A report by Disability Agenda Scotland (DAS) on what it means to have a disability in Scotland today
About DAS

Disability Agenda Scotland (DAS) is a coalition of six of the leading disability charities in Scotland. The members are Action on Hearing Loss Scotland, Capability Scotland, ENABLE Scotland, RNIB Scotland, SAMH (Scottish Association for Mental Health) and Sense Scotland. DAS works on the issues that are going to have the most impact on the one million disabled people living in Scotland.

Together our experience, expertise and interests cover physical disability, sensory impairment, learning disability, communication support needs and mental health. Working closely with the thousands of disabled children, young people and adults, families and carers involved with the member organisations, DAS aims to:

- Influence public policy and legislation to help disabled people and the people around them.
- Provide a forum for decision makers and influencers to obtain advice and information.
- Promote a better understanding of the diverse experiences, needs and aspirations of disabled people.

We believe it is our role to combine the lived-experience of our individual membership networks with our collective policy expertise to deliver effective, solution-focused, policy analysis to effect positive change with and for disabled people across Scotland.

“There is a lot of discrimination; we should be able to do the things other people do, like work, and that is not happening.”
Introduction

DAS is proud to present this report about what life is really like in Scotland today for disabled people. What you will read throughout this report are the real words of over 80 people who live in a variety of different areas, and who live with a variety of disabilities. The similarities in the experiences and concerns are striking.

As we developed our work plans, the DAS group felt that this should be guided by what our respective members, customers and service users were telling us about their lived experiences. We wanted to understand what would really make the difference to the lives of disabled people in Scotland, and then consider what actions we could take forward to lead towards a more equal society.

This is the summary of a longer report, which is available on our website (www.disabilityagenda.scot). The aims of this report are to identify and highlight key areas for improvement, with clear calls and recommendations. We do not believe we have outlined – nor did we intend to – all relevant policy issues or all areas for improvement. This is in order to focus on key calls, supported by direct input from disabled through focus groups, which will continue to inform DAS’ work and priorities and wider discussion and debate about Scottish and UK policy that affect disabled people in Scotland, and ensure positive change. The focus is mainly on Scottish policy, given the extent to which relevant matters are devolved but does also touch on reserved issues.

The policy and legislative context around equal opportunities for disabled people in Scotland is strong. There have been a number of recent policy initiatives focused on progressing this agenda, including the Fairer Scotland Action Plan, the accessible Transport Framework, the British Sign Language (BSL) Act, and the most recent commitment, a new Disability Action Plan. DAS recognises the positive intention that exists in improving equality and the everyday lives of disabled people. Indeed, our focus group feedback shows notable improvements in some areas, at least for some people.

However, years of cuts have exacerbated inequalities. Budgets for social care, education, welfare benefits, further education, and community based support services, which disabled people rely on, are rapidly diminishing. And with them, so is the equality agenda. Disabled people face extra financial costs of living with disability which average £550 per month. Recent research shows almost half of people in poverty are in a household with a disabled person or are disabled themselves.
The most recent projections from Audit Scotland, for instance, predict that the public purse will continue to tighten.

The road to equality cannot therefore rely on more investment. But DAS is clear that there are real potential opportunities from the further devolution of employability and social security functions, not only in their design, but in how we can now think creatively about a holistic approach with existing devolved areas of support, such as social care.

Whilst it is tempting to look at the policy and legislative levers for change and identify opportunities therein, the only real way to know what life is like for disabled Scots is to ask them. And that is exactly what DAS has done. We are pleased and proud to present in this report the real life, lived experiences and feelings of over 80 disabled people across Scotland, known to us through the membership and supporter network of the DAS organisations.

These are not necessarily people who are familiar with the current policy context, or who regularly participate in these sorts of things. The role of this report is twofold.

Firstly, it is to present to decision makers the unfiltered reality of living with a disability in Scotland today. Secondly, it is an opportunity for DAS to point to areas where action across all levels of government and society could really make a difference – on the issues which disabled people tell us need to change.

