



Activate

**Young disabled
people's issues and
activism in Scotland**

A report about Activate:
Scotland's Disabled
People's Annual Summit

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ABOUT THIS REPORT

This is a report about the issues faced by young disabled people in Scotland, and about their activism for change.

It is for change-makers; policy and decision-makers and those who can influence them, and young disabled people themselves. It talks about the issues raised by young disabled people at Scotland's Annual Disabled People's Summit in 2018, Activate, which aimed to give space to young disabled people to talk about their lives and about activism, as well as the 'how to'.

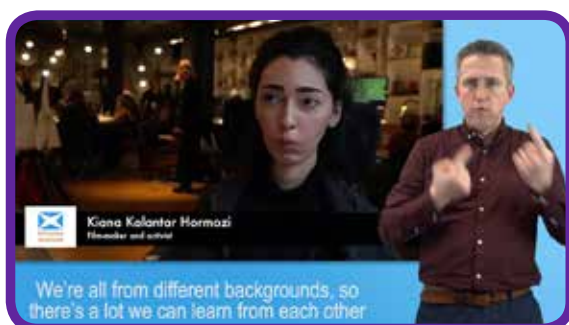
At Activate, many young disabled people stressed that being part of a movement and being included in events organised by Disabled People's Organisations is key to them feeling a positive sense of identity.



"It is coming to events like this that makes me feel proud to be disabled. Sometimes I keep quiet about being disabled in other settings because I can't be bothered to deal with other people's reactions to it. Here I felt safe and confident. So often I am on the outside of things, it's so nice to be at the centre of something, it's really affirming."

Many young disabled people want to engage with change-makers and to lead the changes which need to happen. Throughout this report you can see messages from young disabled people about activism – their hopes for change and the issues they have as disabled people wanting to campaign.

You can also view a short film featuring young disabled people at Activate speaking about the issues they face and what activism means to them. The film has British Sign Language and subtitles and is available at www.inclusionScotland.org



ABOUT ACTIVATE

Held to mark Scotland's Year of Young People and the International Day for Disabled People, Activate: Scotland's Young Disabled People 2018 was an opportunity for young disabled people to speak about what matters most to them, what barriers they face in their everyday lives and what issues they want to take action on. It had a focus on both the concept of activism and the 'how to'.

Inclusion Scotland co-produced Activate with a group of young disabled people. They wanted a supportive, accessible inclusive space to connect with each other, to learn about activism and how to make change happen. They were clear that they did not want an old-style conference but wanted to hear from people who were activists and campaigners in Scotland about how they themselves had achieved positive change for marginalised groups. Activate was about creating a space that young disabled people wanted. It was accessible, it was held in a pretty stylish hotel and it was rounded off with pizza and a wee gig of comedy and music.

As one member of the co-production group put it:

"We didn't want [to be] 'talked at' – it needed to be a comfortable space where we could connect and laugh, where we can come together and feel confident to discuss our own lives and our ideas for change."

With this in mind the Activate programme included the following:

Eight successful anti-discrimination and anti-prejudice activists and campaigners were 'books' in the living library, lending themselves out to young disabled people to ask questions about their experiences of activism and campaigning and to test out their own ideas.

Then, to put these ideas into action, Robert McGeachy, an experienced public affairs professional, ran a workshop on campaign planning. This explored how to move from raising awareness about an issue to actually getting elected representatives and other decision-makers to act.

Social media is fundamental to how young people organise, share stories and take action for change. The BBC's 'The Social', a digital platform for young people, led a social media workshop about sharing content online. Shortly after, Activate followed up with a workshop to help young disabled people create content for 'The Social'.

ABOUT ACTIVATE CONTINUED

There is no recognised symbol for disabled people to link up under and to use to promote a community identity, akin to the rainbow flag of the Lesbian Gay Bisexual Transgender Queer and Intersex (LCBTQI) community. Design company Traffic led a group that started work on designing an emblem for young disabled people's activism.

Helen De Main ran consciousness-raising discussions where young people were able to discuss what mattered most to them as young disabled people, the barriers they faced in their everyday lives and their own priorities for change.

Being comfortable with all parts of their identity is a particular challenge for young disabled people and can take time, making it all the more important that policy and decision-makers work in a way that explicitly respects disabled young people's multiple identities, champions the civic and political rights of other marginalised groups in society and involves young disabled people in challenging intersectional discrimination.

"I'm not just a disabled person, I'm a woman and I'm gay, each layer of my identity affects what causes I choose to support and which campaigns I want to be part of. The wider social justice and feminist movements need to make sure they are involving young disabled people and are accessible for all."

In a 'chat with the Chief' in the afternoon Chloe Whyte, a member of the Scottish Youth Parliament, quizzed Sally Witcher, our Chief Executive, about her own experiences of activism and why young disabled people should get involved with the work of Inclusion Scotland and what Inclusion Scotland needs to do to engage with a younger audience.

To keep the day interesting and lighten the space between conversations, Activate was MC'd by Rosie Jones, a well-known stand-up comedian, herself a disabled person.

"I don't speak for all disabled people, and we all come from a whole different place but for me, I love my disability because it makes me who I am and I don't know who I would be without it. So, when people patronise me, I don't get it, it's like me saying to a non-disabled person: "Ooh, bless you...you can't fly!"



ABOUT ACTIVATE CONTINUED

Eight successful anti-discrimination and anti-prejudice activists and campaigners were 'books' in the living library, lending themselves out to young disabled people to ask questions about their experiences of activism and campaigning and to test out their own ideas.



Book 1

Amal Azzudin
Mental Health Foundation and
Glasgow girl activist

Amal Azzudin is a campaigner for human rights and social justice in Scotland. She is the Human Rights and Equalities officer (refugees) at the Mental Health Foundation.



Book 2

Kiana Kalantar-Hormozi –
young disabled film maker
and activist

Kiana is 25 and ambitious: a graduate filmmaker, semi-pro rapper, and aspiring to live in a boat someday so she can go on endless adventures.



