Our Rights, Right Now

Inclusion Scotland's Annual Conference 2021

A short report about disabled people's lived experience and why we need our rights, right now

Inclusion Scotland
Disabled People's Organisation
Our voices ■ Our choices
www.inclusionscotland.org

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Inclusion Scotland is Scotland's national Disabled People's Organisation. Our Rights, Right Now online Annual Conference (28 October 2021) brought together disabled people and Disabled People's Organisations from across Scotland to learn, to connect and to share both experiences and solutions.

This short report calls attention to disabled people's everyday lived experiences shared at the Conference. Disabled people spoke about their denial of rights to support services, problems with structures and institutions and their cultures, barriers for those who live in rural areas, and about the barriers caused by the Covid pandemic and the actions taken to address it that continue to hamper everyday living. Many attendees raised intersectional barriers – where they experienced inequality due to one or more protected characteristic

> As one person said,
>
> **"Rights don't count - rights just don't count now."**

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Our Rights, Right Now

Inclusion Scotland's Our Rights, Right Now Conference reaffirmed what we already know – as disabled people we do not have access to our human rights to enable us to fully participate in society. The conference called out for Our Rights to be the rights we enjoy Right Now.

Us disabled people have waited too long to enjoy the rights afforded to others. We are going through the pandemic like everyone else but the impact of it - and the actions being taken to tackle it - disproportionately strips us of so many of our rights and still 'supercharges'[1] the inequalities we have faced for years.

Lots of people think that we are 'getting there' with Covid but that is not a view shared by many disabled people. The essential support many people lost at the start of lockdown has not yet been reinstated everywhere. Some disabled people are still shielding despite this no longer being part of the national Covid response, because they know best what the huge risks to themselves. There is little understanding of this in wider society.

Right Now because Scottish Government has plans to enact a new Scottish Human Rights law. This is a vital opportunity to put things right and pave the way for disabled people to participate fully throughout Scottish society.

We have been telling legislators, policy and decision makers and service providers about the barriers that disable us and what the solutions are for years. The time for change is now.

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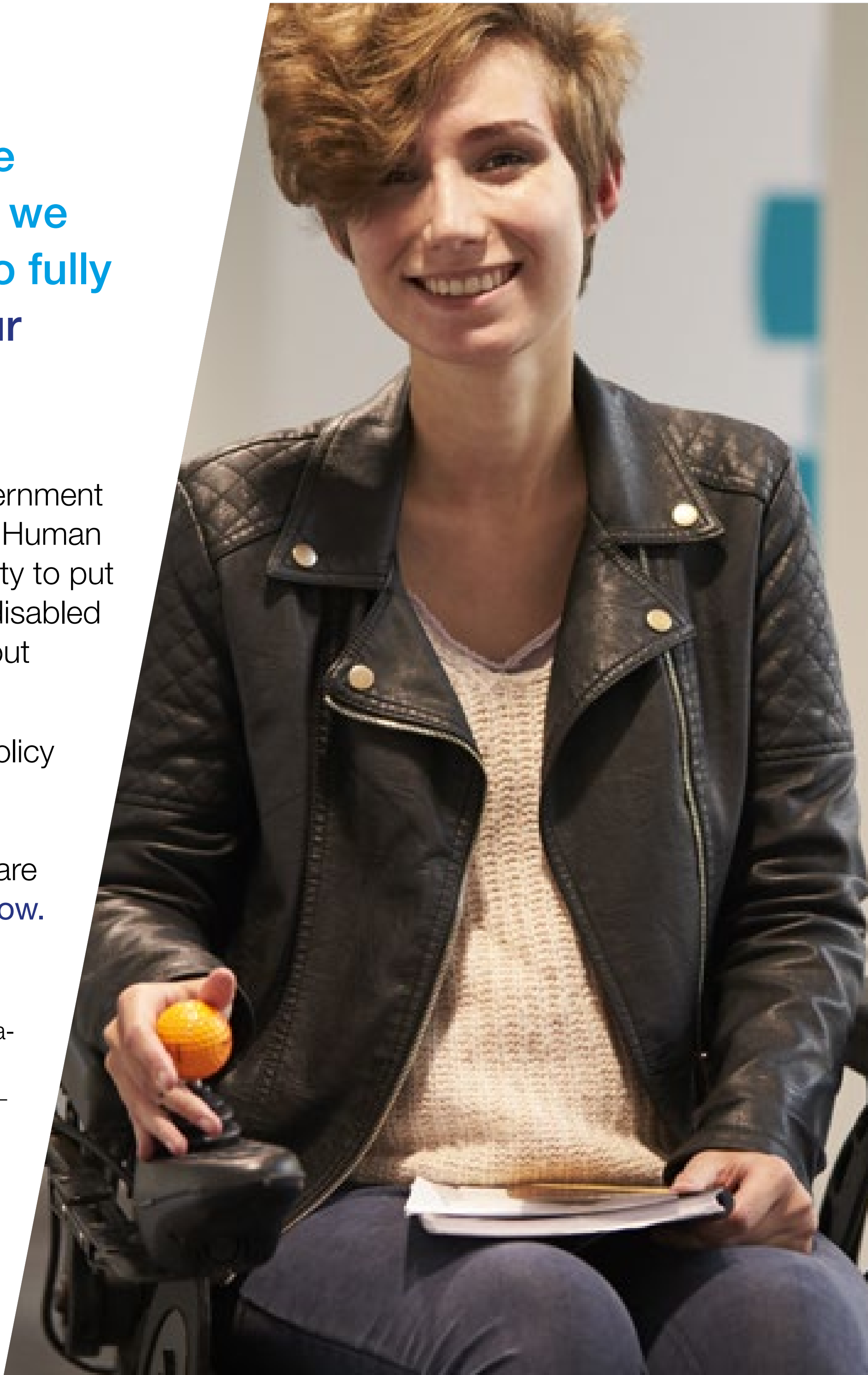
[1] https://gda.scot/resources/supercharged-a-human-catastrophe-summary-report/



