms so that people know why it is taking on the investigations that it does.

Richard Meade: First, I agree with the rest of the panel on what they have said so far.

Carers Scotland supports the general principles of the bill. There is a need for the role of a disability commissioner and its ability to, we hope, expose some of the bad practice that we are seeing, shine a light on the inequities and inequalities that are faced by people with disabilities, and create an opportunity to see positive change.

As I said in my statement, we need to look at how we can include unpaid carers as part of that, because they are often so intrinsically linked to supporting people with disabilities. We hear all the time about families and people not getting access to their rights and to the services that they need, which has an impact on their quality of life not only in the short term, while they are not getting the support that they need, but in the long term and well into the future.

The Convener: I will ask my second question, first in sign language.

I asked: people fed back that there was strong support for the bill. Why do you think that that is the case?

Tomas Gerrard: Thank you for your question, Karen. I am sure that I am not the only person on the panel who, as people who are seeing disabled people living their everyday lives, believes that it is a constant struggle. There are barriers to communication, and issues with information not being in the correct format. For example, deaf people leave school a full grade behind their hearing peers at the age of 16. That has a massive knock-on effect on the levels of unemployment that pervade the deaf community.

Therefore, an opportunity for the disabled community to have a voice in Government will be a huge benefit. That level of support will help with the frustration of not having a seat at the table in committees or meetings. If we have an issue, there is no clear point of contact to feed back to and report the issue. The correct representative could make decisions that directly influence the lives of disabled people, and that is why there are positive levels of support for the bill.

Amy Dalrymple: I would suggest that the strong support for the bill—which we have seen from organisations such as ours and you have heard directly from disabled people—is predicated on the fact that there is a frustration that the existing framework has not led to change and improvement in disabled people's representation and participation in the workforce. I do not know the number but, in your evidence sessions on a disability commissioner bill, you have heard from more people without a disability than with a disability. That is as much to do with structures in organisations as it is about anything else, but it is symptomatic of the low levels of participation from disabled people in many decision-making structures. As a policy person, I would suggest that that is one of the things that lead to a low level of service provision. People are not able to get the services, support and accommodations that they need in order to access services and participate in the workplace, so we end up with higher levels of poverty among disabled people and an inability to access care and support. Richard Meade described the issues around carers, and Tomas Gerrard correctly described the issues around access to education and participation and how decisions are made. From Marie Curie's point of view, the lack of participation results in higher levels of need but lower levels of service access, so people are not able to get the care and support that they need.

Kirstie Henderson: I will echo the points that Amy Dalrymple made. There is strong support for the disability commissioner because disabled people across the board have faced massive challenges over the past few years. There is no taking away from the fact that the pandemic brought a number of challenges. Many social distancing measures were inaccessible to blind and partially sighted people—for example, changes to streets and environments were primarily communicated through visual means. An RNIB survey reported that two thirds of blind and partially sighted people feel less independent now than they did prior to the pandemic. We have heard numerous stories of care packages vanishing overnight during the pandemic.

As Amy Dalrymple touched on, the cost of living crisis, in which the cost of everyday essentials has gone up, has presented more challenges for blind and partially sighted people. They have had to limit their expenses, including purchases of the essential equipment, aids or adaptations that enable them to live independently.

Generally, support for disabled people in Scotland, whether that is through health or social care, is a very mixed picture. Often, what people can access and the support that they can get are dependent on the services that are available in their area.

Currently, we are working on raising awareness of the need for visual rehabilitation. When a person is first diagnosed with a visual impairment, accessing visual rehabilitation is crucial for their ability to adapt to living at home and to gain skills that enable them to navigate successfully and get out in the community. In some cases, there is a backlog for such treatment, but there can also be a dearth of service provision.

Overall, that is why there is a need for a disability commissioner and strong support for that.

Richard Meade: I agree with the rest of the panel. There is a feeling among the population that they are increasingly marginalised and removed from opportunities that everyone should be able to enjoy or expect as part of what society offers, whether that is access to education, employment or health and social care services. People are not enjoying those opportunities, and it has got worse.

As colleagues have mentioned, many services have not returned to pre-pandemic levels, and that is disproportionately impacting on people with disabilities and, by extension, it is often impacting on their carers. Even if people are getting some service support, it is not person centred and it does not meet their needs. People are feeling increased marginalisation from the support that they should be getting from society, and that has a huge impact on everything from health and wellbeing to financial security and poverty.