Book 3

Zara Todd
- Project Scotland

Zara Todd is a disability right activist and campaigner who started campaigning at the age of 10! Zara is a human rights educator and specialises in supporting young people, women and disabled people in having a say in policy and decision making.



Book 4

Colette Walker
- The Parliament Project

As a disabled woman who has brought up a disabled child, now a 17 year young adult Colette has been a lone parent for last 15 years. She had to give up her career firstly to look after her son, relying on social security.

ABOUT ACTIVATE CONTINUED



Book 5

Allan Lindsay
– Young Scot

Allan Lindsay is the Participation and Co-design Director at Young Scot, Scotland's National Youth Information and Citizenship Charity. Young Scot works with young people ages 11-26 across Scotland, providing them with information, ideas and access to opportunities to help them make the most of their lives, particularly at times of transition.



Book 6

Marianne Scobie
– Glasgow Disability Alliance

Marianne has been a disabled person since the age of 7. She is Depute CEO of Glasgow Disability Alliance (GDA) and strategic lead for their programmes supporting young disabled people. Marianne was a founder member of GDA before joining the team in 2010.



Book 7

Jamie Szymkowiak
– One in Five

Jamie Szymkowiak is a successful disability rights campaigner who also writes children's books.



Book 8

Alys Mumford
– Engender

Alys works for feminist organisation Engender. Engender is a policy organisation, pushing for the Scottish Government to make changes to improve the lives of women and girls in Scotland.

THE ISSUES

The issues raised at Activate reflect the everyday lived experience of young disabled people. Rather than set up an event to explore policies, Activate centred on people's lives as they happen.

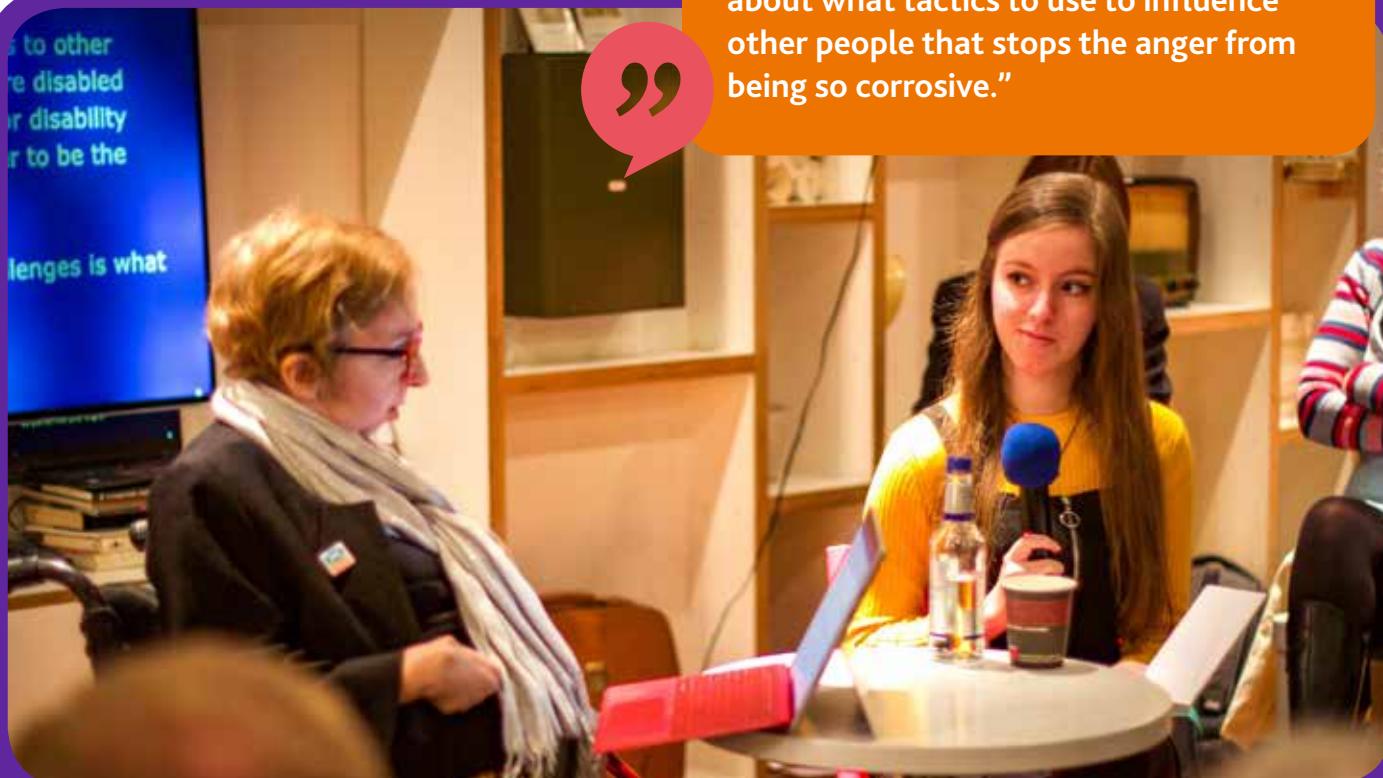
It is possible to see the interaction between these and the accumulative barriers. Many of the policy issues referred to below do not apply exclusively to young disabled people. However they are often developed without taking account of young disabled people's own voices of lived experience. Too often, the consequence of this for young disabled people is exclusion, stigmatisation and lack of opportunity at a pivotal time of life. This section tells you about the issues raised by young disabled people at Activate. It briefly explores parts of the most relevant current policy landscape and suggests what changes needs to happen.

Getting involved in activism was thought by some participants at Activate to be a healthy way of channelling the anger felt by young disabled people.