Participation

Disabled people’s participation, based on our expertise gained through actual lived-experience, needs to be front and centre of policy and decision making – not only for things that are specifically about disabled people, but in all decisions that affects us and society.

#NothingAboutUsWithoutUs For this to be achieved policy and decision makers and service providers need greater understanding that our lives are complicated, and we are not just disabled people. Our rights **“are indivisible, and you can’t meet one right without meeting others.”** We are employers, employees, learners, parents, carers and we live in different parts of the country and are more likely to be living in poverty, and with higher daily costs to meet.

Policy and decision makers and service providers already have the best resource possible to inform policy making and service delivery and get things right - Scotland’s disabled people. We know what is needed and we know what works and what does not work. Public services need to make our participation possible and provide the right support so that we can contribute and lead, including enabling required communication such as Easy Read and British Sign Language and equipping staff with the resources and the right knowledge and training.

For example, without engaging with disabled people, many towns and cities relaxed policies about street furniture as lockdown eased to support the hospitality industry. This has had a significant impact by making town centres – and all the services and opportunities that happen there - virtual no-go areas for many disabled people.

The pandemic is still an emergency. Scotland needs to learn the lessons from what happened – and is still happening - to disabled people because we were not involved in planning the changes to address the emergency. In the future we will face other emergencies – like flooding and the other impacts of climate change, food shortages and recession, and other pandemics. Scotland must not make the same mistakes again; disabled people’s leadership and participation, based on our lived experience, must be embedded in emergency planning. One person with diabetes reported that they had to wait outside a healthcare building in the cold because of changes to the system, making it difficult for them to manage their condition.

Other people highlighted a lack of engagement and where engagement happened it ignored what was said. Disabled people have been sharing our lived experiences and our solutions for what needs to happen for years. Now, disabled people need to see action to tackle the barriers we are sharing.

Post code lottery

There is still a postcode lottery in Scotland. What a national policy says should happen and what happens in real life are two different things, and this can depend on where you live.

This is particularly true of social care support. Where you live determines what support you get and how you get it. Moreover, if you want to move to another local authority area, it is simply not that simple.

The proposed new National Care Service could change this. To do that disabled people say that it needs to take account of the differences between cities and rural areas. In rural areas, when a Personal Assistant or carer is unwell, there is much less or no back up available. Disabled people who live in rural areas spoke about how much harder it is for them to complain when things do not work. It is easier to be anonymous in cities and there is less risk of becoming viewed as a 'troublemaker' and risk having support delayed or stopped.

Mental health services vary depending on where you live and treatment has not been sustained in some areas. Demand is growing because of the impact of social isolation during the Covid pandemic. There is no access to counselling in some rural areas and a widespread lack of accessible support, many individuals are having to pay for support.

One person spoke about their experience during Covid and how where they lived had a devastating impact.

