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.

1 http://www.gov.scot/Topics/People/Equality/disability
There is a lot of discrimination; we should be able to do the things other people do, like work, and that is not happening.
Executive Summary

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\(^1\). Recent research shows almost half of people in poverty are in a household with a disabled person or are disabled themselves\(^3\).
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)
<table>
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<tr>
<th>'confusion'</th>
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<td>'scary'</td>
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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)

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.

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.
The need to improve employment opportunities and access to work

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. 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)

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.

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 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 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.
Methodology

A total of five focus groups were conducted in early 2016, facilitated by Steven Lawther from Red Circle Communications. The exact breakdown of the focus groups is shown below.

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<tr>
<th>Location</th>
<th>Group</th>
<th>Number of participants</th>
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<tbody>
<tr>
<td>1</td>
<td>Edinburgh RNIB</td>
<td>9</td>
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<tr>
<td>2</td>
<td>Glasgow Action on Hearing Loss</td>
<td>7 (2)</td>
</tr>
<tr>
<td>3</td>
<td>Perth Capability Scotland</td>
<td>8 (3)</td>
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<tr>
<td>4</td>
<td>Stirling ENABLE Scotland</td>
<td>7 (3)</td>
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<td>5</td>
<td>Glasgow Sense Scotland</td>
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<td>Total</td>
<td>81</td>
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Figures in brackets denote additional support workers present in the focus group. Focus groups 1-4 were audio-recorded and analysed for consistency of response although this wasn’t possible for focus group 5 due to the size of the group. Verbatim quotes have been used throughout this report to illustrate findings.

At the start of several sections, we briefly outline some policy context. Most quotes included in this report although a few have been edited out to keep the length of the document manageable and focus on key points. We have left the vast majority in to give a sense of the different voices and perspectives, and also commonality, on key issues.

There were a number of common themes that emerged throughout the focus group discussions. These are now detailed in the following sections with the relevant verbatim quotes. In order to ensure that as many voices as possible are heard we have included a wide selection of quotes.

The final section of the report concentrates on the themes from the focus groups and recommendations for action to ensure there is greater equality for disabled people in Scotland.

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 – not did we intend to – outlined all areas for improvement or provided lots of detail. This is in order to focus on key calls 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 primary area of interest is mainly Scottish policy, given the extent to which relevant matters are devolved but does also touch on reserved issues.
The challenge of living with a disability

POLICY CONTEXT

Nearly one in five (19%, one million) people of working age in Scotland are disabled. There has been equality and anti-discriminatory legislation for a number of years now. The Equality Act 2010 came into force in October 2010 and provides a legal framework to protect the rights of individuals and advance equality of opportunity for all. There are nine protected characteristics under the Act, one of which is disability. The Disability Discrimination Act (DDA) came into effect in 1995. It has been amended since. Anyone with a disability is protected by the DDA. The DDA defines disability as “a physical or mental impairment which has a substantial and long-term adverse effect on a person’s ability to carry out normal day-to-day activities”. The DDA was extended, for instance in 2005, to cover public transport, and the introduction of a duty on public authorities to promote equality for disabled people.

There are a number of cross cutting policy plans relevant to disability. In particular:

- The Fairer Scotland Action Plan was published on Wednesday 5th October and outlines 50 actions to help tackle poverty, reduce inequality and build a fairer and more inclusive Scotland by 2030. The Fairer Scotland Action Plan is built on five high-level ambitions: a fairer Scotland for all; ending child poverty; a strong start for all young people; fairer working lives; and a thriving third age. At the heart of the Plan are 50 ‘fairness actions’ for this parliamentary term to help the Government meet these ambitions, ranging across the responsibilities of government. The Action Plan features commitments from a range of organisations from across the UK who want to help build a Fairer Scotland and is the start of a long term commitment to help shape a fairer Scotland. Key points for disabled people including more affordable homes, fairer social security and crisis support, doing more for carers and fair working lives and support for greater representation of disabled people in politics and public life.

- The Scottish Government is a vocal supporter of UNCRDP (UN Convention on the Rights of Disabled People). The Scottish Government has a clear aim: for disabled people to have the same equality and human rights as non-disabled people. This means disabled people having the same freedom, dignity, choice and control over their lives as everyone else, with rights to practical assistance and support at home, at work and in the wider community. A Disability Action Plan is expected to be published in December 2016 the consultation on the draft plan stated ‘however, for many disabled people living in Scotland, this is still a long way off being a reality’. The plan aims to take practical, targeted action across all policy areas and services to deliver on the key outcomes that disabled people have identified as being important to making positive change. There is also research being undertaken to review the impact of implementation of the UNCRDP in the UK, which will report to the UN.

- Years of cuts have exacerbated inequalities. Disabled people also 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.

There has been some progress in terms of a British Sign Language (BSL) Act (Scotland) and greater awareness of the need for, and support for, accessible communications.
Most respondents talked of living with a disability as a challenge. For most, their disability presented very practical problems with day to day life.

“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)*

In addition to the practical challenges of living with their disability, there was also an emotional challenge for some. This was at times difficult to cope with and could be isolating.

“The words I think of are ‘own world’. If you don’t hear what is going on you switch off and can just retreat into your own world.”
*(Action on Hearing Loss Scotland focus group)*

“I lost my sight suddenly so I had to learn to live again and adapt my life. It was the emotional side I struggled with.”
*(RNIB Scotland focus group)*

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

“Leaving the house when I couldn’t see was terrifying at first. It becomes less scary as you get older but it never stops being scary.”
*(RNIB Scotland focus group)*

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. This may highlight the importance of the ‘social model’ of disability, as opposed to the ‘medical model’, being rightly given a greater focus for professional interaction from the point of diagnosis to ongoing assessments for public services.

“That was very much part of my therapy. Focusing on what can you do rather than dwelling on what you can’t do.”
*(RNIB Scotland focus group)*

“As a visually impaired person you have to be very determined. There is a certain degree of pre-planning that you have to do. It always takes you far, far longer to do things. You might get to the same end result but it will take you a hell of a lot longer.”
*(RNIB Scotland focus group)*
“I don’t get embarrassed. I just get on with it. If we are just meeting people on the street we just persist and carry on with it.”

*(Action on Hearing Loss Scotland focus group)*

“I can still do things as I am determined enough to keep going. It is almost like problem solving in a great way. That kind of challenge is great. Yes there are problems and things that get in your road, but for every problem there is a solution.”

*(RNIB Scotland focus group)*

“Attitudinal barriers mean that for some people they have no choice but to stay at home or be limited to where they can access public transport on their own. Or to use passenger assist services which may not be a great experience.”

*(Sense Scotland ‘Our Voice’ 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)*

“Having to rely on public transport which are not always accessible or with friendly staff, passenger assist not always reliable.”

*(Sense Scotland ‘Our Voice’ group)*

“Sometimes the barrier is other people assuming just because you have a disability you can’t do certain things. For example if you want to be a film maker they will say you can’t do that because you are not qualified and you can’t do that. That is the barriers. I think that anyone should have the opportunity to do anything they want to do and not have barriers put in front of them. We need food, care and love. We don’t need evil.”

*(Sense Scotland group)*

“The need not to be defined by your disability but by who you are and be judged by your merits and not by your label that society has imposed on you.”

*(Sense Scotland group)*

Beyond these strong messages around challenge, isolation, emotional impact and determination, there were a number of common themes that emerged throughout the focus group discussions which point to clear cases for action. These are now detailed in the following sections with the relevant verbatim quotes. In order to ensure that as many voices as possible are heard we have included a wide selection of quotes.
The need to tackle stigma and discrimination

POLICY CONTEXT

The number of disability hate crimes reported continues to increase. In 2014-15, 177 charges were reported with an aggravation of prejudice relating to disability, 20% more than in 2013-14. Whilst this could be perceived as a positive indicator of people’s awareness of disability hate crime, as the report from the Crown Office and Procurator Fiscal Service (COPFS) noted, ‘there is a broad consensus however that this type of crime continues to be under reported compared to other forms of stigma’. There is a commitment from the Scottish Government and across all political parties to tackle hate crime but little or no further detail of how this will be progressed.