"One of the biggest challenges for disabled people and our young people in particular, is what do you do with your anger? How do you take that anger, which most disabled people have, that passion for change, and channel it in ways that are going to be effective in making changes? It's that judgment about what tactics to use to influence other people that stops the anger from being so corrosive."

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IDENTITY

Young people talked at length about 'coming to terms' with their identity as disabled people and 'finding their place' in society in Scotland, which one young person described as a 'minefield'.

'It took me a long time to feel comfortable talking about myself as a disabled person and still I sometimes miss that bit out when I'm describing myself.'

Young disabled people with hidden impairments were particularly vocal about the fragility of their identity as disabled people.

"I can "pass" as a non-disabled person but also have a role in the disability community. Sometimes I feel like I'm trapped between the two sides. There shouldn't be sides. That's why what matters to me the most is raising awareness of those with invisible impairments because so often their experiences are ignored."

This feeling of being ignored, particularly common amongst young people with hidden impairments, impacted significantly on their feelings of self-worth.

"I was eventually diagnosed as autistic, I have spent my whole life feeling different ...but I now finally feel comfortable with my identity and now it makes sense and I can come off medication for anxiety issues that I no longer have. It was those years of being ignored and being treated differently that really took their toll."

Young people with more visible impairments described having little choice about how they presented themselves to the world.

"As a person with a visual impairment, I am "boxed up" as a "blind person", with other people's ideas of what that means and what they think I can't do...I have no choice about whether to tell people or not."

Whilst identifying as disabled people was not without its complications for young people, looking at the world through the lens of the social model of disability gives young disabled people a sense of pride, community and a positive sense of identity.

The social model was developed by disabled people and it is supported by organisations led by disabled people. It says disability is caused by barriers that arise because society is not designed to accommodate people who have impairments. It is these barriers that disable people who have impairments. They stop us from being included in society and participating on an equal basis. If these barriers are removed, a person may still have an impairment but would not experience disability. Barriers could be environmental, organisational, attitudinal or organisational. None of these barriers are inevitable.

IDENTITY CONTINUED

Challenging the traditional view of disability as a medical or personal 'tragedy', it is clear that the social model and the choice to define oneself as a disabled person has supported some young disabled people to understand that it is not their impairment that disables them, but the way society is organised to take little or no account of their impairments.

"When I describe myself as a disabled person rather than a person with a disability, I feel part of a community. It seems like a small change in language to a non-disabled person, but it is a big thing really. It's important to feel that we are part of a movement, and that we're not facing barriers on our own."

Coming to feel proud of multiple identities however took some time for some young disabled people, as Rosie Jones herself explained:

"As a young person I struggled to find my place and how I fitted into society, but now I embrace my labels. As a teenager, I never came to terms with my sexuality because I was too busy coming to terms with my disability and how that would affect my life. I was too bothered learning about how to make pasta with a wobbly hand. I couldn't be bothered with shagging!"

An experience that resonated with many young people was described by one young person as 'living in two separate worlds' – one world where the impacts of their impairment (visible or not) are deliberately emphasised to obtain benefits, receive a diagnosis, or during a SEN assessment for example, whereas in other situations those impacts are actively underplayed – in their social life, or when trying to access employment for example. These two contrary positions lead to a form of cognitive dissonance for young disabled people which they described as 'confusing' and 'depressing'.

For some young people, other people's reaction to their identity as a disabled person created a deep sense of frustration:

"I get fed up with being the token disabled person expected to know all about all sorts of impairments. I haven't told my current employer that I'm disabled, I just couldn't be bothered to deal with the fall-out. It can be very tiring."

For others their feelings of unease with their own identity have impacted on their ability to request and receive the support they need:

"I don't always feel comfortable identifying myself as a disabled person, particularly when applying for employment or registering with events. I actually do need support to travel sometimes and PA support at events is crucial, but I don't always feel comfortable asking for it."

BULLYING AND POOR EXPERIENCES AT SCHOOL

Most of the delegates at Activate described bullying and exclusion as an 'everyday' experience at school. Sometimes the impact was so severe that young people had left school early. Bullying took place in and outside the classroom, on the way to and from school, as well as online.

"I was asked to go to particular areas of the library to stay away from "trouble" – it always felt as though it was me that had to change my behaviour rather than the school actually tackling the problem."

"I was bullied a lot when I was young. Bullies don't understand hate is learnt, really important to break down those barriers."

"It was every day, name-calling, insults, and remarks about my family. It got so bad I left school early."

A number of young people described a lack of support for alternative methods of schooling, which they considered vital for some young disabled people.

"A lot of us just don't fit the current school model or it is not working for us, we need to make sure young disabled people who home-school get the support they need."

A number of young disabled people at Activate described a sense of belonging when they had got involved in activism and a feeling that they were more in control rather than passive subjects in their own lives.

"Campaigning about the care tax has provided me with a channel to make my voice heard on a whole range of other issues. I have spoken publicly about sex and relationships and the do's and don'ts about communicating with disabled people, I now have a profile within the community that I didn't have before and I feel more in control of my life."

"If we recognise that it is social barriers that disable us, we may have different impairments but we can come together in a collective movement for social change."

BULLYING AND POOR EXPERIENCES AT SCHOOL CONTINUED

The policy context

Bullying at school can lead to low self-esteem, social isolation, anxiety, poor mental health, and self-harm or suicide. It impacts on school attendance and attainment, which in turn leads to reduced life chances for those who are bullied. In an online survey sent to all schools in Scotland in 2014, 30% of children aged between eight and 19 years reported they had experienced bullying since the start of the school year¹.

Whilst there is not much evidence that is specific to Scotland, most of the evidence that does exist suggests disabled children are twice as likely to be bullied at school as non-disabled children. Recorded incidents of bullying in schools across Scotland are not necessarily an accurate reflection of what happens, as incidents are not being recorded in a way that denotes prejudice-based bullying, or data is kept in individual pupil records and is therefore not analysed in the round.