Issues like stigma, discrimination, access to employment, a more dignified and empowering system of social security, isolation and loneliness, and access to advocacy support to overcome barriers to achieving the life you want to live.

All of these issues are within the gift of Government at all levels to take positive action on. Throughout the report, DAS makes specific recommendations on key actions that will address the issues disabled people want to change.

DAS commends this report to all key stakeholders, and commits to working constructively and collaboratively to deliver solutions that will support a more equal society for disabled people in Scotland.

The conclusions from the focus groups and discussions for this report are summarised below, along with recommendations for action which would help improve matters and make lives more equal for disabled people in Scotland. We have concentrated on key issues highlighted in the focus groups, and reviewing the policy context.

A recurring theme is that while some matters may have improved, disabled people still do not feel equal and while there are many nice words and documents that aim to further improve matters, they are not being felt in their lives.
Most respondents talked of living with a disability as a challenge. Their disability presented very practical problems with day to day life.

In some of the sessions respondents were asked for a word to describe living with their disability. These tended to focus around the emotional impact of living with a disability and included ‘confusion’, ‘uncertainty’, ‘scary’, ‘frustration’, ‘judgemental’, ‘lonely’, ‘problems’, ‘angry’, ‘discrimination’ and ‘limitations’. The word ‘determination’ also featured with some stating that they were resilient and determined to not let their disability stop them doing things. Some talked of having a positive focus on what they could do rather than what they could not.

“The big one is communication. It is the hardest thing. It is alright on a one to one basis but when you get in to a group it becomes very hard to hear what people are saying”
(Action on Hearing Loss Scotland focus group)

“We live in a very fast moving world and everything is instant. Because everything is instant and because with a visually impaired person it takes that little bit longer we are still four steps behind. It has become harder.”
(RNIB Scotland focus group)

“You get the sense that people don’t want to be in the same room as you or be involved with you in anyway. It makes me feel depressed.”
(Capability Scotland focus group)

“Dealing with limited funds and support. Having to pay extra for support like going to concerts etc. Not always able to get companion tickets. Not able to find out information about concerts until your support staff is with you and by that time the tickets for the concert are sold out.”
(Sense Scotland ‘Our Voice’ group)
'confusion'  'uncertainty'

'scary'  'frustration'  'judgemental'

'lonely'  'problems'  'angry'

'discrimination'  'limitations'
The need to tackle stigma and discrimination, and educate people and improve understanding of disability

Most people living with a disability had experienced some form of stigma and discrimination. This ranged from very minor incidents to more serious cases of harassment and bullying.

This was a key challenge in living with a disability. Some had experience of verbal abuse from other people in society. Raising awareness of disability was seen as critical to help improve understanding. The lack of understanding was not restricted to just the general public. Many had experience of encountering discrimination or poor treatment by health professionals and other groups such as social workers, carers or the police. Many also had positive experiences of support from health and other professionals, but there was a sense that this was them ‘getting lucky’ as treatment tended to be mixed.

“People don’t talk to me directly. They assume that I can’t understand. We are trying to be a normal human being and if they speak to your carer it’s like you aren’t like any other person.”
(Capability Scotland focus group)

“You get called names and picked on when you are on the bus. It is horrible. I get called names by people and it is the same people who picked on me when I was at school. Can they not get on with their lives and leave me alone? It makes you feel small and worthless”
(ENABLE Scotland focus group)

“Some people suffer a great deal of isolation because they can’t follow conversations and are left out of social groups. Some people don’t want to talk to deaf people because they are not used to them signing.”
(Action on Hearing Loss Scotland focus group)

“I think part of mental illness, you feel like a fraud, you stigmatise yourself a lot and you doubt yourself and you think you’re making a big deal out of nothing... I think sometimes I’m fine, just get on with it, so having an acknowledgement that actually you aren’t well definitely helps.”
(SAMH focus group)

“I think things have improved. People talk to you more.”
(Capability Scotland focus group)

“Many of the bad experiences people experienced are caused by staff attitudes and education and improving understanding of disability may help with this.”
(Sense Scotland ‘Our Voice’ group)