The Scottish Government established in 2015 an Independent Advisory Group on Hate Crime, Prejudice and Community Cohesion. And only very recently, a campaign to eradicate all forms of hate crime has been announced, which is good news.

There are also very few cases through discrimination legislation although again, a perception that there is underreporting or people are not able or willing to go through redress processes.

There are plans to set out a path for a five-year rights agenda, building on Scotland’s National Action Plan for Human Rights. This will aim to explore how to better reflect international human rights obligations in domestic law, including by inviting a cross section of people from all over Scotland to examine how human rights protections might be enshrined in law.

The Equality and Human Rights Committee in the Scottish Parliament has also called for efforts to tackling prejudice based bullying through fostering understanding about protected groups by embedding this across the school curriculum.

The Disability Action Plan is also expected to include actions this key topic.

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.

“People treat you differently because you have a learning disability. People look at you and think you are not a normal person. You don’t feel a normal person.”

(ENABLE Scotland focus group)

“They sometimes think that because I can’t see then I don’t exist. They talk to my sister and ask ‘how is your brother?’ and I am standing right there.”

(RNIB Scotland focus group)

“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)
“Sometimes I’ve gone into shops and they have told me to get out as dogs aren’t allowed in. I told him it was a guide dog but it didn’t matter. I was put out.”  
(RNIB Scotland focus group)

“You do get the stares and the ‘why is that boy in a wheelchair?’ as if they are looking down on you.”  
(Capability Scotland focus group)

Many talked of being judged because of their disability.

“A lot of people are not in your situation so they don’t know what you are going through. They look down on you”  
(ENABLE Scotland focus group)

“I feel like you get discriminated against. It’s like just because we are blind then people think you can’t do anything”  
(RNIB Scotland focus Group)

“When I was at school people used to talk about me”  
(Capability Scotland focus group)

“Everyone makes judgements about you and not just in the sighted community but sometimes in the visually impaired community as well. You are judged if you ask for more support. You are judged if you don’t ask for more support”  
(RNIB Scotland focus group)

“In general life we are belittled and treated like second class citizens and like we do not have opinions”  
(Capability Scotland focus group)

Some had experience of verbal abuse (or worse) from other people in society.

“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)

“We are not saying to people that you have to like disability. You don’t have to like it, but don’t just come up to people and say ‘she’s a spastic”  
(Capability Scotland focus group)

“I used to have people asking me for a ride on my wheelchair and calling me a spastic. I felt so defeated”  
(Capability Scotland focus group)

“(Anon) has had experiences at home with him and his mum with young people throwing stones at their house and having to call the police. He felt really scared.”  
(Sense Scotland Hate Crime workshop for service users, run in conjunction with Police Scotland)

“J felt sad about the anti-bullying discussion as it brought back memories of being bullied a long time ago.”  
(Sense Scotland Hate Crime workshop for service users, run in conjunction with Police Scotland)
“It is not right that those who bully you get away with it, it is good to know that we have support that helps us to understand”  
(Sense Scotland Hate Crime workshop for service users, run in conjunction with Police Scotland)

Many, especially those with a learning disability had experience of encountering stigma on public transport.

“Travelling is difficult. Two or three years ago I travelled up to Elgin and had a support worker with me at the time. She left us at Aberdeen and we got bullied all the way through. We had to get Transport Police involved. You are scared to travel yourself in case you get the same hassle again”  
(ENABLE Scotland focus group)

“Sometime I just get off the bus because I am being called names and being picked on. I just get off the bus and wait for the next one. I just don’t like it”  
(ENABLE Scotland focus group)

“Some of the drivers can be nasty or cheeky or boss you about. They tell you where to sit. The driver told me to sit at the back and once I got put off the bus for complaining about him driving off before I had sat down. I had to wait twenty minutes for the next bus”  
(ENABLE Scotland focus group)

“I have the bus driver taking the pass off me to look at and make sure it is me. It is like they think I have nicked it”  
(ENABLE Scotland focus group)

“I got on the bus one time and the driver refused to tell me when I was at my stop. He felt so uncomfortable having to talk to me. I was terrified”  
(RNIB Scotland focus group)

Stigma and discrimination can lead to people feeling isolated.

“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 was doing a work experience at a school when I was younger and one of the mums at school said to her kids, ‘don’t play with that lassie, she is in a wheelchair’. I felt a bit funny.”  
(Capability Scotland focus group)

“People make assumptions which just make you feel more and more isolated, like people don’t understand me and they don’t even want to. People should know better. People should understand.”  
(RNIB Scotland focus group)

“I feel as if people aren’t really keen to invite me to go along to the pub and socialise. I don’t have the same connection and people tend to forget about me.”  
(Action on Hearing Loss Scotland focus group)
Some people with a mental health condition talked about isolating themselves from friends and family due to self-stigma.

“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 don’t feel the need to say to everybody I’m autistic…. initially she said ‘Oh well that was down to you to tell us’. That’s not appropriate. It’s not something that you should automatically have to announce to somebody. It’s a big, big thing. It’s been a shameful thing for me at times in my life.”  
(SAMH focus group)

Encountering discrimination had a negative impact on respondents.

“You are doing your best to fit in with the big wide world and it is little things that annoy you. People should just treat us normally”  
(RNIB focus group)

“There are times when you feel quite vulnerable and you don’t know how to deal with it.”  
(RNIB Scotland focus group)

“They talk to our carers first, this takes away a rich experience from us, all we want to do I communicate”  
(Capability Scotland focus group)

“You can be very open and determined and doing things but when you do come across discrimination then you feel blind. Then you feel like you have a disability”  
(RNIB Scotland focus group)

“You do get lots of kindness randomly and I am trying my very hardest to concentrate on the acts of kindness and it is not easy sometimes”  
(RNIB Scotland focus group)

There were a number of respondents who felt that discrimination was not an issue for them personally. The focus group least likely to talk about discrimination was the Action on Hearing Loss Scotland group.

“I have been involved in society for a long time, out socialising and in bars and attitudes seem to be fine. People try to be welcoming to deaf people. There is more awareness for deaf people. People go out more and socialise more”  
(Action on Hearing Loss Scotland focus group)

“I have never really encountered discrimination”  
(Action on Hearing Loss Scotland focus group)

“Personally I have never seen discrimination as a big issue in my life. I have got just as much sighted friends as I have visually impaired friends and I don’t really see any difference between them to be honest”  
(RNIB Scotland focus group)
“Discrimination is something that happens that upsets you and I am not easily upset”
(RNIB Scotland focus Group)

Some felt that attitudes were improving.

“Maybe there was discrimination a long, long time ago but not now”
(Action on Hearing Loss Scotland focus group)

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

“I have grown up with it and come through a lot of changes of what is available for blind people. If there is a good time to be blind then this is it”
(RNIB Scotland focus Group)

“In BSL zone which is a TV programme there is a lot of information about the BSL Act and what we have achieved so far. I think attitudes are improving”
(Action on Hearing Loss Scotland focus group)

“I am in my 40s and when I was young I remember very rarely meeting people with disabilities. They were hidden away and there were some dreadful attitudes”
(RNIB Scotland focus group)

“I feel it is definitely better now than it was a long time ago. Going back there was discrimination but there is more awareness now. People do have a better attitude now”
(Action on Hearing Loss Scotland focus group)

Others were more sceptical and felt that there was still a long way to go to change attitudes.