There is no specific statutory duty in Scotland to prevent, monitor, or proactively deal with bullying, although the social, emotional or behavioural needs which can arise from bullying may be considered as an additional support need if it is having an impact on the child or young person's learning.

The harassment provisions of the Equality Act 2010 do not protect pupils from harassment by other pupils, although the provisions on discrimination mean that schools have an obligation to ensure that bullying by pupils that is related to a protected characteristic is treated with the same level of seriousness as any other form of bullying. The Scottish Government has been keen to develop a consistent and uniform approach to recording and monitoring of bullying incidents.

Following the publication of Respect for All; The National Approach to Anti-Bullying for Scotland's Children and Young People in November 2017², the Scottish Government established a Working Group and guidance was published in 2018. However the Scottish Government currently has no plans for the numbers of bullying incidents to be collated at a national level³.

As a result of successful campaigning by the Time for Inclusive Education (TIE) campaign, there has been clear recognition across the political divide that high numbers of LGBTI young people experience homophobia, biphobia and transphobia while at school and a significant number of those attempt suicide. As a result of campaigning the Scottish Government announced that LGBTI themes would be embedded into the national curriculum in all public schools across Scotland⁴.

However, this has not been the case for disability-related bullying in schools. Young disabled people at Activate felt that disability-based bullying and harassment are under-reported in schools because there is no systematic recording in the school system.

What needs to change?

- 1. The Scottish Government's approach to anti-bullying must ensure that incidences of prejudice-based bullying are collated at a national level – and action is taken, with young disabled people, to address the issues highlighted.**
- 2. Given the prevalence of prejudice-based bullying against young disabled people in schools across Scotland, disability equality should be a part of the national curriculum in Scotland.**

SOCIAL SECURITY

Young disabled people described very negative experiences of the social security system. Common problems involved the inflexibility of the system, the stress caused by assessments and appeals and the financial and other difficulties experienced by young people when their claims were limited or refused.

"My experience of the benefits system has been pretty horrific and stressful. When I moved from DLA onto PIP the assessment was dreadful. I lost some of my support and I had to go through a lengthy appeal process. I did eventually get the support back but it took ages and I was really stressed out by it."

"Being assessed for PIP was terrible, I didn't get anything because they said I could manage fine. I am autistic, I have ME and I need support every day to travel safely. I'm now completely reliant on my mum whereas I'm 26 and I want an independent life and was hoping to get a PA."



SOCIAL SECURITY CONTINUED

The policy context

Under the terms of the Scotland Act 2016, 11 benefits will be devolved to the Scottish Government, including Personal Independence Payments. A Ministerial Statement in February 2019 explained the transfer plans⁵.

The Scottish Government are seeking to create a system of social security that will embed the values of dignity, fairness and respect. In line with these principles they set up the Social Security Experience Panels. The Experience Panels are made up of over 2,400 people who have experience of at least one of the benefits that are being devolved to Scotland. The Scottish Government works with panel members to inform key decisions in the design of social security.

Many people have described to the Scottish Government their dissatisfaction with the way in which assessments are currently organised by the UK Department of Works and Pensions. Experiences include people who have had to travel for hours to get to assessments, those who are too ill to leave the house being refused home assessments and people unavoidably missing their assessments being told they must start the entire application process again.

Significant attention has therefore been paid to trying to improve the assessment and application process for Scottish Disability Assistance benefits that will replace the PIP, Disability Living Allowance for children and Attendance Allowance for older people.

For example, the Scottish Government has stated that no one applying for devolved Social Security Benefits should have to be assessed by a private sector provider, and that all face-to-face assessments will be delivered by individuals employed by Social Security Scotland. These face-to-face assessments will only be required when there is no other practical way to make a decision about an individual's entitlement to assistance. People will be offered a choice of an appointment date and time that suits them and home visits will be available when they are required. There has also been an assurance that the application process for Disability Assistance will be inclusive and accessible.

What needs to change?

- 3 Further scrutiny is needed to ensure that the actual implementation process leads to improved experiences for young disabled people being assessed for PIP in Scotland.**
- 4 The design and scrutiny of policies and practices in relation to devolved powers to social security should involve young disabled people so that the particular issues they face, particularly during transitions from childhood to adulthood, are taken into account.**

TRANSPORT

Poor experiences of using public transport were an issue for many young disabled people at Activate. This included not being able to spontaneously travel because of the need to book assistance, having difficulties accessing priority seating and finding buses infrequent and inaccessible, particularly in rural areas.

"I'm reliant on the bus because I can't drive due to my visual impairment. It's so infrequent in my local area that I'm very dependent on getting lifts from my family – this makes looking for work and eventually accepting a job offer really difficult."

Young people with less visible impairments said they often find it difficult to access priority seating because of attitudinal barriers –

other passengers refuse to give up these seats. As one young person put it:

"Transport is a real nightmare for me. I have trouble using priority seating on buses and trains. I have ME and am sometimes extremely fatigued but because I don't always use a stick people have a go at me for using priority seating or just don't move for me to sit down."

The policy context

Work to develop Scotland's National Accessible Travel Framework (2016)⁶ revealed that disabled people are more likely than others to use a local bus service, yet around a third experienced difficulty doing so, largely due to infrequent services. Whilst most transport operators provide designated priority seats for use by elderly, disabled, pregnant women and those with injuries, there is no regulation to restrict the use of priority seats by others, and disabled people report not being able to use them at will.

One of the aims of the Framework is to ensure that disabled people feel comfortable and safe using public transport. This includes having suitable access to priority seating on trains and buses, and frequent and reliable services in both directions.

In 2017 this was repeatedly mentioned by disabled people with hidden impairments who tweeted about their experiences at the hashtag

#InvisiblyDisabledLooksLike⁷ – and described either being refused seats or feeling reluctant themselves to ask for a seat because of fears they would be refused.

What needs to change?