When unpaid carers are compared with non-carers, that exposes the massive levels of inequity and inequality between the two groups. However, even among the unpaid caring population, carers who have disabilities report even greater levels of inequality and inequity. Even in those marginalised communities and among those who are more vulnerable, the impact on people with disabilities is disproportionate. That explains exactly why there is a clamour for something like the proposed commissioner.

Maggie Chapman: Good morning to the panel. Thank you for your comments so far. I want to ask some questions about the cluttered landscape, its complexity and the potential for duplication that Amy Dalrymple and Kirstie Henderson raised specifically and which everybody has touched on. It has been suggested to us that a new disability commissioner might complicate and fragment an already cluttered and complex landscape of human rights commissioners. However, it has also been suggested that that could be overcome by working together closely and by memorandums of understanding. What are your views on that?

Amy, as you raised that issue earlier, could you comment on it?

Amy Dalrymple: I cannot really comment without also mentioning the other proposals on the table. There is a pre-legislative consultation on a learning disabilities, autism and neurodivergence bill, which includes a proposal for a commission or a commissioner and options for that that would overlap with the proposals for a disability commissioner. We already have the Equality and Human Rights Commission, the Scottish Human Rights Commission and the Children and Young People's Commissioner Scotland. There are some discussions about the scope of the disability commissioner and whether that would include children.

The convener asked why there is such strong support for the bill. That is because the existing commissioner landscape is not working for disabled people. If it is not working, it needs to be changed to ensure that disabled people can have the accountability that is required. A commissioner is about making sure that existing rights and legislation that are meant to work for disabled people are working for them, be that the Equalities Act 2010, the Human Rights Act 1998 or the UNCRPD—that is the United Nations Convention on the Rights of Persons with Disabilities; I should not use acronyms—which I hope will be incorporated into Scottish law at some point soon.

10:30

It is about working with existing legislation; therefore, either the existing landscape needs to improve, or the proposal needs to be enacted, the commissioner needs to be appointed, and they need to have appropriate powers—that is also important. I do not think that Marie Curie would support the appointment of a commissioner if it was done in a tokenistic way—if it was done to pay lip service by saying, “Look, of course we support the enactment of those rights,” without the commissioner having the teeth to do something.

There is a problem with some legislation; for example, the Patient Rights (Scotland) Act 2011, as well as the Carers (Scotland) Act 2016, which Richard Meade might talk about. They include provisions that are meant to enable people to improve their lives, but they do not have the mechanisms for impact. Support is conditional on it having an impact and being able to achieve what it is meant to achieve.

To get back to your original question about the cluttered landscape, you must take all that into account. It is worth looking at the landscape as a whole and at how it is working, and then using that context to describe why this is an important proposal that enjoys our support and the support of many others.

Maggie Chapman: Thanks, Amy. I will delve a little bit deeper. You said in your response that there are many other commissioners and statutory bodies, as well as legislation that is clearly failing. You talked specifically about the need to have mechanisms that will have an impact. Will you elaborate on that? Why are all those statutory bodies and commissioners failing? Is it purely about resource or is there something else going on?

Amy Dalrymple: I would not want to speak for other bodies, but we have all described—Kirstie Henderson and Tomas Gerrard in particular have described it very eloquently—the way in which disabled people in Scotland are living their lives, including the lack of opportunity and the lack of ability to participate in services and the discrimination in services, either because people do not know what to do or because they find it too hard or too expensive. We can see that there are problems, which means that something else needs to happen, possibly in relation to resource or the ability to pay attention to the needs of disabled people, or because the remits of those bodies are so broad that the needs of disabled people are only one of a number of sets of needs that they must respond to.

As I say, I would not want to speak for those bodies, but it is very clear that something needs to happen. We need to be very careful in considering the different proposals that exist—there is a proposal from another MSP around a commissioner for older people, for example. Older people are often the people with disabilities; acquired disabilities come with age. There is a need to pay attention to existing structures and to structures as they emerge, but there is also, on the face of it, quite evidently—whether you look at statistics, research or people's experiences—a need for disabled people in Scotland to get a better deal.

Maggie Chapman: Thanks, Amy.

Richard, I will ask you the same question about the cluttered landscape and duplication.

Richard Meade: I will have a little ramble about a couple of those issues but, first, I will come back to the question about why there is failure between policy intent and implementation and whether it is due to resource or other issues.