“In this day and age I think people are trying but they need to do more. We should be able to get over negativity. People have managed to accept things like gay marriage but they still haven’t been able to accept us”
(Capability Scotland focus group)

“We live in a very discriminatory world. It is never going to change. I want attitudes to change but I know I can’t change the world”
(RNIB Scotland focus Group)

“It is when you suddenly realise that you are up against an immovable object that you can’t solve, like trying to reason with a cyclist on a pavement or a driver blocking a pavement. It is when you realise that you are up against attitudes like that in society that can be really frustrating”
(RNIB Scotland focus Group)

A number of respondents in the RNIB focus group felt that there was an onus on people who were blind or visually impaired to respond well to people offering help, even if it wasn’t required.

“An awful lot of disabled people can be a bit rude to sighted people. If people offer help then you have to be polite even if you decline it”
(RNIB Focus Group)
POLICY CONTEXT

There have been some efforts to improve people’s understanding of disability, whether that be the public and also professional groups. There is greater awareness of positive stories from the Paralympics, for instance, and also greater understanding of the ‘social model’. However, the coverage and perceptions of disabled people in the media more broadly has been negative including increased representation in the media of disabled people as ‘scroungers’ and possible links with increased hate crime. The austerity agenda has helped to create a sense of disabled people don’t wish to live independent lives and do not have anything to contribute to society. This has been raised in previous campaigns like the ‘Hardest Hit’ highlighted several years ago but if anything, this has just got worse and worse.

Within this broad sense of going backwards, there have been some elements of improvement For instance, the ‘See Me’ programme to end mental health discrimination, which is funded by the Scottish Government, has been effective in improving the understanding of mental health issues. The similar ‘Time to Change’ campaign in England has also been shown to have impact. The ‘Access to Politics’ project, launched in December 2015, and the ‘Access to Elected Office Fund’ which is running until the local elections in May 2017, should hopefully help to address the under-representation of disabled people in politics and public life. Some service users / individuals who work with DAS members will be looking to apply to access the fund to support their political aspirations.

There was a sense that people made assumptions about what it meant to have a particular disability.

“It is a struggle. You are constantly dealing with people’s perceptions of you and what you should be. People aren’t aware enough, what it is to be blind, what it is to be disabled” (RNIB Scotland focus group)

“There is a lack of understanding but I have to keep reminding myself that people don’t go out to upset my day. They just don’t understand” (RNIB Scotland focus group)

“I have had people on tills and stuff say ‘oh, you are very brave’ and I didn’t want to be dismissive because their heart is in the right place, but I’m not brave, I don’t have a choice” (RNIB Scotland focus group)

“It is just human beings and if we are honest about human beings, then if it isn’t happening to us then we aren’t going to understand it” (RNIB Scotland focus group)
Some had experience of people assuming that they could not do things that they could.

“A lot of sighted people have these ideas about visually impaired people and what we can and can’t do. I am only blind. It doesn’t mean to say I can’t do anything”  
(RNIB Scotland focus group)

“People assume you can’t communicate. They are taken by surprise that you can communicate. They assume that you are somewhat impaired mentally because you are in a wheelchair. I have to let them know that I can communicate and I am not an idiot”  
(Capability Scotland focus group)

“I had my child and this nurse pulled the chair in and said ‘Well, Mrs XXXXX what are we going to have to do for you?’ I said ‘You won’t have to do anything for me because I have been to all the parenting classes and I know how to change a nappy and do bottles’ I just felt so inadequate”  
(RNIB Scotland focus group)

Raising awareness of disability was seen as critical to help improve understanding and this would improve other aspects of people’s lives.

“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)

“The bus driving too fast which makes it difficult for someone to balance and stay on her feet.”  
(Sense Scotland ‘Our Voice’ Group)

“People need a lot more training and a lot more awareness and acceptance of difference.”  
(RNIB Scotland focus group)

“It is education and training so that people dealing with the public know about these things.”  
(Action on Hearing Loss Scotland focus group)

“You get training days where people have to spend a day in a wheelchair to see what it is like. That is a good thing.”  
(Capability Scotland Focus group)

“The bus drivers should have training so they speak to you more nicely.”  
(ENABLE Scotland focus group)

“I would like to see sign language and particularly finger spelling taught at primary school to help with communication and understanding.”  
(Action on Hearing Loss Scotland focus group)
“There are so many eye conditions and people have so many degrees of what they can and can’t see. It is letting people know that there are so many different types of sight loss.”
(RNIB Scotland focus Group)

Promoting positive images of disability in the media was also felt to be important.

“I would like to see more positive and realistic images of blind people.”
(RNIB Scotland focus group)

“You need greater profile of visually impaired people on television, on soaps, being presenters, doing different types of things.”
(RNIB Scotland focus group)

“It increases my confidence to see people signing on television. Subtitles are ok but I prefer to have someone signing. So it affects my confidence in a good way. Because the communication is valid, I can see someone signing. I would love more people to be able to sign.”
(Action on Hearing Loss Scotland focus group)
The need to improve understanding of health professionals and other groups

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.

“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 didn’t get treated properly at the hospital. I had to wait ages for the specialist and then they just said ‘I can’t help you’.”
(Capability Scotland focus group)

“I volunteer in care homes and some of the nurses in care homes don’t know what they are doing. We asked for people with hearing aids and they just brought us a bunch of hearing aids and they didn’t even know who they belonged to. Also they change the batteries on the Monday so if your battery ran out on Friday you can’t hear until Monday. They are left isolated.”
(Action on Hearing Loss Scotland focus group)

“I have been trying to get help off my doctors for a while and I just feel like the doctor is doing everything he can to put me off so I can just say ‘oh to hell with it, I am not bothering’”
(ENABLE Scotland focus group)

“Well I was in crisis in December, and I phoned NHS and I was absolutely hysterical, beyond hysterical, and the lady told me to put my head out the window, and I just kind of thought, if I out my head out the window my whole body is going out the window”
(SAMH focus group)

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

(Phase Scotland focus group)

“They’re not geared up for the type of stuff that I’ve been through, and they just don’t know how to deal with it. They’re not interested”
(SAMH focus group)

“I had a social worker who wasn’t very nice to me and who was very patronising”
(RNIB Scotland focus group)
“I feel the doctors are just handing out prescriptions to me just to keep me quiet. It is like sweeties.”
(ENABLE Scotland focus group)

“The woman that diagnosed me... it was a battle. I just felt that she was enforcing her will on me and I was going to walk out the room with no help whatsoever.”
(SAMH focus group)

“I have actually come across that as well, as so do some GPs, some people in the health profession, after they’ve found out that you’re a veteran, they just shut the door sort of thing, don’t want to know you. They don’t even want to listen to what your problems were.”
(SAMH focus group)

“Signage could be in bigger print in hospitals . . . and could be lower . . . arrows quite confusing.”
(Sense Scotland ‘Our Voice’ group)

“Some of us experienced good outcomes from health professionals and others have bad experiences. As a BSL user I had a bad experience of lack of communication support while in hospital. On the other hand I know of another individual who is blind had a good experience with the hospital being very accommodating with her when a relative was ill and passed away in hospital. The hospital were [sic] very understanding and allowed a lot of time for family to visit and to say their goodbyes in their own way.”
(Sense Scotland ‘Our Voice’ Group)

Many had positive experience of support from health and other professionals, but there was a sense that this was them ‘getting lucky’ as treatment tended to be mixed.

“She [CPN] is a very good listener. She’s very calm and she doesn’t talk down to you and when she goes away she’s left you with some suggestions of things to do, or she’s going to contact the doctor or something.”
(SAMH focus group)

“I have a good social worker who fights my corner but it depends on who you get”
(Capability Scotland focus group)

“The psychologist I saw was brilliant – there was no time restriction which was really good.”
(SAMH 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)

“Rather than helping me with things I can’t do, she [social worker] is good at helping me do it myself. Some of the other agencies or whatever you call them, when they hear what your problem is, they tend to assume you can or can’t do something, or that you have a problem”
(SAMH focus group)
“I’ve got somebody now who I think is very good, but I’ve lost any faith that he’s going to be around for any length of time”
(SAMH focus group)

For those with a mental health condition, poor treatment was most frequently experienced in a hospital setting or from someone not familiar with their circumstances.