- 5. Work is needed to find solutions to the issues with priority seating. Signage for accessible toilets, in part due to the Grace's sign campaign now often include hidden impairments and the statement 'not all disabilities are visible' – this could form part of signage for priority seating on all public transport.**
- 6. Public transport providers should be charged with consulting with the communities they serve regarding frequency of services in inclusive and accessible ways so that disabled people's needs are taken into account. This should include work to engage with young people who may want to travel at particular times.**

HOUSING

A significant proportion of the young people at Activate face a lack of housing options due to financial barriers as a result of cuts to Housing Benefit/Local Housing Allowance for those under 35, compounded by a lack of accessible housing to rent.

"It's very difficult to find an accessible home to rent. I have been to numerous letting agents and they showed me some flats that really wouldn't have suited me, I couldn't even get into the kitchen in one of them and then they have all said they cannot help me any further."

Disabled people's housing options are also restricted by their lower income compared to non-disabled house-seekers. 2018's 'Is Scotland Fairer?' report by the Equality and Human Rights

Commission found that disabled people still earn less (15% less) than non-disabled people and that this gap has grown since their last report, and that disabled people are more likely to live in poverty⁸.

"I get so tired of thinking that I will never own my own home and as a young single person I really can't afford to move out of my parents' house. What I would get in benefits would not cover the rent for a private let in my local area. This is stopping me from having an independent life".

Many described activism as being vital to them making friendships and social connections that made them feel part of a community and not so isolated.

"When I posted about my experiences on public transport I connected with so many others who were in the same boat. I really felt like I wasn't on my own tackling this stuff."



HOUSING CONTINUED

The policy context

From January 2012 as part of the UK government's welfare cuts, the Shared Accommodation Rate (SAR) within Local Housing Allowance was extended to those under 35 years old, where as previously it had only applied to those under 25. Even if a young person under 35 years is not living in a shared house they will only receive Local Housing Allowance or Universal Credit housing costs at the rate they would be paid to rent a room in a shared house.

Some young disabled people at Activate said this was unfair because it failed to take account of disability. Housing options were restricted as they were unable to afford to leave the parental home or were struggling to afford single accommodation when living in shared accommodation was not possible for them for reasons related to their impairment.

The Shared Accommodation Rate has been problematic for all young people for many years with thousands across the UK having to top-slice their other income replacement benefits or their disability benefits to be able to afford accommodation that is not fully covered by Housing Benefit/Local Housing Allowance or Universal Credit.

Figures from the Department for Work and Pensions in 2012 showed that 67% of claimants on the shared room rate already had a shortfall on average of £29 per week when it was limited to the under-25s. Extending the rate to the under-35s meant an extra 88,000 young people across the UK were affected.⁹

Only young disabled people entitled to a Severe Disability Premium are exempt from the Shared Room Rate, yet young disabled people at Activate raised concerns about a lack of accessible and adapted shared housing for rent for those who do not meet the criteria for this exemption.

What needs to change?

- 7. The Scottish Government should commit to improving the design and space standards for all new-build housing in Scotland as one way of ensuring an adequate new supply of accessible housing across tenure.**
- 8. The Scottish Government needs to work with the lettings industry in Scotland to improve identification and marketing of accessible homes to let.**
- 9. The Scottish Government should consider options, such as discretionary housing payments (DHPs), for mitigating the Shared Accommodation Rate (SAR) for young disabled people who are not exempt on the grounds of disability.**

ADDITIONAL SUPPORT FOR LEARNING AND DIAGNOSIS

A medical diagnosis can be an essential gateway to support for young disabled people, particularly when applying for additional support for learning at school, college or university, without which they can be denied education. Despite this, many young people at Activate described their frustration with medical professionals when trying to obtain a diagnosis.

This delay in getting support had even resulted in a number of young people leaving school early.

"I left school early because I couldn't get the support I needed in the classroom. It was all based on diagnosis and I couldn't get one."

"I asked for an autism referral but no one listened – it took several more years to get the Autism diagnosis and so I didn't get the support I needed...at school. Having the formal diagnosis it's been very hard to have any changes. It's very important to find a different way to go about this, seeing the person and the support they need rather than the label which is the gateway to getting help."

Young disabled people described often having little time or energy left to campaign because of the multitude of everyday barriers they experienced as disabled people.

"After I have negotiated the benefits system, the social care system, the transport system and my university disability support system I am often exhausted. It's all I can do to sign an online petition. I have the passion, the experiences and the knowledge about what needs to change but having the time and the energy to get involved in campaigning can be another matter!"



ADDITIONAL SUPPORT FOR LEARNING AND DIAGNOSIS CONTINUED

The policy context

The Additional Support for Learning (ASL) system in Scotland is under strain. There is clear evidence that the number of pupils in Scotland with recorded additional support needs is growing at a time when resources are becoming ever more limited.

Figures from the annual Scottish Government Pupil Census indicate that between 2012 and 2018, the number of specialist teachers supporting those with Additional Support for Needs (ASN) decreased from 3,840 to 3,437, representing a new low. The figures also highlighted a fall in the number of specialist support staff in key categories such as behaviour support staff, where the number has dropped by 58 from 2012 (from 180 to 122) and by 43 in the number of educational psychologists (from 411 to 368)¹⁰.

The declining number of educational psychologists, an ageing learning support profession and a reduction in the number of classroom assistants across Scotland can make it very difficult for parents to get a proper assessment or diagnosis for a child or young person.

Meanwhile, the number of pupils identified with ASN rose from 118,034 in 2012 to 199,065 in 2018 – with the total now representing 28.7 per cent of Scottish pupils.¹¹

A strong theme of evidence from parents and teachers to a 2017 call for evidence by the Scottish Parliament's Education and Skills Committee was the gap between the experience envisaged for inclusive education and the actual experience of children with additional support needs. Again, the lack of resources for effective diagnosis and recognition was regularly cited as key issues in evidence.¹²

Unsurprisingly young disabled people reported harrowing experiences of trying to obtain a diagnosis

and getting the support they need to learn. What is particularly concerning is that two young people in a discussion group of nine at Activate reported that this had led them to leave school early.