The Carers (Scotland) Act 2016 provides a good example. It states that all unpaid carers should be involved in the discharge planning for the person who is in hospital. However, through our survey work, we found that roughly 60 per cent of carers are not involved in that and do not feel like they are involved in the discharge itself. This is anecdotal evidence, but we hear horrendous stories, such as people getting phone calls at 4 o'clock in the afternoon to say that the person they care for is being discharged at 5 o'clock even though they have not got a care package in place. In some cases, the person who is their carer does not even necessarily live with them but has to respond to that all of a sudden, and there can be catastrophic consequences.

The intention behind the policy is great, because we should be involving unpaid carers as equal partners in care, but it is falling down. We hear that there is a lack of awareness around what those rights are and what is in the legislation, so there is a need for training and development to ensure that practitioners understand the legislation and know how they can best support the implementation of that legislation. Again, just skewing to the left a little bit, highlighting to practitioners the rights that people have could be a role for a commissioner.

There is a resource issue in relation to discharge planning, and we know that there are huge pressures on hospital beds and a need to get people through the system and back home or into the community. As a result, decisions are made perhaps not with the best intentions—although certainly not in bad faith—and the rights that the carer has under that legislation to be involved in the discharge planning are not met, sometimes with dire consequences.

As I said, that is a good example, as it involves a mixture of issues to do with resources and awareness—a cluster of activity around rights and entitlements that defeats good policy intent and leads to an implementation gap. All of that needs to be looked at, and I think that a commissioner could help by highlighting those rights and working with partners—practitioners and organisations such as ours—to try to address some of those gaps in policy and implementation.

On the cluttered landscape, a fundamental reason why we are seeing this clamour for commissioners is that people feel failed and marginalised and do not feel that they are getting the support that they need. Regardless of whether the policy intent is good, the implementation gap is huge in lots of circumstances and in relation to lots of groups. People feel marginalised and they want a champion who enables their voice to be heard, and they see the establishment of a commissioner as an opportunity for that to happen.

As has been mentioned today and in previous meetings, we should consider how people in the commissioner landscape can work collectively and collaboratively. There are certainly enough issues and challenges out there among communities to go round the commissioners, and, by working collaboratively, we might be able to shine a light on some of the intersectionality between those issues and bring about positive change in a range of areas.

The landscape might look cluttered, but I do not see that as being a barrier to delivering for the people those commissioners and public bodies could represent, and I think that, because many people feel marginalised and unheard and do not feel that they are not getting the support that they need to live a quality of life that we should all expect, there is a need for that representation.

Maggie Chapman: That is a helpful articulation of the position.

I have a quick question on the ease of navigation of the process. One of the arguments for the establishment of commissioners such as a disability commissioner is that they would be mechanisms of remedy or redress. You say that people should be working together collaboratively, but how do you see people who need redress and remedy navigating that pathway?

Richard Meade: There needs to be clear and inclusive communication. Also, as soon as somebody who is reaching out for support touches the system, there must be a process in which everybody works to ensure that they can navigate the pathway easily. That will require buy-in from public bodies and commissioners to ensure that, when somebody gets in touch with one part of the system, they are not told that they have to go and speak to someone else and end up being referred away so that they are no longer a problem for that part of the system, which we see happening quite often at the moment.

Instead of that, we need to have buy-in from all those organisations that might be involved in the system that we are building, so that, as soon as somebody reaches out for help, they are picked up and brought through that system in a way that is easy for them to navigate and in which there is inclusive communication, and they end up speaking to who they need to speak to, whether it is a commissioner or a public body, so that they get that sense of being heard and, hopefully, a satisfactory response to their complaint, or the investigation that they need.

Maggie Chapman: I ask Kirstie Henderson the same question on duplication and the cluttered landscape.

Kirstie Henderson: Amy Dalrymple and Richard Meade have articulately explained the problems and the current accountability gap. It is a problem if an individual feels that their problem or complaint is not being addressed and dealt with appropriately. Independent advocacy plays an important role in ensuring that marginalised groups have representation and receive support when it comes to seeking redress for an individual or collective problem. It is very difficult for blind or partially sighted people to navigate the system when information is not necessarily always accessible, which means that they have to unpick things and potentially jump through more hoops.