“When I get an emergency appointment with someone who doesn’t know me, they see the word bi-polar and inform me that it’s all me...they don’t have the time to get to read the file”
(SAMH focus group)

“Last time I was at the hospital … I felt that I was still being judged from what happened in hospital last time, and I pretty much just got left to lie in my bed. There was no discussion. There was no encouragement, there was nothing. I just got left to my own devices.”
(SAMH focus group)

“One or two have been indifferent to the point of being insulting because they know they’re only there for a short time so there’s no investment and why should they bother, and I’ve got a file that big, why would they read it if they know they’re moving on?”
(SAMH focus group)

“I’ve been kicked by a patient, I’ve been punched by a patient, I went to the nurse and said I wanted it in the book, ‘Well, she’s not very well so there’s really nothing we can do’, so I said ‘I’ve to go about being kicked and punched and you’re not doing anything about it?’ “We can’t, she’s like yourself, she’s not well”, and I said “But I’ve never kicked anybody or punched anybody.”
(SAMH focus group)

“I felt simply that the nurses were jailors and the ward was locked, that they were simply there to contain me, which to be honest is probably what was needed at the time. They’d call your name the whole time and check you off that you were still there and still alive, and medicated, that’s all I got; locked up and medicated. I thought it was the least therapeutic place I’ve ever been and witnessed”
(SAMH focus group)

“We had to do what we were told. Their exact words were “We’re the bosses, you’ll do what we tell you” Simple as that. You’re not going to have a lot of choice”
(SAMH focus group)

“My experience was that they used to lock the ward if there was one individual on the ward, so you always had to go to a nurse to get out. You couldn’t just go out when you wanted, and that was just because there was maybe one person on the ward that merited it. It just takes away your rights, it takes away being human and it makes you feel like a caged animal. It’s de-humanising”
(SAMH focus group)

“There was a campaign by RNIB to have someone in every hospital in Scotland who knows about visual impairment”
(RNIB Scotland focus group)
Those with learning difficulties talked about not having enough time with GPs and other health professionals to fully understand what was being said.

“If you only have ten minutes with a doctor then they can’t explain. People with learning disabilities need more time to understand”  
(ENABLE Scotland focus group)

Some had negative experience of the justice system and felt that there was no account taken of their disability in how they were treated.

“I went to the police to make a complaint and they said they couldn’t take my complaint seriously because they had a learning disability. They said they would have to inform social work. I didn’t want social work involved. I just wanted to make a normal complaint like anyone else”  
(ENABLE Scotland focus group)

“I was in the cells overnight, 18 hours, banging, trying to break my way out of the cell, .... ‘you’re going to have to wait until you’re in court on Tuesday morning’. This was Saturday night /Sunday. So I said all along to them, this isn’t a criminal situation, I’m a medical case, I need to see a doctor, and they said no one would come and see me, so it was appalling”  
(SAMH focus group)

“Are the police going to take you seriously? No”  
(ENABLE Scotland focus group)

“I had to wait for an appropriate adult. I had to wait in the police cell for five hours until they could find someone. Why couldn’t they just let me go home and speak to me the next day?”  
(ENABLE Scotland focus group)
The need to improve employment opportunities and access to work

POLICY CONTEXT

Disabled people experience lower rates of employment and lower pay than non-disabled people. Some disabled people are not able to work but for other disabled people, being in work, where possible, can have economic and social benefits for individuals, the people around them and beyond. And many disabled people wish to work. Yet, despite the employment rate improving and the advent of the Disability Discrimination and Equality Acts, there is still a significant difference in the number of disabled people in employment compared to those who are not disabled. Due to a range of barriers, only 43.8% of individuals with disabilities in Scotland are employed, compared to 72.3% for the wider population. Employment rates have actually fallen in recent years among some disabled groups.

Published in August 2016 as an integral part of the Scottish Government’s Economic Strategy, the Scottish Government’s Labour Market Strategy, promotes inclusive growth marshalled around the Scottish Government’s five priorities including: Promoting Fair Work and Responsible Business and Employability and Skills. Contained within the strategy, the Scottish Government has committed to develop a Workplace Equality Fund. And the Scottish Business Pledge, launched in May 2015, it is a voluntary commitment made by Scottish businesses to celebrate, promote and encourage business success based on the practical application of the principles of fairness, equality, and opportunity.

The Scotland Act (2016) includes some new powers for some programmes (for those at risk of long-term unemployment and to help disabled people into work). These new powers come into force in March 2017 and will initially be delivered through transitional arrangements ahead of a full programme of services in 2018. The two new transitional programmes, Work First and Work Able Scotland will commence in April 2017 although there are already some concerns about the tendering process. From 2017 an additional £20 million per year, over and above the funding transferred from Westminster, has been committed to delivering and improving employment support. The Scottish Government has canvassing views, and developing plans, on the future of how these new powers should be shaped.

The Scottish Government has committed to review the system of student support for those in further and higher education, and consider any opportunities to make use of new social security powers to support disabled students. There is also the ‘Developing the young workforce’ strategy that talks about careers advice and work experience for young disabled people in school and 16-17 milestones.

An ongoing Review of Enterprise and Skills Services will also make recommendations on the change required to improve social inclusion and its impact on Scotland’s economic growth and productivity.

The Scottish Government has also committed to continue to implement the ‘Equality Action Plan’ for Modern Apprentices in Scotland to increase the number of trainees who are disabled. However, this is starting at a very low figure. Modern apprenticeships (MAs) for disabled people in Scotland are falling well below the UK average. Statistics published by Skills Development Scotland show that of 25,691 Modern Apprenticeship starts in 2015/16, only 63 were taken up by people with a declared disability.
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.

“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)

Some had worked or volunteered and had a positive experience from this.

“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)

“I had my job and it all changed. You were working so you didn’t need much support but then I got made redundant when the Council closed Blind craft and it all started again.”
(RNIB Scotland focus group)

“I work in a charity shop but that’s just because I wanted out of the house. If you sit in the house all day you are going to get depression all day. I think it is nice to meet new people and help the community. You are out of the house and you can gain experience by volunteering.”
(ENABLE Scotland focus group)

“I worked as a volunteer in a charity shop. I did that for ten years five or six days a week. I was training new folk on the till, cash up, lock up, you name it. So I know I can do a job.”
(ENABLE Scotland focus group)

“Many of us are sceptical about the welfare changes as we think it’s making all disabled people having to go to work whether they want to or not. We would like support for people who want to go to work and aspire to become an artist or film maker or anything they want to become but at the same time support to be given to people who don’t want to work or if work is not an option for them as well.”
(Sense Scotland ‘Our Voice’ group)
Many of the individuals said they would like to work but there is the problem of benefits being cut if they did. D says that pay is the problem:

“If you get a job all your benefits will be cut. If you go over a certain amount, they cut your benefits, need to pay your own way. Not worth working if you lose all your benefits.”

(Sense Scotland ‘Our Voice’ group)

“Many people have aspirations for work in the future.”

(Sense Scotland ‘Our Voice’ group)

A common theme across all groups was the barriers to employment as a result of having a disability. Finding work was felt to be problematic for many.

“Looking for work is really difficult. It is a cruel world out there. To say it is like a living hell is no exaggeration.”

(Action on Hearing Loss Scotland focus group)

“There are a lot of employers who will not take on someone with learning disabilities. They don’t want to treat you the same way as others.”

(ENABLE Scotland focus group)

“I did a work placement and the first day the person I was sitting next to was asking me all sorts of questions, which was fine. The second day I went in I was on my own and they told me because the woman sitting next to me had called me a spastic and said she didn’t want to work with a spastic.”

(Capability Scotland focus 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)

Many had experiences of encountering problems with employers as a result of their disability.