There is considerable concern that problems with the current ASN system, including those explored above, are leading some commentators to cast doubt on the cornerstone of inclusion within education in Scotland – the 'presumption of mainstreaming'.

This concern has been heightened by the publication of new guidance by the Scottish Government about mainstreaming which has broadened the categories that exempt children from a mainstream education.¹³

Without parliamentary oversight of the progress of the implementation of mainstreaming, and a process of quality assurance, there is a real danger that an under-funded and under-resourced ASN system could erode the presumption of mainstreaming. This could directly impact on young disabled people's right to an inclusive education.

What needs to change?

10. Organisations that advocate for young disabled people within education in Scotland need to work collectively to investigate the impact of cuts to ASL provision across Scotland.
11. The Scottish Government should undertake a review of the Additional Support for Learning system in Scotland and make recommendations that lead to improved outcomes for disabled young people in mainstream education
12. Policy and decision-makers need to ensure that they engage with young disabled people in both mainstream and special schools as part of this review and be influenced by their views and experience. This engagement needs to be aside from their parents' views.

TRANSITIONS

To achieve their full potential and to reach their personal goals, young disabled people often require support in different areas of their lives, including the move from school or college, or the transfer from child to adult services. These may include: identifying and achieving participation in employment, education or training, managing welfare and housing changes, reviewing healthcare needs, or providing information and advocacy.

Young people at Activate talked about facing 'an abyss' when leaving school and/or when moving from child to adult services. Some talked about difficult and stressful transitions with little support for future planning, a climate of low expectations particularly in relation to gaining employment, and a feeling of 'falling off a cliff' when more rigid eligibility criteria for adult services led to a sudden reduction in support.

"Leaving school was really hard. It just felt like jumping off a cliff. Everything just stopped in terms of support and I have really struggled to find employment. I've had lots of interviews but then the inevitable rejections. I'm volunteering now for three days a week, which is great, but I'm worried it won't lead anywhere. I never felt I was supported to make any kind of plan for my future."

"I got a lot of therapy when I was younger, which suddenly stopped when I became an adult."

"I don't think my careers adviser really expected me to find a job. I want to work in policy but there was no advice or encouragement, it has been really hard to find my way since I left school."

"I want to be a teacher but because I am deaf and a BSL user, I've had so many negative reactions since leaving University and just can't get the communication support I need to start a PGSE at college. It's so frustrating."



TRANSITIONS CONTINUED

The policy context

The policy context of this issue is multifaceted, with a wide range of national and local policies impacting on transitions for young disabled people.

Research findings indicate that young disabled people can transition into a void or can be forced to rely on limited and inappropriate post-school options. It is also clear that more rigid eligibility criteria for adult services can lead to a tapering or a sudden reduction in support when young disabled people move to adult services.

In the Fairer Scotland for Disabled People delivery plan the Scottish Government committed to working with schools, local authorities, health and social care partnerships, further and higher education institutions and employers to improve the lives of young disabled people.¹⁴ This includes points of transition into all levels of education – primary, secondary further and higher-education – and employment. At present this effort appears to be limited to the production by Scottish Government of an information resource for families about rights and support for transitions.

What needs to change?

There is compelling evidence that suggests a climate of low expectations, reductions in support and poor planning for young disabled people leaving school or moving from child to adult services is extensive. This underlines the need for concrete action on this issue.

- 13. There may be scope to lobby for a new statutory duty on local authorities across Scotland to adequately plan for and monitor outcomes for young disabled people during transitions up until age 25 – akin to the extension in support provided to young care leavers in Scotland. New legislation in this regard is likely to garner cross-party support and would provide an opportunity for the Scottish Government to express a tangible commitment and ambition to transforming outcomes for young disabled people in Scotland.**

When describing this lack of energy or time a number of young people described the importance of campaigners making participation in campaigns as quick and easy as possible.

"I need it to be straightforward and simple – retweets or likes if possible, and if they want me to share my lived experience, that's fine, but provide me with a simple way of doing this and if I don't want to share my story publicly that shouldn't preclude me from getting involved."



EMPLOYMENT

Young disabled people at Activate described very poor experiences of trying to find work and some had experienced long periods of un/underemployment after leaving school or university. Many described inaccessible recruitment procedures and stigmatising interview practices and having to underplay the impact of their impairment and the need for workplace adjustments.

"I've been unemployed for quite a long time, just over a year, applying for jobs UK-wide. Getting to interviews has been a real challenge with transport and making sure the information on the application is in an accessible format. [Formatted] tables are tricky for a screen reader. I rely on sight-guided assistance to get a form completed which makes the whole process really time-consuming. Accessible information is vital – having different versions on the website ready to go without me having to request them."

"I have really struggled to find suitable employment and also I can't get access to benefits, which has caused a large level of stress. I don't want to disclose my impairment to an employer and my access needs are sometimes hard to meet. I am working now but I haven't told my employer that I am disabled, which is causing me anxiety and it's also been very hard to access therapy support. The issues are interconnected. I have found employment that doesn't exacerbate my health difficult too."

"I've had some horrible interviews. One person told me he thought I'd be "more disabled". I had all the experience and qualifications they were looking for but I didn't get the job."

A number of young people described the inflexibility of the benefits system when trying to move into temporary work, which is often the only work they can find as a young person:

"I want to be able to take up temporary work (which is all I'm offered) but I'm scared to because I'll lose my benefits. It's very hard to come off the benefits for a temp job in case you never get back onto them again."

Access to Work funding, which is provided by the Department of Works and Pensions (DWP), was described by one young person as a lengthy and difficult process. Throughout the assessment process there was no main contact person to discuss their claim with. A number of young people felt that Access to Work support should be made available to disabled people who are undertaking voluntary work:

"They should provide Access to Work even if you are not being paid. Voluntary work is really important if you are trying to get the experience you need for a paid job."