One person highlighted problems with the Scottish Welfare Fund which they applied to for support to pay for heating but living in a rural area their heating system runs on oil. They were refused that support because their heating system was not gas or electricity. Another person spoke about continuing high fuel bills because the power company had no-one available to read the meter for them.

> **"I lost approximately 3 stone in weight during lockdown and had a shielding letter telling me I could get priority delivery slots from several different supermarkets. However, those supermarkets (which are a 200+ mile round trip from me) don't deliver to homes here. One does click and collect but their computer system only allows priority slots to be booked for home delivery not for Click and Collect."**

Cuts, cuts and more cuts

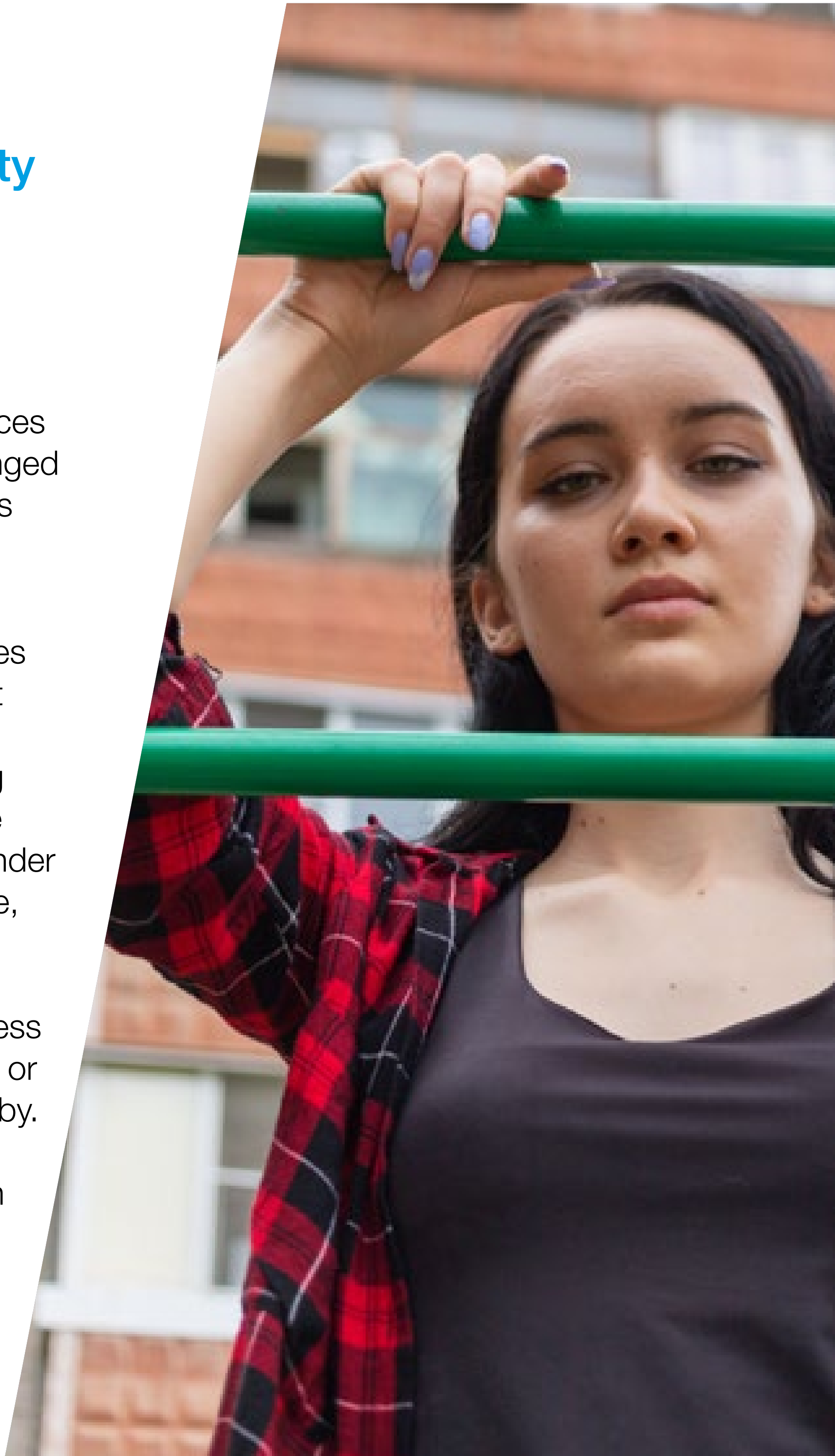
For years, disabled people have borne the brunt of austerity and Welfare 'Reform', and cuts to public services which provide essential support.