“I just feel that because you have a learning disability then some employers don’t want to take you on. I got told it will cost us too much money to train you. They don’t have the patience to train you.”

(ENABLE Scotland focus group)

“Employers don’t understand that you are capable of doing something with assistance.”

(RNIB Scotland focus group)

“My last paid job was back in 2008. Most of the people I worked for took people on with disabilities. Most employers are not interested in us.”

(ENABLE Scotland focus group)

“When I am applying for jobs I am not being seen as employable.”

(Action on Hearing Loss Focus Scotland focus group)

“I got told that employers need to have different insurance to take on someone with learning difficulties.”

(ENABLE Scotland focus group)
“I feel as if a lot of companies don’t have the right attitude to equality and that is not just about deafness, about other disabilities as well.”
\textit{(Action on Hearing Loss Scotland focus group)}

“I was kept back a year at school and I didn’t sit any qualifications and I have applied for a few jobs and all I get back is ‘sorry, your application form is unsuccessful’.”
\textit{(ENABLE Scotland focus group)}

Access to interpreters was problematic for those with hearing loss.

“We apply for jobs and tell them we need an interpreter and they can say no. Again I have come in to Action on Hearing Loss and they will do the phone calls and book an interpreter for me. In an interview situation there is no point in going without an interpreter so it is essential.”
\textit{(Action on Hearing Loss Scotland focus group)}

“I have to tell them I am deaf and I need an interpreter. I had an interview date and it was cancelled and rearranged and I gave them contact details of interpreters and organisations to contact. I got back in touch and asked what the date was and they didn’t even respond so I asked again and again. I was invited for the interview but I never went for the interview.”
\textit{(Action on Hearing Loss Scotland focus group)}

“I have been invited for an interview and then when I say I need an interpreter they get reluctant and the attitude changes.”
\textit{(Action on Hearing Loss Scotland focus group)}

Many had negative experiences of jobcentres. They were felt to be not catering to their needs and requirements.

“I think with the jobcentre they just class us as another statistic. They just want to get you off jobseekers.”
\textit{(ENABLE Scotland focus group)}

“We have one employment advisor up in our area and it is pathetic.”
\textit{(ENABLE Scotland focus group)}

“The jobcentre is the worst place ever. I am still waiting to get it all sorted. It is very hard to get a job and get off benefits”.  
\textit{(ENABLE Scotland focus group)}

“When I contacted the jobcentre and I said I am BSL and I need a interpreter they refused that and they refused it 3 times so I contacted Action on Hearing Loss and they contacted the jobcentre to tell them it was my right to have an interpreter available.”
\textit{(Action on Hearing Loss Scotland focus group)}

“Form filling is a nightmare. Some people are not confident with that. People who were born deaf can find that daunting due to literacy. Their signing might be great but their reading and writing might not be.”
\textit{(Action on Hearing Loss Scotland focus group)}

“I have dyslexia and they told me to go and look on the computer for jobs.”
\textit{(ENABLE Scotland focus group)}
If respondents had not worked in a long time then some had a nervousness of going back to work.

“If you don’t work you forget how to act in the real world.” (Capability Scotland focus group)

“About 15 years ago I felt there was less discrimination but I feel there is more now. I think it is getting worse. Years ago I was looking for jobs, RNID helped me a lot at that time and it was very difficult but there was more respect at that time. I just feel as if attitudes are different now.” (Action on Hearing Loss Scotland focus group)

“I’ve never worked in a job, I’ve had my illness for the last 16 years, and yeah, it would be helpful if I could know what to expect when I went into work, from the job and be able to get something that would just start off gently and maybe twice a week at the most, half a day or something a week, then build me up to something more full time.” (SAMH focus group)

Most wanted a fair opportunity from employers and not to be judged by their disability.

“You need to get employers to treat learning disability people the same as someone else.” (ENABLE Scotland focus group)

“Because I was totally blind and had a guide dog, I feel employers just kept making up excuses. It makes me feel angry because I know I can do it.” (RNIB Scotland focus group)

“Bosses should come and meet us and realise that we are clever people. It takes a little more time to do things but we can do things.” (Capability Scotland focus group)

“I think it should be mandatory that the government make companies take on deaf people. Then people would become more deaf aware, there would be proper integration.” (Action on Hearing Loss Scotland focus group)

“I think maybe we need to have more disability awareness and more strong advocacy for deaf people so that they are able to attain jobs just like hearing people. At the moment there is inequality. It is really important for people to be able to get work.” (Action on Hearing Loss Scotland focus group)
Impact of welfare reform and social security

**POLICY CONTEXT**

The Scotland Act (2016) allows for the devolution of key powers on social security. For disabled people on benefits, there have been significant cuts. Social security and benefits provision have been abolished, reduced or failed to match inflation. Eligibility has been tightened and assessment processes have also been tightened and crudely applied. The 'bedroom tax' is effectively abolished in Scotland. And over half of the £1.63bn social security budget being devolved through the Scotland Act is currently spent on Disability Living Allowance (DLA) and Personal Independence Payments (PIP). This is a clear chance to improve key elements of the current system. The Scottish Government has committed to instilling installing a system that is based on key principles of fairness, dignity and respect. The Scottish also intends to establish a Disability Benefits Commission that will provide recommendations and guidance on reforms.

The changes to the system in recent years have undermined disabled people’s right to live independently and their right to family life in contravention of articles 19 of the UN Convention on the Rights of People with Disabilities (UNCDP) and Article 8 of the United Nations Convention on Human Rights (UNCHR). This affects disabled people, carers and others around them and the wider society and economy.

The Scottish Independent Living Fund has been expanded for new users with an additional £5 million a year committed to the existing budget of £47.2 million a year. The new scheme is currently in development in co-production with disabled people, carers, representative organisations and local authorities.

Many people in the focus groups were upset and angry about recent changes to welfare reform. They felt this made it more difficult to get by on a day to day basis.

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

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

“Life is hard enough without putting obstacles in our way” (RNIB Scotland focus group)

“You are relying on your benefits as that is the only income you have coming in. What are you going to do? You’re snookered”
(ENABLE Scotland focus group)

“They think because we are disabled we shouldn’t be entitled to benefits. It feels like they want to get rid of disabled people. The government should be supporting people with learning disabilities”
(ENABLE Scotland focus group)
“If you are on benefits, you feel like a thief stealing money from the government.”
(Capability Scotland focus group)

“A lot of us got told that we would be on DLA for life and then now they want you to get into paid work and it is really hard.”
(ENABLE Scotland focus group)

“My benefits have been cut. I used to come five days a week and now I only attend two half days a week.”
(Capability Scotland focus group)

“They should stop taking money from the disabled people and take it from the people who can afford to lose the money.”
(ENABLE Scotland focus group)

“They should keep the benefit system the way it is and not try to change it. Stop trying to cut down and take money from people. It is bad.”
(ENABLE Scotland focus group)

There was a desire for the system of support to be clear and understandable.

“People need a clearer and simplistic benefit system so they know what they can get and what they can’t get”
(RNIB Scotland focus group)

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

There was a desire for the system to be more easily accessible for people.

“Stop making people jump through hoops to get the disability they should be having”
(ENABLE Scotland focus group)

“You spend a lot of your time proving to social services that you can’t do this stuff without someone coming to help you. You need a realistic process and an honest and transparent process”
(RNIB Scotland focus group)

“We have tried to get a direct payment but the book you have to fill it, it is like a bible”
(Capability Scotland focus group)

“You can walk, you can talk, you can do lots of different things and because you can communicate really well then it gives you less ability to access things because people think you are more capable”
(RNIB Scotland focus group)
A lack of resources and services

POLICY CONTEXT

Under the UK Government’s ‘austerity agenda’, there has been a greater focus on cutting or restricting public services which has impacted significantly on disabled people in Scotland.