EMPLOYMENT CONTINUED

The policy context

At age 16, the aspirations of disabled and non-disabled young people are broadly the same. By 26, disabled people are more likely to be out of work than their non-disabled peers, and are three times more likely to feel hopeless and to agree that 'nothing I do makes any difference'.¹⁵

What happens in the intervening years that acts to destroy young disabled people's hopes and dreams?

One of the key barriers that young disabled people encounter that may result in them experiencing 'falling off a cliff' when leaving school (as described by one young person at Activate) is that seeking employment becomes much more difficult when young disabled people have few or no qualifications.

Children with Additional Support Needs (ASN) are six times as likely to leave school with no qualifications as children with no ASN. Only one in three (32%) of young people with an ASN leaves school with one or more Scottish Credit and Qualification Framework (SCQF) at Level 6 compared to two-thirds (65%) of those with no ASN. Having no, or far fewer, qualifications than their non-disabled peers puts young disabled people at a significant disadvantage in the modern labour market.

One year after leaving school those with impairment-related ASN are more than twice as likely to be unemployed/workless (18%) as those with no ASN (8%). Yet by age 19 things have not improved but actually got worse, as young people with impairments are three times more likely to be NEET (Not in Employment, Education or Training) than their non-disabled peers.¹⁶

There is no reasonable explanation as to why an individual with only sensory or physical impairment should not be attaining qualifications on an equal basis with their non-disabled classmates. However, the very fact that disabled people are less likely to end up in employment may mean that teachers fail to see the relevance of their gaining qualifications, leading to a failure of expectations.

The problem this creates is that those with little or no work experience they can put on a CV or job application are at a considerable disadvantage when applying for employment. Thus, early worklessness on leaving school that lasts for several years can all too easily become a permanent situation lasting throughout a disabled person's working life.

Disabled 16-24 year olds have the second lowest employment rate (43.2%) of any age group and the highest unemployment rate (20.8%); and are more than twice as likely to be unemployed as non-disabled 16-24 year olds.¹⁷

EMPLOYMENT CONTINUED

The policy context *continued*

What needs to change?

Improving labour market outcomes for disabled young people could therefore have a significant impact on reducing the disability employment gap. If young disabled people in Scotland aged 16-24 were equally as likely to be in work as non-disabled 16-24 year olds, this would achieve 10% of the employment increase required to halve the disability employment gap.

It is unclear at present however that all the specific needs of young disabled people are being adequately addressed in wider work by the Scottish Government to tackle youth unemployment. A recent example of a failure to join the dots is the proposed design of the Scottish Government's new Job Grant to help support young people aged 16-24. Despite a commitment in their employment action plan to ensure access for as many disabled young people as possible, young disabled people and Disabled People's Organisations were not involved in the initial development of the proposed Job Grant.

14. **Scottish Government and other statutory bodies, and those funded by them, should involve young disabled people and DPOs in the design of policies that purport to address the disability employment gap to ensure that the needs of young disabled people are explicitly recognised and addressed at the earliest stages of design.**
15. **In relation to tackling the issues raised about Access to Work the UK Government currently has no plans to extend eligibility to volunteering. There is therefore scope for UK-wide campaigning for an extension in this regard.**
16. **In addition, the Scottish Government should extend the scope of the £500,000 of new funding to provide support similar to Access to Work to disabled people undertaking work experience and work trials to cover volunteering.**

Young people were adamant that accessible social media had been revolutionary in terms of assisting disabled people to complain about poor services, share their lived experiences and collectively advocate for change but were insistent that campaigns need to be accessible to those who do not use social media.

"Social media has been a game-changer for us. If I get left on a platform because my booked assistance has failed to turn up I can tweet Scotrail directly. But we must make systems work for those who don't or cannot use social media."

COMMUNICATION SUPPORT

Being excluded from taking part in events and social and political activity because of a lack of communication support was a very common experience for young people at Activate.

"I have lots of issues with interpreters which excludes me from events. Three or four weeks before [an event] I can't get interpreters. I am excluded from events or meetings if people use interpreters who are not registered, so I don't get a good service which is another form of exclusion."

"Dumfries has a real lack of communication support and a lack of funding to bring in interpreters from outside areas. We need to raise awareness of these issues."

"I joined the Scottish Youth Parliament but there was a lack of communication support. This is a really big issue."

Pressures on a highly over-stretched pool of interpreters and communication support workers will very likely only increase as specialist settings like health, mental health and justice services become more inclusive for people with communication support needs, as envisioned by the Scottish Government.

There are only 70 British Sign Language/English Interpreters in Scotland registered with the Scottish Association of Sign Language Interpreters (SASLI) and a number of others registered elsewhere. They provide communication support to the estimated 12,500 Deaf BSL users in Scotland.¹⁸ Not all of those listed on a register are still active, and the same group of interpreters may be listed by several agencies. In rural areas

there can be a much more limited range of interpreters, not all qualified to interpret the range of things Deaf people might need in day-to-day life.

National Deaf Children's Society, Action on Hearing Loss and others have long campaigned for improved access to interpreters and communication support workers for young disabled people. However policy proposals are not explicitly tackling this issue at present. Whilst the Scottish Government's BSL Action Plan makes ambitious commitments to making services more inclusive to BSL users, it makes scant reference to increasing the pool of BSL interpreters in Scotland. It only commits the Scottish Government to 'review[ing] a range of current and on-going Scottish and UK evidence about the BSL/English interpreting landscape'.¹⁹

What needs to change?

17. The Scottish Government needs to commit to supporting an increase in the pool of BSL interpreters and communication support workers in Scotland.

YOUNG DISABLED PEOPLE AND ACTIVISM

Since the mid-1970s, disabled people of all ages in Scotland have been challenging marginalisation, isolation and discrimination, with individual and collective activism being an important part of finding radical solutions to the full inclusion of disabled people.