There is legislation that backs up people's right to have information provided in accessible formats, but we regularly hear that, due to financial constraints, requests for accessible information to be provided cannot always be met, with services not being provided in a way that would meet a person's needs.

The difficulty with the current landscape is that, if commissioners are not adequately resourced to do the work that they were set up to do, as set out in their policy statement, that can lead to a bit of disillusionment. I suppose that I am presenting more challenges than solutions. However, health, social care, welfare and transport systems all operate differently, and it is difficult for a person with a visual impairment or a different condition to unpick everything and navigate through those systems when they are trying to find an accountability mechanism. If a disability commissioner was established in Scotland, one of their key roles could be to unpick things for disabled people across the impairment spectrum. If the accountability structure—whatever it was—was not working, they could ask why that was the case and make recommendations to make it work better for people.

Maggie Chapman: You talked earlier about the commissioner—as an advocate and as the point of focus, if not the point of contact, for disabled people and others—potentially having a unifying role. Are there challenges in that regard, given how diverse disabled communities are? Even in relation to RNIB Scotland's work, there is diversity among the people whom you support. How do you see one person—or one commissioner's office, because it would not be just one person—being able to deal with that diversity?

Kirstie Henderson: That is a really tricky question. The commissioner would have a unifying role when there were shared experiences of barriers and injustice. Irrespective of the condition or impairment that people are affected by, whether it is a mental health issue or a physical or sensory impairment, they might have similar experiences. The commissioner would have a role in highlighting such shared experiences, trying to unify people and recognising the various sectors that exist in Scotland, including the sight loss sector.

We have a cross-party group on visual impairment in the Scottish Parliament, and that is an effective vehicle for bringing the sight loss sector together to discuss and highlight some of the issues that blind and partially sighted people across Scotland experience. There may be similar cross-party groups for other areas of work. That is one important role.

10:45

Having spoken to the various organisations that exist—such as disabled people's organisations, which have a crucial role—I do not think that there is an easy answer to unifying. It would require the disability commissioner, if that role was established, to reach out in the early stages to try to unpick who the key players are and what is already out there. A lot of work would need to be done to establish memorandums of understanding and engagement before the commissioner could even look at getting involved with the day-to-day work of investigations and promoting and safeguarding the rights of disabled people.

Maggie Chapman: You have highlighted that it is not easy. If it was easy, we would have sorted these issues by now, so it is going to be complex.

Tomas, you talked about the need to have disabled people very clearly involved. If we think about how the landscape works and consider the potential for duplication and overlap, how easy is it for disabled people and the people that Deaf Action works with to navigate the existing landscape, before we think about having a new disability commissioner?

Tomas Gerrard: I am not going to beat around the bush. This is a systemic issue and it is going to take decades of hard work from very talented people to unravel the huge barrier. I am not just speaking for deaf people here; I am speaking for disabled people across the spectrum. We all have a lot of overlap, but my expertise is with deaf people.

As Richard Meade mentioned, inclusive communication will be key, but that is not happening right now. It feels as though the landscape is moving forward without any consultation with or valuable input from the community of people who, each day, experience issues with their lives, families, education, health and social care. The point that I am trying to make is that, although the landscape might be cluttered, which is seen as a negative for the disability commissioner, it is cluttered because there is a systemic issue. The disability commissioner will go a long way towards starting to unravel that for the disability landscape.

The commissioner will need to identify key stakeholders in each of the disability sectors. I cannot even begin to count how many such stakeholders there are, and I am not going to pretend that I know them all. They will need to identify a key stakeholder from each group who is an agreed-on voice for their community, and bring them into a room—or many different rooms, because there are so many different varieties—to feed back to the commissioner and be involved in a framework where they can agree on the general direction that the commissioner should take. That is a big ask, but it is what needs to happen. We need to unify behind a disability commissioner who has the power and the ability to take things forward and provide a voice for us in the Scottish Parliament and the Scottish Government. That is my take.

Maggie Chapman: In your opening statement, you talked about the importance of intersectionality in Deaf Action's work. Can you say a little more about how we can ensure that we embed intersectionality in how we think about the disability commissioner and the broader landscape?

Tomas Gerrard: That is a good question, but I am not sure whether I have an answer. Deaf people experience a lot of intersectionality. For example, people might lose their hearing as they age. If someone goes overseas with the British Army, they might experience hearing loss as a result of things that happen there, or they might come back with additional physical disabilities or mental health issues. Children who are born with meningitis or have complications at birth can become deaf. We deal with many different crossovers.