Disabled people spoke about the ever-deepening impact of these cuts and how this has led to a reduction in essential support. Social care support, reduced over and over, was cut again because of the Covid pandemic and has still not been fully reinstated. One person spoke about being a carer for elderly parents who were admitted to hospital and their care package was removed and not returned when they were well enough to be discharged. They are now stuck in a community hospital.

Some people spoke about being pushed back into going out to work despite the risks to their own lives and those they live with or care for. Getting there, or to other places, on public transport is also seen as a risk and services have been cut. People are being forced to use costly taxi services to get about.

One person spoke about continuing cuts to funding for British Sign Language which meant that the right support was not in place when needed to access vital services and support. Others spoke about prolonged waits for different kinds of health services including access to ongoing treatment including for cancer.

Demand for scarce mental health services is growing rapidly because of the impact of the Covid pandemic. Disabled people need access to these services, including those who did not need them before the Covid pandemic. Disabled people are under tremendous stress due to loss of income, risks to employment, and lack of social care support. They are more likely to be carers themselves with all the added stress this brings when support is non-existent or haphazard and extremely hard to come by. Recreational and respite opportunities are diminished, and anxiety and isolation are affecting disabled people's mental health profoundly.



Lost in the system

Organisations and systems that exist to support us should never be a source of more barriers to our rights. Yet their structures, cultures, attitudes, and processes can all contrive to do just that.

A recruitment drive for social care staff, someone reported, said that applicants needed no qualifications which **"sends out the wrong message"** and does not take account of the skills required, the workforce or on the job training. Carers and Personal Assistants come into people's private homes and lives to carry out difficult tasks. There needs to be **"a re-evaluation of the idea that Personal Assistants are just an expense"** given that they are an essential support for disabled people to contribute to society. It was noted by one participant that attitudes towards carers and personal assistants as a career in this country are very different to experiences in other places where it is a highly respected profession.

People also spoke about what should be happening and what is really happening - **"The Self-Directed Support Act was very clear but Local Authorities didn't implement it properly."** Disabled people are given a set budget by their Local Authority to employ their own staff, but they find themselves in competition with Local Authorities who can pay better wages.

Many services increasingly rely on people having ready access to digital capacity, including for essential services such as social security and health services, such as appointments for vaccines or to see a GP. Digital options can be inaccessible, and many disabled people simply do not have the financial means to buy the equipment or pay for Wi-Fi. One person spoke about being refused permission by their housing association to install a decent internet connection to access the support they require.

An advocate spoke about trying to support a disabled person in court and being told by a judge to 'be quiet', and about how disabled inmates are worse off than others in the criminal justice system, sometimes being sent to a more accessible facility hundreds of miles away, but in the process isolating them from family and other visitors.

Even some charities and community groups, who used funding to respond quickly to the Covid pandemic and the need for essentials such as access to food, did not think about disabled people. One person shared an example of a food distribution point which was housed in an inaccessible container unit.

Many services simply do not understand disability or disabled people's lives and rights. This prevailing culture and the lack of knowledge is an enduring problem. One person spoke about how there is little understanding of Deaf culture throughout social work, and that there is little being done to address this. Another spoke about being suspended from their gym for trying to enforce boundaries around Covid. There was evidence of abuse and victimisation for things like not wearing a mask even though they were exempt, or for people who are not visibly disabled using accessible parking bays – whilst these are not new things the consensus was that it has been **"ramped up."**

People also spoke about individuals working in different sectors who were supportive and understanding of adjustments needed, but sometimes hampered by the policies and processes in their own organisation.

Our final message is not a new one

Scotland's policy and decision makers and service providers need to listen to disabled people's voices, act on the solutions and **"stop the tokenism"**, and more disabled people should be in decision making positions to make this a reality.

Work with us, Scotland's disabled people, towards change to remove the barriers we are hindered by every day so that we enjoy our rights and participate fully and equally in our communities.

Inclusion Scotland is a ‘Disabled People’s Organisation’ (DPO) – led by disabled people ourselves. Inclusion Scotland works to achieve positive changes to policy and practice, so that we disabled people are fully included throughout all Scottish society as equal citizens.

See our website at www.inclusionscotland.org

You can become a member of Inclusion Scotland by visiting our membership page. Membership is free and open to disabled people, disabled people’s organisations and our supporters.

www.inclusionscotland.org/become-a-member

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www.inclusionscotland.org

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