

Equalities, Human Rights and Civil Justice Committee

Disability Commissioner (Scotland) Bill engagement session

Online session - 10 September 2024

5 participants including support orgs, Maggie Chapman MSP

Participant 1

Disparity between those living in the central belt and those living with a disability in rural area. Glasgow and Edinburgh and central belt services are much better.

Participant 2

Came to Oban in 1997 and there was a lot of support from the Scottish Government for disabled people. That was a positive and wanted to highlight that. At the moment one of the things that we want to drive forward is braille labelling on food. It is simple to put in place but incredibly difficult to achieve. We need more proactive activity to achieve this.

We have braille labelling on pharmaceuticals, and it has made a huge difference. The coop has done it and we would like to see it elsewhere.

We have a parliamentary petition that is going to be reviewed on the 25th of this month. We have had positivity from the committee and are moving forward with it. Hoping that there will be positivity from the committee.

Everyone's needs are different.

Maggie – what are the experiences for disabled people?

Participant 3

I have worked with people with cerebral palsy and learning disabilities on the education side. We have made progress as time went on. We realised that people can be educated and have talked about empowerment and being able to be independent in the 80s and 90s. I was working with Scope in South Wales in a sheltered housing system which took couples as well as single people. They all had their own flats and there was a communal area. We helped people get out into the community and it was great to see that. I went on in Scotland but one part of it was people who have gone out in the community were coming from one stay hospitals - those with learning disabilities coming into the community for the first time. They were able to live in the community with support, making food and environment choices and about their living situation. They were able to get out. Social inclusion was improving. Am very sad now that some of this seems to have reversed. I am disabled and have had cerebral palsy all my life. I need support and still see some of the young people that I used to work with and I am sad that they are no longer supported the way they were before. They are just wandering around on the streets on their own. This is where we have backlogs in hospitals because of lack of resources and lack of understanding. When I started needing support it was great, they put a stairlift in my house and when this broke down after 11 years it could not be replaced, and social services decided that I could not use the upstairs and to come downstairs and only use the living room because I had a toilet downstairs. One social worker said "that is good enough for you, you don't need any more than that". There are other people who are suffering in this

way. I don't believe it's all lack of finance. It's about attitude and that feels like things have fallen off a cliff.

Maggie- Why has this happened? What about geographical equalities?

Participant 1

I'm from Lochaber and Fort William is the second biggest town and we have one daycare centre for an area of over 3000 square miles. Getting to a day care centre is impossible. We are suffering because we don't have social care providers, but transport is also an issue. We have gone backwards in the last 15 years in terms of transport. It's the worst I've ever seen it. There is too much dependency on charities. Tomorrow I'll be spending a day in the highlands. There are problems with mental health provision too.

On proposals for a commissioner – They were talking about introducing a czar. Is this all going to be based in the central belt? Are they going to experience travelling the country like a disabled person does? You have to be careful when employing a disabled person if that is what is going to happen as they would invariably focus on their own disability. Would they be independent or a shield for the MSPs? I think it could be another potential barrier.

Maggie – Do others have the same concerns?

Participant 2

One thing that I value about the access panel is it stabilises things as you have to be involved in things that affect a whole cross section of disabled people. I hope the Scottish Government will continue to support Inclusion Scotland and other groups as they can support work that needs to be done. Transport in a rural area is difficult. Some of the situations are almost unavoidable as it can be difficult to support them as we don't have the people there. Bodies who work for disability and have contact with SG. I hope SG will sustain funding. We need the groups to fly the flag.

Participant 3

I don't think that it is always the case that the people who take these positions realise what disability is. We could put it into one as it is the way in which we are affected in society. We are all under the same umbrella in that sense. A good commissioner needs first to understand disability and go right back to disability awareness. We need good communication. Different local authorities do things differently. They interpret SDS legislation (self-directed support) differently. We need consistency. The money they get to use for disabled people should be ringfenced. There would need to be good communication between the commissioner and the local authorities. Let's have someone and maybe someone who is disabled but that is not the most important thing. We need someone on our side. We feel like we are at the bottom, and we feel we get the crumbs at the bottom once all the other spending takes place. People can get £15 an hour working for Tesco and get much less working as a carer so they may be good people but the cost of living crisis means they are going to take those better paid jobs.