Rates of various measures of health inequalities remain poorer for disabled people. There are several policies addressing disability in this context. Examples include the ‘Keys to life’, Scotland’s learning disability strategy. It has a strong focus on tackling the significant health inequalities faced by people with learning disabilities and includes many other measures to improve the quality of their lives. The Mental Health Strategy for Scotland sets out a range of key commitments across the full spectrum of mental health improvement, services and recovery to ensure delivery of effective, quality care and treatment for people with a mental illness, their carers and families. And the Scottish Strategy for Autism aims to improve outcomes for people with autism and ensure that progress is made across Scotland in delivering quality services. The Christie Commission Report, the NHS Healthcare Quality Strategy, and ‘Equally Well’ are also relevant.

There has been a greater focus on self-directed care and independent living over recent years. And the Scottish Government has committed to exploring the Buurtzorg model of care that has been developed in the Netherlands. However, there remains – and increasingly so – inconsistent charging for social care across Scotland.

The Scottish Government has also announced an intention to develop a strategy for families with disabled children, linking to activity to develop the Child and Adolescent Health and Wellbeing Strategy. Yet, there remain challenges for people trying to navigate services for themselves or for others, and in transitioning different services.

Being able to get around is vital for an independent life. For example, cuts to mobility have affected large numbers of disabled people. The SNP manifesto made a commitment to consulting on how people on disability benefits can best access adapted vehicles, aids and appliances, and the social security consultation included this. Transport Scotland published an Accessible Transport Framework in September 2016 – a ten-year plan to improve travel access for disabled people. And through the National Entitlement Card, Scotland’s older people and disabled people will continue to be able to travel for free on local or Scottish long distance buses.
A common theme across all groups was frustration with access to services.

“Getting to tourist places or concerts there is not a lot of information on websites on accessible parking or how accessible the venue is which would be helpful in a website.”
(Sense Scotland ‘Our Voice’ group)

“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 experiences and the impact of college to those who went to it and those who did not go to college.”
(Sense Scotland ‘Our Voice’ group)

“We are experiencing real difficulty in getting college places after school.”
(Sense Scotland ‘Our Voice’ group)

“People’s experiences of having to find alternative support when their day care centre closed before they attended Sense Scotland.”
(Sense Scotland ‘Our Voice’ group)

Limited in their provision which can result in long waits.

“I mean it can be 6 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)

“Booking interpreters for doctors and hospital appointments is difficult. When I am there on my own everything is very brief but when I am there with my interpreter it is a much better experience.”
(Action on Hearing Loss Scotland focus group)

“There were too many people and not enough carers to go around so I had to move away so I lost all my friends and stuff.”
(Capability Scotland focus group)

“In Scotland the interpreter numbers are very small compared to the population. I am not exactly sure of numbers but it is small.”
(Action on Hearing Loss Scotland focus group)

“It can be difficult to book interpreters and things need to be put off to different dates because there are so few interpreters in Scotland.”
(Action on Hearing Loss Scotland focus group)
“I had just come out of XXXX the first time, and I was still very suicidal. I was just moving house and there was a lot of things going on at the time, and my referral to psychiatry...to a CPN through the NHS took a good 4 and a half months.”
(SAMH focus group)

“If I make an appointment at the doctor’s I sometimes have to wait two weeks to get an interpreter”
(Action on Hearing Loss Scotland focus group)

Not available in their geographical area.

“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)

“It’s about more than an hour away from my home in an area I don’t know at all...it would be quicker to go to Glasgow than to go to this place.”
(SAMH focus group)

“Upper Springland is a life saver for me, but why can’t we be in our own community and living where we want?”
(Capability Scotland focus group)

For some, services had been cut or reduced in recent years.

“So much has been pulled back on lots of disabilities in terms of money. Everything is dependent on budgets.”
(RNIB Scotland focus group)

“I think it comes down to money and the cutbacks they are doing. There is a fund in place but it doesn’t cover what you need.”
(Capability Scotland focus group)

“Money, that’s what I put it down to. So GPs hands are tied sometimes, they can only do so much.”
(SAMH focus group)

Or, some services are not available at all.

“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)

“I’m not getting any support. The reason the GP said...something about chronological issues, whatever that means...well chronological is time issues, but that was that”
(SAMH focus group)

“I don’t get any support. They feel that my needs aren’t severe enough to need any support. If I wanted to support I would have to pay for it, but I don’t have that kind of money so I just have to get on with it myself.”
(ENABLE Scotland focus group)

“I feel when you’re in crisis that they don’t have anybody to refer to, you know, for talking?”
(SAMH focus Group)

“I ended up in a dementia home and the place just wasn’t suitable.”
(Capability Scotland focus group)
“They closed all the day centres in Aberdeen.”
(Capability Scotland Focus group)

“I would like support on budgeting, helping me going shopping and helping me choose the right kind of food. I would like support about how to deal with benefits and fill in forms.”
(ENABLE Scotland focus group)

Some felt that funding and provision was inconsistent between different areas.

“It seems to be so inconsistent. What you pay to the council seems to be different depending on where you live.”
(ENABLE Scotland focus group)

Funding was seen as a critical area to address.

“I would have liked to stay in my own flat with carers coming in, but the direct payment you get doesn’t cover for twenty four hour care.”
(Capability Scotland focus group)

“Looking to the future, I think the problem is going to be the amount of funding available. We have to try and keep that level up. Money is being chopped left right and centre. That affects services.”
(Action on Hearing Loss Scotland focus group)

“If you had a infinity pot of money it would be to have support for people individually to help them go and out and do the things they want to do.”
(RNIB Scotland focus group)

“I feel slightly weird when I go places. I have a one-to-one and she gets in free to most places. But some places I go then because I don’t have a certain card she has to pay. I wish there was a general card. It is limiting people to go places because you have to pay double. Me being on benefits I can’t afford that.”
(Capability Scotland focus group)

“It is time we lived in a society that supported people with a disability. It is not all about money. It is about people’s happiness.”
(Capability Scotland focus group)

“The services are under-funded. You can only get so much because the funding isn’t there.”
(RNIB Scotland focus group)
Having to fight to receive support

POLICY CONTEXT

People should have the same access to services and support across the country – through equality legislation and other explicit and implicit commitments that exist. However, there are often inequalities in access and availability and that people who know their rights and are able, or have advice and advocacy or other support from carers, friends or family etc, are able to get what they are entitled to from the system. There are also geographical variations, due to the different provision in different areas.

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)

“I always assume that because of my disability then I don’t get the priority.”
(ENABLE Scotland focus group)

“I met a lady called XXXXXXX and things changed. I started to get the help I needed. She fought to get me a job and fought to get me a job in blind craft.”
(RNIB Scotland focus group)

“There is a lack of loop systems, you have to fight for what you want whereas they are more accommodating to people with sight or mobility problems. We are still fighting for things that should have been in place 20 years ago.”
(Action on Hearing Loss Scotland focus group)

“If you have managed to do some things there can be a wrong evaluation of you that you can automatically find other things. It is like ‘ok he can find his own way.’”
(RNIB Scotland focus group)
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.

“You finish school and you think ‘where do I go now and what do I do next?’”
(Capability Scotland focus group)

“In children’s services everything is there for you. It is only now going through the transition and it is an absolute minefield.”
(RNIB Scotland focus group)

“My son has just left full-time education and now he has been thrown into the big bad world they call adult services. That is frustrating because there is not as much information out there as I thought there would be.”
(RNIB Scotland focus group)

“One thing, when looking back, this was when I turned 18, I’d been in the junior system, the children’s hospital in XXXXX a few times, and the minute I turned 18, that care was withdrawn, and they did not offer or give me any other support for several months, until I got taken into XXXX, and I think personally, if I had had the help after my 18th birthday then I probably would not have landed up in the hospital when I did, for as long as I did”
(SAMH Focus Group)

“Once you are an adult, it is like there is nothing more when can do for you”
(Capability Scotland focus group)

Some felt that children with disabilities were viewed more favourably than adults.