We ensure that our services are effective for those people by having good relationships with organisations across the sector such as Deafblind Scotland, the Royal National Institute for the Deaf and the British Deaf Association. Each of those has its own specialisation, as does Deaf Action. It is about sharing that knowledge and how we do things and being involved in the same policy-making systems, such as for the BSL national plan, which was published in November. We were part of a key stakeholder group that included Deafblind Scotland, the British Deaf Association and the National Deaf Children's Society, and we discussed and agreed on the issues that impact the deaf community, how to address those intersectionalities and how that would be reflected in the plan. That is a good example.

Maggie Chapman: That is helpful. I will leave it there.

Marie McNair (Clydebank and Milngavie) (SNP): You have all touched on the growing commissioner landscape in Scotland. What are your views on having a disability commissioner and a learning disabilities, autism and neurodivergence commissioner? How might the two operate? I will start with Amy Dalrymple. Amy, will you expand a wee bit on that?

Amy Dalrymple: I declare an interest in that, aside from my work, I am also a trustee of Down's Syndrome Scotland and I have been working with it on that.

The proposal for a disability commissioner is on the table, whereas the accountability mechanisms for the learning disabilities, autism and neurodivergence bill are still being explored. The two bits of legislation development probably need to be looked at together, because the scope of the proposed commissioner under the LDAN bill and the scope of the disability commissioner need to be clear.

I talked earlier about age and the interaction with the children's commissioner, which does extremely good work. You would need to look at the scope in relation to the Equality and Human Rights Commission and its responsibility for reserved matters, and also the potential legislative gap, even if not in action and impact terms, around rights in relation to devolved matters. Clarity about the scope is crucial. If that is clear, and if the points of potential overlap are identified and a decision is made on where responsibility lies, having two commissioners is perfectly navigable.

Richard Meade said that there needs to be a mechanism whereby, as soon as someone touches the system, they are directed to the right place. In the dying and palliative care policy world, one bit of administration that works is the "Tell us once" service whereby, when somebody dies, you tell the Government and the information goes to the Driver and Vehicle Licensing Agency, His Majesty's Passport Office and HM Revenue and Customs, so that all the relevant bits of national Government, including the Scottish Government and the UK Government, know that the person has died and the relevant administration kicks in.

That mechanism shows that, in that very important circumstance, it can be done. I do not know the number of times I have had people ask me, “If we can do it for that, why can’t we do it for other things?” I put that thought to you as you are considering how a multicommissioner landscape might work. We need clarity about the scope and we need to get the administration right for the people—the users, if you like. It can then be made to work for people.

Marie McNair: Does anyone else want to comment? Tomas?

Tomas Gerrard: Sorry—you lost me. What was the question again?

Marie McNair: It was about the growing commissioner landscape in Scotland. It is okay if you do not want to comment. There is no pressure to do so.

Tomas Gerrard: At this point, I am okay. Thank you.

Marie McNair: No problem.

Richard Meade: I think that I have covered quite a lot of it already, and Amy Dalrymple has just made it very clear. There is room for both. There is room for all the commissioners, because the challenges are huge. We need to be clear about their roles and their remits, and it is then about collaboration—it is about bringing the commissioners and public bodies together to understand how they can work together. They could do really powerful work collaboratively. That is a positive that we could look at. Having the commissioners working together to resolve issues where there is intersectionality could be hugely beneficial, so I think that there is room for all of them.

Marie McNair: Last week, we heard from two panels, and one of the witnesses suggested that the success of the Disability Commissioner (Scotland) Bill could jeopardise the LDAN bill. Do you have any thoughts on that? Given your comments, Richard, you may not agree.

Richard Meade: I think that there is room for both. Amy Dalrymple made the point about the need for clarity on remits and roles. If we get that correct and it works, if there is space for collaboration as well as separating out who does what, and if we make sure that people who are in contact with the system get support, I think that having both commissioners should work.

Marie McNair: Thanks for that.

I will move on to finances. Again, my questions in that area are similar to the ones that I asked last week. Under the financial estimates, we are talking about a cost of possibly £1 million. Do you think that that underestimates the costs of set-up and so on?