“It is education and training so that people dealing with the public know about these things.”
(Action on Hearing Loss Scotland focus group)
“Even doctors don’t understand. It is like they aren’t interested. I just feel that people look down at you when they are talking to you.”
(ENABLE Scotland focus group)

“The [hospital] staff speak to you like dirt on your shoe, like a second class citizen.”
(SAMH focus Group)

“I have had from carers, ‘oh you’re so smart, I only thought I would be working with retarded people’.”
(Capability Scotland focus group)

“It is very dependent on individuals and companies whether they have had the education and training or not. I have been to some places where I couldn’t hear well and they told me just to turn my hearing aid up. In other places people understand about loop systems. It is very dependent on the people you are dealing with.”
(Action on Hearing Loss Scotland focus group)

DAS is keen to work with the Scottish Government, Police Scotland, Crown Office and Procurator Fiscal Service (COPFS) and others to ensure all disability hate crime is reported but to reduce such incidents over all and the stigma and discrimination faced by disabled people. This should include low level harassment and discrimination, acknowledging that ‘hate crime’ and many episodes of discrimination are perceived to be underreported. Awareness campaigns on other types of hate crime have been shown to be effective. We are calling on the Scottish Government and others to support us in this – to fund a national campaign to raise awareness of disability and reduce stigma. To get the most value from this campaign, there should be an associated training programme for people to better understand the range of needs of disabled people, and evaluation of the campaign to highlight what was particularly effective.

This call is also based on the experience and success of the ‘See Me’ campaign. We believe it is important that there is a more positive narrative to encourage greater awareness of disabled people and integration between different people. And that awareness campaigns need to talk about the positives of difference as well as equality.

Training should be available for people in all sorts of roles, including public services, but also for professionals on how to support disabled people to access public services equally and with dignity.

Recommendation 1:
We are calling for the Scottish Government to fund a significant national campaign to raise awareness of disability and to reduce stigma and discrimination, including education and training and the necessary evaluation. This should highlight the positive contribution of disabled people and challenge negative perceptions.

Recommendation 2:
The Scottish Government should consider introducing a national standard for communication and other ways to ensure greater availability and support for accessible communications. This should include greater support for infrastructure for, and accountability on, public bodies to deliver accessible communications.

Recommendation 3:
DAS calls for the full implementation and monitoring of the Accessible Transport Framework, which was published in September 2016.
Work was seen to be important as a source of income, something to do and as a way of feeling that they were contributing to society. A common theme across all groups was the challenge of overcoming the barriers to employment as a result of having a disability. Finding work was felt to be problematic for many.

Many had experiences of encountering problems with employers as a result of their disability. Many had negative experiences of job centres. They were felt to be not catering to their requirements. Access to interpreters was problematic for those with hearing loss. If respondents had not worked in a long time then some had a nervousness of going back to work. Most wanted a fair opportunity for employers and not to be judged by their disability.

For some people, they are not able to work and that needs to be recognised and supported. But for others, the focus needs to shift from what people can’t do to what they can do, to take advantage of their talents and skills. Evidence demonstrates that young disabled people have a similar level of career aspiration at the age of 16 to their wider peer group\(^5\). By the time they are 26, they are nearly four times more likely to be unemployed. We need to foster that early aspiration and reinforce it with support which enables the young person to take control of their own journey toward and into employment.