Participant 1

It is harder now getting SDS. Social work is a mess with SDS. It is a postcode lottery if you have a speech and language problem in the Highlands. Too many of these things are box ticking. It would have taken me two days to come to Edinburgh to attend this live. You are speaking to volunteers here.

Participant 2

Communication is a major problem. Good communication is the basis for any success and is key. It is very difficult. This is where Disability Equality Scotland, Glasgow Alliance, Inclusion Scotland and others do provide assistance as they are communicators and that's what we need.

Participant 1

There must be practical action taken too. All we do is speak.

Maggie – I hear your frustration and anger and that we can't just keep doing this we need practical action

Participant 4

Our members' view on our research encapsulates the challenges. "We need a voice to tell the government about all the problems we face and we are not second class citizens. We cannot be impulsive. We have to plan our days." It is not just transport and bullying. The scope of disability is huge. The original consultation that was issued by the Member was only available in word so it almost failed at the first hurdle by not being accessible.

Participant 1

On Scottish Adult Disability Payment – none of the detail needed that is included in the form relates to mental health and invisible disabilities. It asks the wrong questions. There are lots of issues there. The system is highly flawed.

Maggie - Would having a disability commissioner unpick that?

Participant 1

It depends on the remit and what powers he/she is given. It's like having commissions - the remit can be broad and cost a lot of money but it doesn't change anything.

Maggie – Is there something that we could do to support disabled people -social care, transport, housing. You've all talked about the need for understanding of the different needs of disabled people.

Participant 3

I'm not sure we do need to be hear more from people. We have done this for a long time and it doesn't really help. Instead of a commissioner, we need 3 or 4 people working with that person and could network out from that. Instead of having a commissioner sitting in a computer. The 3 or 4 people around him could link in with the reps from each service user. That would bring people with disability a better voice and bring better disability awareness. Representing different groups – eg people with dementia and those in hospital who are there for too long. That would be more effective than just one commissioner.

Participant 2

For something to work there has to be a robust structure or it quickly disintegrates. What that needs to look like would require some thought. We shouldn't ignore that we need a structure. I think that various bodies giving support is a good structural start. We have dozens of charities and I'm often not sure if we wouldn't be better if there were fewer as there is some overlap. If somehow we could have clarity about what each section and then if you had a problem you could go to a particular place. For example, there is a lot of overlap with charities supporting the blind – I am totally blind. With a bit of thought, they could do this better. In Australia, they have one charity for sight loss and they have

different areas within that. I don't know if that works or not, but we should look at all the options.

Participant 4

LDAN bill - do we need a separate commissioner for every disability or can these things be brought together under one banner?

Participant 1

That bill had good intentions but was never going to work. A person with autism going to school can be the most disruptive person in the class due to no-one picking up the trigger points being displayed. How can you have autism pupil not be considered to have a learning disability as you are not able to learn. Parents and carers are fobbed off. Sometimes they only get support when a charity representative comes to the meetings with them. There should be a cradle to grave policy introduced. Nurseries should have programme for autistic children which follows the individual throughout their education and beyond. The current transition process is a farce. The parents are not being listened to even though they know their child the best. Disabled groups are also often all fighting for the same fund.

Participant 2

We need coordinators. This used to be the role of the GP. A lot of problems occur as we are too far down the line before someone is referred or on track to where they need to go. GPs were ideally positioned for this. The lack of coordination is a big issue.

Participant 3

We need to sort out the barriers. Some well-meaning social workers are visiting people are communicating people's needs and they can't get approval for what is needed from higher up – from COSLA. I wish we could turn it around and mend it. I would like to change the attitude in hospitals I have angina and a bad heart and had to go into acute assessment day centre and had to sit there for 7 hours. People with a disability are not treated very well not just in hospitals but in other places as well.

Participant 1

Previously, I told my clients to go to their GP for a letter of support for applying for a blue badge, PIP, and attendance allowance but GPs are now refusing to do it. People are sending away a form without medical evidence. The council then need to get in touch with the GP with a 10 page form when a simple GP letter would do. This causes problems for clients' claims.

Instead of a disability commissioner we should have a disability minister with powers (other participants were in agreement). We need more sessions like these where we can openly discuss things and know it will go back to where it needs to. This meeting has felt prominent and like it going somewhere. We are grateful for the opportunity to participate. Every disabled person is an individual and we must remember that.

We would be happy to join any future meetings.