Amy Dalrymple: The costs of ensuring that disabled people can access services and the same mechanisms in public administration that others can access are often underestimated, so I would be wary about suggesting that this can be done cheaply. It will depend on what you are trying to do with the commissioner role. As I mentioned, our support for the bill, the LDAN bill and other legislation is predicated on the role having a point and not being tokenistic. If there are no teeth, that £1 million may be wasted. You might get better value from spending £2 million each year in order to make sure that there is actually some impact.

The financial input should have an impact and it should be seen as an investment. Otherwise, there is no point in doing it. There is no point in spending the money and seeing it go down the drain. It needs to be seen as an investment to make sure that existing resources that are spent across health, social care, education and justice are spent more effectively and have the intended effects, impacts and outcomes. At the moment, that is not happening, which is why the commissioner is needed. Any resource that is spent on the commissioner should be seen as an investment and not just as spend.

Richard Meade: I apologise that I have not read the financial memorandum line by line—I have seen only the top-line numbers. However, if the commissioner’s role creates greater opportunities for people with disabilities to engage more in society and to access services earlier, the economic benefit might outweigh the cost. Have we done any assessment of the potential economic benefit of having a commissioner to support such a significant population to access more rights and more opportunities in education and employment?

11:00

Marie McNair: Referring back to what we heard last week, we want to know your thoughts about the concern that the funding of a new disability commissioner could divert money away from other public policies aimed at those with disabilities. I throw that out to the witnesses—but we do not want to be tokenistic on this point.

Richard Meade: Generally, we are all concerned about the level of public and statutory funding that is available to support services, organisations, the third sector and public bodies. We have seen resources dwindle.

I return to an earlier point and to what Amy Dalrymple said. If proper investment in a significant function can deliver and support change, the benefit might outweigh the cost and it might make a real, positive contribution—not only to the population but to the system, through creating more opportunities for people to engage in the system and to get the services that they need. That could bring benefit both economically and socially.

Marie McNair: I appreciate your comments. Does anybody else wish to add something before I hand back to the convener?

Tomas Gerrard: I completely echo what Marie Curie Scotland and Richard Meade have said. On the question of investment, if we put in X, Y and Z, we will get Y coming out at the end. It is very difficult for disabled people to become players in the economy, because of the lack of opportunities from a very early age, which has a knock-on impact. It costs much more to support them through social care and in relation to employment opportunities. That far outweighs what we would put in now. The investment needs to be used wisely, and the money should be spent with due consideration to address the actual needs of disabled people, rather than being tokenistic—"Here's X pounds: you can go and do this," and that is the end of it. There needs to be an on-going process.

That process needs to be fluid, as the landscape is always changing, especially in the light of the pandemic and the cost of living crisis. It is very important for us to recognise that anything that we do now needs to have a strong framework, with room to adapt to the changing landscape of disabled people. I agree with what the rest of the panel is saying here.

Marie McNair: That is much appreciated. Thank you. I will hand back to the convener.

The Convener: Thank you, Marie. We will now move on to questions from Evelyn Tweed.

Evelyn Tweed (Stirling) (SNP): Good morning, panel, and thanks for all your comments so far.

I want to ask some questions about the definition of disability that is being used. Can you give the committee your views on using the disability definition under the Equality Act 2010 as the definition in the bill?

Amy Dalrymple: We would support that. We believe that the definition is comprehensive. From Marie Curie's point of view, I note that it includes people with a terminal illness.

We have done a lot of work on definitions in our work on a right to palliative care, which some of you may have looked at. One of the points that came up is that we can have a definition in the legislation but also have guidance about what it means for different organisations' responsibilities. There can be a definition in the legislation, but that can be clarified and expanded upon when needed. It is important to think about how a definition would be operationalised.

From our point of view, there is value in using a definition that already exists in legislation. As I said before, having a commissioner is about putting into effect an existing legislative framework. There is also the question, which you, as a committee and as a group of MSPs, look at every day, of whether that legislative framework is correct. As we have discussed, a set of commissioners are there to ensure that that legislative framework is having the correct impact. The legislative framework that sits underneath what a commissioner does is important, so there is an advantage in the definition being an existing legal definition of disability. We support using the definition in the Equality Act 2010.

I hope that that makes sense.

Evelyn Tweed: It does. Does anyone else want to come in on that? Are there any other comments? I see that there are not.

What are your views on the general powers in the bill? I will read them out. There are quite a few of them, and the remit is quite broad. They are to promote awareness and understanding; to keep law, policy and practice under review; to promote best practice; and to publish research.