“If you are working it makes you feel better rather than having to sit in a room because you have nowhere to go and no money to go out and do something.”
(Capability Scotland focus group)

“I want to move forward and get a job.”
(Action on Hearing Loss Scotland focus group)
“I’ve always thought my work is the important thing, it’s how I was brought up, get out and work.”
(SAMH focus group)

“The employment opportunities are not out there for deaf and hard of hearing people.”
(Action on Hearing Loss Scotland focus group)

“I used to work but not any more so I don’t have anything like that anymore. I wish I could do something.”
(ENABLE Scotland focus group)

“I do want to work. I don’t want to be on sick benefit, I want to contribute.”
(Capability Scotland focus group)

“I used to work. I used to get to meet people and all the customers. I have nothing now. I wish I had something to do.”
(ENABLE Scotland focus group)

“Many people have aspirations for work in the future.”
(Sense Scotland ‘Our Voice’ group)

“There is a lot of discrimination, we should be able to do the things other people do like work and that is not happening.”
(Action on Hearing Loss Scotland focus group)

**Recommendation 4:**
DAS calls for a concerted effort by the Scottish Government, UK Government and local bodies to reduce the disability employment gap. This must include necessary action and the opportunity provided by enhanced devolution to reshape and improve the way employment services work in Scotland, including providing more personalised support for disabled people.
Impact of welfare reform and social security

Not all disabled people are on benefits, but people affected by disability have been disproportionately affected by many of the changes to welfare in recent years. Further devolution of an array of disability benefits and employment programmes as well as taxation powers brings both challenges and opportunities.

“Lots of us have concerns that our benefits have been cut.”
(Sense Scotland ‘Our Voice’ group)

“I am going to be losing £300 a month. I don’t know what I am going to do.”
(ENABLE Scotland focus group)

“Things need to be clearer. The package that I was given needed to be fought for.”
(RNIB Scotland focus group)

A lack of resources and services

A common theme across all groups was frustration with access to services. As services are limited in their provision, people can face long waits or services available in one area but not in another. There is strong evidence that services that were previously available have been reduced or cut entirely, in recent years. Funding was seen as a critical area to address.

“Lots of college places have been cut. G went to college for one year but would have liked to continue. G thinks that more research on transitions is needed to compare young people’s experiences and the impact of college on those who went to it and those who did not go to college.”
(Sense Scotland ‘Our Voice’ group)

“I mean it can be six months, 12 months, 18 months. You’re basically...you’re usually given the impression that it’s never going to happen so just don’t even think about it, which is the last thing you want to be told.”
(SAMH focus group)

“This is a very good place but it is a shame that they can’t keep you in your own community with carers.”
(Capability Scotland focus group)

“There are no services in Falkirk for me. That is why I come here (Perth). I had to fight to get to be able to come here. I got angry.”
(Capability Scotland Focus group)

Recommendation 5:
The Scottish Government should seize the opportunity presented by the devolution of parts of the social security system to design and deliver a system that empowers disabled people and recognises everyone’s contribution and value to society. The system is complex and there will be two systems in operation, with different expectations and cultures. There will therefore need to be ongoing coordination with Westminster and reserved powers and benefits.

Recommendation 6:
The Scottish Government should instigate an independent Commission on integrated support for disabled people in Scotland to consider ways best practice can be shared, better connect public services, and develop and pilot innovative approaches to support people with disabilities.
equal? still not, why not?
Having to fight to receive support

Many people in the focus groups felt that even when support was available it relied on them knowing about it and they had to effectively fight to receive it.

“I feel it is very much people having to fight for everything they have got. Support is there but you have to fight for it.”
(RNIB Scotland focus group)

Recommendation 7: Ensure public services provide clear and accessible information on what people are entitled to, their rights, and access to advice and advocacy. This includes well resourced advice and advocacy services.

The difficult transition from children’s service to adult services

The transition from children’s services to adult services was felt to be a particularly difficult time with a perception that support dropped off as people became adults. And for some, the impact of mainstreaming and inclusion is that people don’t regularly have the opportunity to meet with other people who have the same disability as them, or share experiences.

“There are a lot of fun resources when you are a child but when you become an adult it is totally different. It’s like the rainbows get taken off the walls, the bright colours go and now you have landed in the real world.”
(Capability Scotland focus group)

“People look at a child with a disability different to how they look at an adult with a disability. I think they are more caring when they are a child.”
(RNIB Scotland focus group)
The value of peer support

Many talked of positive experiences through meeting people and obtaining support from peers with a similar disability. It was a valuable way of meeting people experiencing social interaction. People could also learn directly from others about how to deal with their disability. The value of meeting other people was a strong theme of the Sense Scotland focus group. Respondents talked positively about the opportunity to meet other people in a different environment. The chance to take part in activities was particularly welcomed.