“When you are a child with a disability you are treated as cute and cuddly. As soon as you cross that barrier of 18/19 then suddenly people become uncomfortable with you.”
(RNIB Scotland focus group)

“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

Policy Context

There are a range of peer support projects across Scotland, often local projects funded by local authorities, the Scottish Government and/or charities. However, with cuts, they have – like lots of other services – struggled to continue to provide support to people. Other peer support is often ad hoc and loose with people making links and providing support informally although it can be vital to people. 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 and gaining social interaction.

"We meet on a Tuesday night and there are people there with wheelchairs and other disabilities. You get to meet new friends" (ENABLE Scotland focus group)

"I can go to Horizons where everybody there is like us, we’re all the same and there’s always something to do, the staff are really good and things like that. You’re not feeling different from everybody else" (SAMH Scotland focus group)

"Why isn’t there just a place for people with disabilities to meet new friends? There is nothing for people to do" (ENABLE Scotland focus group)

"I liked it at school. There were other people at my school with cerebral palsy" (Capability Scotland focus group)

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

"I love coming here and seeing what people can do. It makes me feel part of the community and it is normal" (RNIB Scotland focus Group)

People could also learn directly from others, including friends and family, about how to deal with their disability.

"My mum is blind and she taught me a lot of things to help. Things that the social work can’t tell you" (RNIB Scotland focus group)

"Most of the people that have been helpful towards me and improved my mental health have been other service users, more than professionals, and so situations where you’re around other service users are the helpful ones" (SAMH focus group)

"The main benefit for me is meeting other people. They are the only ones who know what it is like" (RNIB 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)
“The approach that the peer workers used facilitated my recovery and made me believe in myself, in recovery, and gave me a meaning and purpose to my day”
(SAMH focus group)

“I went up to XXXXX and started meeting other people. That was good, just learning how other people got on”
(RNIB Scotland focus group)

The value of meeting other people was a strong theme of the Sense Scotland focus group. Respondents talked positively about the opportunity meet other people in a different environment. The chance to take part in activities was particularly welcomed.

“Enjoy the Friendship Group in Dundee but find it challenging finding a venue for a meal that suits everyone.”
(Sense Scotland ‘Our Voice’ group)

“I met (Anon) who I went to nursery with, have not seen her since then, was great and we are pals again”
(Sense Scotland ‘Our Voice’ group)

“I know how to sign (language) with my pals, it was good to learn how to be able to talk with them, I need support from others and because we help each other I enjoy being involved”
(Sense Scotland ‘Our Voice’ group)

“We like chatting and meeting up but we know we have a serious role and we support each other with difficult times”
(Sense Scotland ‘Our Voice’ group)
The need to continue support from the third sector

**POLICY CONTEXT**

The Third Sector makes a direct impact on the growth of Scotland’s economy, the wellbeing of its citizens and the improvement of its public services. The Third Sector – comprising community groups, voluntary organisations, charities, social enterprises, co-operatives and individual volunteers – has an important role in helping the Scottish Government achieve its purpose of creating a more successful country with opportunities for all to flourish, through achieving sustainable economic growth. The Scottish Government is committed to the development of an enterprising third sector in Scotland. More than eight out of ten Scottish households used a charity and nine out of ten people in Scotland supported a charity in 2015. Levels of third sector activity are particularly high in rural areas, where local support services, village halls, and recreation groups are at the heart of their communities.

Third sector organisations receive a combination of direct funding, contracts for service provision and/or fundraising. In the disability sector, the third sector includes small and relatively large charities, disabled people’s organisations (DPOs) and other organisations, all of which have a role to place in supporting inclusion and representation and providing advocacy, advice and other services.

The support that people received from Third Sector organisations was viewed as critical.

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

“We mostly would come here to Action on Hearing Loss because we know the staff and the staff are very helpful. We would come here and they would book interpreters for us.”
(Action on Hearing Loss Scotland focus group)

“RNIB are very useful at certain times in your life. You know it is somewhere you can get information.”
(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)

“Really value coming to Sense Scotland as a group member.”
(Sense Scotland ‘One Giant Leap’ project)
“Different activities are good because we learn new things that we have never done before, I made lots of mistakes but we were all the same and were okay to laugh about it.”
(Sense Scotland ‘One Giant Leap’ project)

The access to services and training was welcomed.

“RNIB were able to take me and other carers on a course to explain what it is like to be blind and explain different types of blindness. It made me understand what my son faces and that was really, really helpful.”
(RNIB Scotland focus group)

“I am able to communicate with the staff here where I might have difficulty with other organisations. I benefit from coming here.”
(Action on Hearing Loss Scotland focus group)

“They give a good service to the older people through the libraries. People can come to the library once a month and get batteries. I think it is a service that should be kept.”
(Action on Hearing Loss Scotland focus group)

“I found XXXXX [third sector organisation] to be really really helpful for me, and I think it’s definitely created more of a shift with me and my ability to deal with life and reality more because I think it’s much more flexible, it’s much more informal, so there’s more of a we’re both human being rather than this kind of hierarchy of you know best because you’re the professional.”
(SAMH focus group)

“They don’t boss you around, they help you make your own decisions and ideas about things. They don’t boss you around. They just talk things through and what you want…they go with the patient’s preference.”
(SAMH focus group)

“SAMH has been an unbelievable help for me. Amazing, because it got me from the day that I got out of hospital until I was seeing my CPN, and actually they’re still seeing me through, and sometimes I’ll actually phone somebody from SAMH rather than somebody from the NHS because SAMH deal with it better than the NHS do, which is shocking.”
(SAMH focus group)

The positive impact of engaging with Third Sector organisations was clear.

“Here is heaven to me. People know me and understand me.”
(RNIB Scotland focus group)

“I always felt like the outsider. I always felt like I didn’t really fit. Through doing this I realised I could fit in. All I needed to do was keep trying at it.”
(ENABLE Scotland focus group)

“I come in here for support and the staff are very deaf aware. I am very confident.”
(Action on Hearing Loss Focus group)
“ENABLE has made a heck of a difference to me. It has made me more confident. A year ago I wouldn’t have travelled on the train on my own but now I can.”

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

“ENABLE has made a heck of a difference to me. It has made me more confident. A year ago I wouldn’t have travelled on the train on my own but now I can.”
(ENABLE Scotland focus group)

“I just feel that having somewhere to go and meet up with people is good as it is giving you something to do and it is letting you meet new people.”
(ENABLE Scotland focus group)

“I have had a lot of confidence from ENABLE. It is nice going to the branch and meeting up with people and coming down to events. You feel more confident.”
(ENABLE Scotland focus group)

“I come here and they help me look for work. I eventually got a job and Action on Hearing Loss helped me with that. I might not have got it on my own.”
(Action on Hearing Loss Scotland focus group)

“I have met quite a lot of friends and if it wasn’t here I would be stuck. I would be sitting in the house looking at four walls, nothing to do.”
(ENABLE Scotland focus group)

“When you have been part of it for so long, if it was to close down you would go into depression or something because it wouldn’t be the same”
(ENABLE Focus group)

“If it wasn’t for the local volunteers at my ENABLE branch then I wouldn’t be here. So this place means quite a lot to me.”
(ENABLE Scotland focus group)

Adequate funding for organisations was believed to be an issue.

“They (RNIB) are a good resource but a stretched resource.”
(RNIB Scotland focus group)

“I think Action on Hearing Loss could do with increased funding and put that to good use. Any money put in can be used to good purpose.”
(Action on Hearing Loss Scotland focus group)
A lack of understanding and action from Government

POLICY CONTEXT

There have been numerous plans, particularly by the Scottish Government and enhanced devolution, as outlined in earlier sections of this report, and while these could certainly go further, particularly in certain areas, what has been attempted or achieved does not seem to be being picked up by people except the most high profile and well publicised.