Would Richard Meade like to come in on that first?

Richard Meade: Yes. I absolutely support all of those powers. What I will say has been mentioned before. The commissioner should have more teeth, as far as possible, to ensure that there is some redress for people's complaints or investigations that are undertaken. How those powers might be beefed up is certainly worth considering, to ensure that, when investigations reveal failures in the system or failure to supply, action must be taken and organisations or services are held to account.

Broadly, we support the general principles, but greater power and more teeth would certainly be welcome.

Tomas Gerrard: I agree with Richard Meade. The wording of "promote awareness and understanding" especially could do with more teeth. What does that really mean? What are the tangible actions behind that? What are the boundaries of the commissioner's powers? Something that is a little bit more robust would be a positive for me. That is very broad, and the meaning can be stretched. It could mean an email or a collective campaign by all the charities. I would appreciate a bit more robustness behind some of the wording.

Kirstie Henderson: I echo what Tomas Gerrard said about having something tangible and the proposals having more teeth. We would hope that the disability commissioner would be a beacon of inclusive communication and accessible information. We realise that, in reality, it is about having the resources to be able to provide information in a range of formats, so that it can be provided in a timely way and it does not take weeks for somebody to get information in their preferred medium. That is an important point.

Amy Dalrymple: The proposed power to investigate is important. We are all talking about teeth and what we mean by teeth. That investigatory power, obviously limited to devolved situations as it is, would complement the EHRC's responsibilities extremely well because its responsibilities are limited to reserved matters in a lot of its work. It is important to add that to the more championing powers.

It is proposed that the role would be that of a commissioner, not a champion, although there have been champions across Government on other issues. I am not saying that the promotion of best practice and communication, as well as campaigning for understanding and research and reviewing what else goes on, are not important. I work in a campaigning charity and that is a lot of the work that we do—it does have an impact. You would want a disability commissioner to have more clout than I would have.

The Convener: We will move on to questions from Annie Wells, who is joining us remotely.

Annie Wells (Glasgow) (Con): Thank you, convener. Apologies for not being able to get online earlier. I am still working on it.

I have a question about inclusive communication. What are your thoughts on the provision for inclusive communication? Do you think that it overlaps with the Equality Act 2010 duty to make reasonable adjustments? I ask Tomas Gerrard to answer first.

Tomas Gerrard: For me, a tangible example of inclusive communication and of things that would improve accessibility would be having a BSL interpreter in the room and having a laptop in front of me that has subtitles on it. However, it would look different for people with different disabilities and different needs. I am not saying that that is how we should do it all the time, but I think that we need to be more flexible and more aware of people's needs in order to understand them and provide the correct communication tools for people with certain needs. That would go a long way to getting the voices in the room that would influence the disability commissioner.

Annie Wells: Does anyone have anything to add?

Kirstie Henderson: We said quite a bit about inclusive communication in our response to the call for views. As I have said before, the provision of accessible information is crucial to enabling the participation of blind and partially sighted people. The harmful impact of not receiving information in a preferred and accessible reading format cannot be overestimated. We have seen bold action with the Social Security (Scotland) Act 2018, which enshrined and made explicit people's right to inclusive communication as well as accessible information. That has been a beacon and is a great example of a public body that has enshrined that right in the legislation and has also delivered on it.

I have said it before, but I think that, should the disability commissioner be established, they would have a key role in providing information in accessible formats as well as highlighting and calling into question when that is not happening. As we already know, medical and health information is not always provided in accessible formats, which undermines blind and partially sighted people's right to patient confidentiality in many cases. There are many reasons why that is important.

Amy Dalrymple: I want to highlight the value of specificity—I am really pleased with myself for getting that word out without stuttering—and of talking specifically about inclusive communication as something that is required as a reasonable adjustment. We should also indicate who ought to be communicating inclusively. In palliative care and in health and social care services, we see how disabled people are often not accommodated in service provision because terms such as "reasonable adjustments" and the "care that is required by the population" can be interpreted too widely, which means that the service that is provided can end up missing the people who have the greatest need.

Kirstie Henderson has described the positive impact of the inclusion of the specific term "inclusive communication" in the Social Security (Scotland) Act 2018, and I think that it would be important to include a specific reference to "inclusive communication" in the Disability Commissioner (Scotland) Bill.

11:15

Annie Wells: Thank you. Richard, do you have anything to add?