“You want to meet people but it is not so easy to do.”
(ENABLE Scotland focus group)

“You get help from other visually impaired people, just bouncing ideas off each other. How do you cope with this or that?”
(RNIB Scotland focus group)

Recommendation 8:
The Government, working with the third sector, needs to ensure continued funding, for peer support and community engagement/involvement services, even in a difficult financial climate.
The need to continue support from the third sector

The support that people received from third sector organisations was viewed as critical.

The access to services and training was welcomed. Adequate funding for organisations was believed to be an issue.

“Most of my support has come from RNIB.”
(RNIB Scotland focus group)

“My SAMH worker, she’s a treasure. She’s fantastic.”
(SAMH focus Group)

“I think Action on Hearing Loss is a wonderful resource for information and support.”
(Action on Hearing Loss Scotland focus group)

“I don’t know where I’d be today if it wasn’t for Sense Scotland. Nothing is ever too much trouble for them.”
(Individual supported by Sense Scotland)

“If ENABLE was to close down then you wouldn’t have anything. I have made loads of friends through this. You would be very lost if you didn’t have ENABLE.”
(ENABLE Scotland focus group)

“The people at Capability Scotland have been great.”
(Capability Scotland focus group)
A lack of understanding and action from Government

While the policy context is clear that there has been action, and Government interest in improving equality, most participants in the focus groups said that the UK and Scottish Governments weren't doing enough to support people living with a disability.

Many felt that politicians, like wider society, lacked understanding of the needs of people living with disabilities. And many felt that the governments were not listening.

Some felt they were actively working against the interests of disabled people, especially with changes to welfare reform. Many wanted to see more investment in service provision.

Some questioned the lack of MSPs with a disability. DAS welcomed the recent fund and ‘One in Five’ campaign. Some DAS members are likely to access this fund to support people with disabilities to stand in the elections and DAS will continue a tradition of holding hustings at key points in the election cycle to support access and participation.

“I think the government could do more. I think they should mentor children at key stages, at school, at university and at work. At key stages in life.”
*(Action on Hearing Loss Scotland focus group)*

“There is a great mistrust of the UK Government because of the punitive measures against disabled people and benefits. There’s lots of confusion about benefits.”
*(Sense Scotland ‘Our Voice’ group)*

“The government is skint that’s why I cannot have the support I need, my pals feel the same way and it worries me.”
*(Sense Scotland ‘Our Voice’ group)*

“The higher up you go the less they know what it is like to be a disabled person.”
*(Capability Scotland focus group)*

“I am not saying all MSPs or MPs but a percentage of them don’t understand the problems of losing your hearing and it is back to education.”
*(Action on Hearing Loss Scotland focus group)*

Recommendation 9:
Recent efforts to promote representation of disabled people in civic life are continued to be supported, to ensure positive outcomes.
We recognise the cross-cutting nature of many aspects and the publication of a Disability Action Plan. There needs to be robust and uniform monitoring and evaluation, through a framework that ensures the various plans and initiatives commissioned by various Government departments, fit together and collectively deliver. Related to this, there must be accountability and clear responsibility, with objectives and timelines, for the delivery of relevant plans. Along with this, people need to be empowered to use legislation that already exists, such as discrimination and human rights legislation.

**Recommendation 10:**
Ensure rights and strategies and plans, such as the Disability Action Plan, have meaningful impact for disabled people throughout Scotland through effective coordination, evaluation and accountability.

**Recommendation 11:**
DAS believes the Ministerial Advisory Group (MAG) has potential to pull together actions across government and create an information sharing infrastructure which guides sensible and effective policy decisions and includes representatives from other Government departments from time to time.

DAS and its members look forward to taking these recommendations forward, along with the Government and other organisations, and continuing discussions about how we can make equality a reality for disabled people today.
Notes

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