For some disabled people, activism conjures up images of mass protests, demonstrations and placards with strong political slogans. For others, activism might bring to mind certain viral campaigns, social movements or even simply signing a petition. What underpins all acts of activism, however, is more than simply standing against something. It is fundamentally about bringing change.

Centred on the self-organised movement of disabled people, the disabled people's Independent Living Movement has grown in Scotland, alongside Disabled People's Organisations (DPOs), because disabled people know that they are best placed to make decisions about their own lives. Put simply, in terms of policy and decision-making in Scotland, disabled people's rallying cry has long been 'nothing about us without us'.

This wish to be included from the start when policy is developed was present in all the discussions with young disabled people at Activate. Young people were very keen to tackle the barriers they experienced. As one young person explained:

"For me as a Deaf person, the barriers are access to communication support, access to interpreters for events, health appointments, job interviews – education – often being isolated and not having the proper support in a

classroom setting. That can only be addressed by having more Sign Language interpreters. So...I want to be part of the activism movement to improve access for Deaf and disabled people so we can live our lives in a way that is more accessible and not quite so stressful."

However, our work to co-produce Activate highlighted that there are some significant structural barriers to youth engagement with disabled young people by decision-makers in Scotland and a lack of formal support for young disabled people's activism.

There is currently no national youth wing aligned to a Disabled People's Organisation in Scotland, no recognised national network for engaging with disabled young people, no formalised mentoring scheme or national leadership programme for young disabled people and no recognised structure for nurturing and supporting their activism in Scotland.

This presented significant challenges when planning and delivering Activate, as there are few established methods for making direct contact with young disabled people in Scotland. We engaged with over 40 organisations who work with young people in Scotland but only a handful purported to specifically engage with young disabled people and even fewer were pan-impairment.

YOUNG DISABLED PEOPLE AND ACTIVISM

CONTINUED

In this context, meaningful co-production with young disabled people can be difficult for decision-makers, and for Disabled People's Organisations seeking to influence them. Unless there is specific funding for this process or job roles that involve inclusive youth work the outreach work required to make direct connections with young disabled people and build relationships of trust with them can be very resource intensive.

The positive response to Activate, whilst encouraging, made plain that events like it are extremely few and far between and many young disabled people in Scotland can feel extremely isolated, and as though the social barriers they experience must be tackled by them alone. As one young person said to us:

"This event has been amazing, it been overwhelming in the best way possible. I don't know what I was expecting to find but it's been incredibly welcoming and everyone's been so generous. It's just been so affirming to meet people who have the same problems as me. The biggest take away for me is that I am not alone. I know everyone feels at like that at some point in their life. But for the things that I'm dealing with, I struggle to find employment, I struggle with the idea that I will ever own my own house, and it's really felt like it's just been me, it's my issue and it's just such a relief that other people are fighting that battle as well."

From facing negative attitudes from others, experiencing bullying and isolation at school, struggling to get the right care and support, having difficulties getting the right communication support, facing a cliff-edge when moving from child to adult services, feeling socially isolated or struggling with getting into and on at work, we heard young disabled people at Activate describing everyday barriers that stopped them from living the lives they choose. They also said that coping with these everyday barriers gave them little time or energy for campaigning.

When stacked on top of the issues facing all young people in Scotland – unstable work, worries about identity, issues around sex and relationships, rising rents and austerity-driven cuts to services, it was clear that everyday discrimination and inequality is still leaving young disabled people in Scotland feeling disconnected and undervalued.

It was clear that work by Disabled People's Organisations in Scotland to suggest reforms to the social security and social care systems in Scotland, ensure improved access to affordable and accessible housing or improve access to transport for example is still of real relevance to young disabled people in terms of what matters most to them. There was also a strong collective desire and eagerness from young disabled to be part of this movement for change.

YOUNG DISABLED PEOPLE AND ACTIVISM

CONTINUED

Whilst the barriers young disabled people described at Activate were not new or particularly unique to them as young disabled people (as opposed to older disabled people), many described simply not having the emotional or financial resources to overcome barriers or work around them. As one young person explained:

"I don't have the money for taxis if the bus is inaccessible. I don't have a PA who can support me to fill out a job application form if the file is not readable for me. I don't have the support networks that older disabled people have developed to get them through...I'm young, I'm just starting out and I'm getting pretty bruised by it all to be honest."

Perhaps the key message from the whole event is just how important it is that policy-makers and decision-makers take into account what matters most to young disabled people, what they think needs to change and what is getting in the way of them reaching their full potential as equal citizens in Scotland.



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ABOUT INCLUSION

SCOTLAND

We are a registered charity governed by a board which is made up of a majority of disabled people. 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. Find out more about our approach and work by clicking here.

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

ABOUT ILIS

Independent Living in Scotland is Inclusion Scotland's developmental and innovation team.

ILiS works to develop innovative solutions to the barriers that disabled people encounter every day. ILiS organises the Disabled People's Annual Summits and produces the report.



Our voices ■ Our choices

ALTERNATIVE FORMATS

If you require a copy of this report in an alternative format please get in touch with us via the details below.

Please watch our accessible film of Activate at <https://inclusionscotland.org/>.



ABOUT SCOTLAND'S

DISABLED PEOPLE'S

ANNUAL SUMMITS

The Annual Summits are hosted by Inclusion Scotland to link disabled people, their lived experience and their solutions for change with policy and decision makers. They aim to gather the lived experience and solutions of disabled people to support the Scottish Government to deliver the ambitions in their Fairer Scotland for Disabled People: Delivery Plan. They also contribute to our reports to the United Nations Committee on the Convention on the Rights of Disabled People about the hindrance or progression of our rights by Governments.

You can learn more about Inclusion Scotland and our work for the UN Convention at www.inclusionscotland.org

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