Richard Meade: I do not have anything specific to add other than to say that it is absolutely right that inclusive communication is embedded in the role of the disability commissioner and the office that will support them.

By way of an extension of that, I make the point that the issue is about reach. We need to make sure that the disability commissioner and their office are accessible to everybody who might benefit under that remit. I am talking about people such as those in our hardest-to-reach communities and people whose first language is not English. We need to make sure that the commissioner has sufficient reach so that everybody who might benefit from them does so and that, when people get in contact with the commissioner, there is a process of inclusive communication that allows them to articulate their challenges, concerns and issues, and to navigate the system and understand what the process is and how their complaint, investigation or whatever will be progressed.

Annie Wells: Convener, I have one final question to ask, if you do not mind.

The Convener: Absolutely—go ahead, Annie.

Annie Wells: Thank you. This question is about the involvement of disabled people. What is your view on the provision in the bill to involve disabled people in the work of the disability commissioner? What are the benefits and the challenges in that regard?

I do not know who would like to answer first. It is very strange when you are participating remotely, as you cannot see who would like to answer.

Tomas Gerrard: I will jump in there. I will say point blank that the bill will not work without the involvement of disabled people. It is absolutely crucial that disabled people are involved in the process from the get-go, for the reasons that I mentioned earlier. We have the lived experience, so we are aware of the impact that policies have on our everyday lives. If a policy has any impact, we know where the resources should be redirected in order to make the greatest impact. I am sorry to say that you will not get the same quality of information from a hearing person.

As we have already discussed, there is a challenge. When there is such a wide spectrum of disabled people, how do we address the needs of such a wide spectrum through a single disability commissioner? We have discussed the need to have a framework in place and to include key stakeholders. Inclusive communication is important as well. We need to be absolutely sure that we can reach out to all the hard-to-reach communities. I thank Richard Meade for mentioning that, because the BSL community is one such community where people's first language might not be English. We assist very hard-to-reach communities, in which some people might not have digital skills and might not even know how to access emails, websites and all the rest of it, so the support has to be face to face.

It is absolutely crucial that disabled people from across the spectrum and key stakeholders are involved. Basically, we need to get as much reliable information as we can from those communities, because, ultimately, the Disability Commissioner (Scotland) Bill is for those people and it should be influenced by them.

Annie Wells: Thank you, Tomas. I do not know whether anyone wants to add to that.

Amy Dalrymple: I am really glad that Tomas spoke first, because he articulated extremely well the importance of involving disabled people, as well as the challenges in doing so.

I would add that, if the process is done properly—it will be a challenge in itself to do it properly—that, in turn, will present a challenge. If all the various voices are involved and heard through the commissioner, that will present a challenge to the way in which many organisations in Scotland work. It will present a challenge to the way in which the Parliament, the Government, health boards and local government work. It will present a challenge for education. Resource demands might result from that, so we need to go into the process with our eyes open. We need to realise that the existing marginalisation exists because it is difficult and expensive for those organisations to include people properly.

The establishment of a disability commissioner is a commitment to doing things differently—or, at least, it should be. There is no point in setting up a disability commissioner if that is not the case. Therefore, as Tomas described, it is hugely important that disabled people are fully involved in the process. That brings us back to the question of resource. In order that the process is done properly, it needs to be properly resourced.

In addition, the process needs to be given time, and we must realise that it will take time. We will not necessarily see an impact in six months or 12 months, because it will take time to engage with different communities and different people and to develop the role. Therefore, we need to make sure that everyone approaches the process with their eyes open.

The Convener: Thank you. I do not think that anyone else would like to comment. Annie, have you finished your questions?

Annie Wells: I have, thank you. Sorry about the technology at this end.

The Convener: Thank you. I have just one more question. Is there anyone whom our witnesses feel that the committee would benefit from hearing from?

Amy Dalrymple: I know that the committee has spoken to a number of disabled people's organisations, but, rather than asking people to come in to speak to you, perhaps you could go out to speak to people where they are. I do not know whether you have done that. There are people who might find it difficult to come to the Parliament in Edinburgh and speak in a committee room environment but who have a strong interest in the outcome of your deliberative process.

The Convener: That is helpful. Thank you.

I thank everyone for their participation today. That brings our questions to an end. We now move into private session to consider the remaining two items on our agenda.

11:22

Meeting continued in private until 11:38.

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