Most participants in the focus groups said that the UK and Scottish Governments weren’t doing enough to support people living with a disability.

“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)

“I just don’t think that the Government have a clue.”
(RNIB Scotland focus group)

“The Government needs to get something better. There is hardly anything for people with learning disabilities to do.”
(ENABLE Scotland focus group)

“There are decisions that are positive but they don’t communicate it very well. Or if it isn’t positive then they don’t communicate why they aren’t doing whatever it is. If you can’t do something just tell them you can’t.”
(RNIB Scotland focus group)

“The government are not helpful with disabilities. They maybe assist people with poverty but not people with disabilities.”
(Action on Hearing Loss Scotland focus group)

“A lot of lip service is paid to disabled people and they promise things that they don’t deliver.”
(Capability Scotland focus group)

“We have got our disabled pass in Scotland with the new travel scheme. It is one of the big things that made a big difference to a lot of visually impaired people.”
(RNIB Scotland focus group)

“Who is supposed to talk to councillors and politicians? How does it work? I don’t know what gets done at Parliament and council.”
(RNIB 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)

Many felt that politicians, like wider society, lacked understanding of the needs of people living with disabilities.

“Government doesn’t understand. It is as if they have this notion of what it is to be a blind person.”
(RNIB Scotland focus 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)

“They need to listen to someone with a learning disability so they know what it is like.”
(ENABLE Scotland focus group)

Many felt that the governments were not listening.

“They don’t listen to you and they don’t listen to what you need.”
(RNIB Scotland focus group)

“The Government needs to listen and hear people.”
(Capability Scotland focus group)

“I feel that the government don’t listen and people have had bad experiences and frustration creeps in. Hopefully the government will change attitudes and have more respect.”
(Action on Hearing Loss Scotland focus group)

“I think the voice of disabled people is heard but it is not taken on board.”
(Capability Scotland focus group)

“I wrote to my MP as we wanted to keep our disability living allowance and I got screeds and screeds of paper back from my MP and it was almost as if he didn’t know what he was talking about.”
(RNIB Scotland focus group)

Some felt they actively working against the interests of disabled people, especially with changes to welfare reform.

“I often think the Government see disability as a negative. They should start seeing it more positively.”
(Capability Scotland focus group)

“The Government have no awareness of what it is like in real life, on a day-to-day. They just look at budgets and say ‘cut that and who cares what the consequences are!’”
(RNIB Scotland focus group)
“We have opinions, we have the right to speak out, we have the right to a life, we have the right to choose what we want to do with our lives and the government should be working to empower us to make our own choices rather than trodding on us.”
(Capability Scotland focus group)

Many wanted to see more investment in service provision.

“I think the government need to provide more interpreters and it is about awareness building. We want very good interpreters so we need to encourage the government to provide more interpreters.”
(Action on Hearing Loss Scotland focus group)

“I think the Government should pay a wee bit more. We have to sacrifice a lot of things.”
(Capability Scotland focus group)

“The Government needs to provide certain services. I am not asking them to be free. They just need to be affordable.”
(Capability Scotland focus group)

“Please make things happen. Don’t just sit there and talk. Make changes and make things happen.”
(RNIB Scotland focus group)

Some questioned the lack of MSPs with a disability.

“The Scottish Government, MSPs, where are the disabled, blind, deaf MSPs? If they were there things would change.”
(Action on Hearing Loss Scotland focus group)

“It feels as if there is no representation in Government.” (RNIB Scotland focus group)
Conclusions and recommendations

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 focused on key issues highlighted in the focus groups, and reviewing the policy context.

A recurring theme is that while matters 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 on the ground.

The challenge of living with a disability

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.

Recommendation: DAS calls of the full implementation and monitoring of the Accessible Transport Framework, which was published in September 2016.

Recommendation: The Scottish Government should consider ways to build on the success of the BSL Act, including a national standard for communication and other ways to ensure greater availability and support for accessible communications.

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.
Many, especially those with a learning disability had experience of encountering stigma on public transport. Stigma and discrimination can clearly lead to people feeling isolated.

Some people with a mental health condition talked about isolating themselves from friends and family due to self-stigma. There were a number of respondents who felt that discrimination was not an issue for them personally. Others were more sceptical and felt that there was still a long way to go to change attitudes.

There was a sense that people made assumptions about what it meant to have a particular disability. Some had experience of people assuming that they could not do things that they could.

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 had positive experience of support from health and other professionals, but there was a sense that this was them ‘getting lucky’ as treatment tended to be mixed. For those with a mental health condition, poor treatment was most frequently experienced in a hospital setting or from someone not familiar with their circumstances. Some had negative experience of the justice system and felt that there was no account taken of their disability in how they were treated.

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

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 to 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’. 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 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.

The need to improve employment opportunities and access to work

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 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. 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.

In the last seven years, ENABLE Scotland’s employment services have supported over 2000 people into work but only around 10 people into an apprenticeship. There are a few key reasons for this lack of equality. Many Modern Apprenticeships (MAs) require minimum standards of attainment. This discounts otherwise great candidates who just happen to have a learning disability but not the right number of standard grades. Often the application process isn’t accessible. Experience, a positive attitude and star potential count for nothing if you can't complete online assessments or persuade the stranger calling your mobile you’re the one for the job! Then there’s higher competition, such is the popularity of MAs, and candidates face the fear and inflexibility many employers and training providers feel when considering someone who has a disability. A targeted grant to specifically support disabled people into apprenticeships, through apprenticeships and into work after the apprenticeship is completed and support reasonable adjustments where needed. MA providers should be supported to develop their workforce skills and processes to be inclusive. This funding should be reported against and measurable directly in the number of people they support through their programmes.
Recommendation: 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.

This should include new, targeted employability programmes promoting skills for work as outcomes. And there should be greater education for businesses to understand the opportunities of employing disabled people. Encouraging strong partnership working between support providers and business is essential in ensuring that needs are aligned with programme outcomes.

The type of support services that would work best for disabled people would bear the following characteristics:

Specialist: The 2011 Sayce Review recommended specialist, personalised and local schemes that provide flexible person-centred tailored support.

Flexible: The Sayce review found that evidence from across learning disability, mental health, physical rehabilitation that support that is flexible, personalised, long lasting when needed, with a rapid focus on job search, is more effective than a series of stepping stones to employment.

Person-centred: employment support services that are shaped by a person-centred outcomes-focussed assessment/dialogue, that recognises personal ambitions, will result in positive and sustained outcomes for disabled people. Disabled people overwhelmingly want personalised employment support and this corresponds with the evidence on what type of support is the most effective. The Supported Employment Framework for Scotland (2010) emphasises the need for job coaching for individuals with a disability or long-term health condition to support them into work that matches their needs and aspirations, and hence has a much greater chance of being sustainable.

Impact of welfare reform and social security

Recommendation: 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, with different expectations and cultures. There will therefore need to be ongoing coordination with Westminster and reserved powers and benefits.

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.
Disabled people often face extra financial costs such as heating, laundry, transport, care and therapy charges which, taken together, can average as much as £550 per month. Benefits should support all citizens, when required, including ensuring those who are disabled, due to a physical, learning, sensory or mental health issue can live as independently as practically possible and fulfil their true potential. DAS believes there is an opportunity for positive welfare reform to bring about a genuine system of social security which is enabling and underpinned by a commitment to human rights, dignity and respect. A ‘cut price’ welfare system is a false economy in the form of social exclusion, lost talent and added pressure on other public services, especially health and social care, as well as other costs of inequality.

DAS’ position on key aspects of social security being devolve include:

■ For disabled people on benefits, there has been significant cuts, which have been well publicised. Yet, over half of the £1.63bn social security budget being devolved through the Scotland Act is currently spent on Disability Living Allowance (DLA) and Personal Independence Payments (PIP). This is a clear chance to improve key elements of the current system.

■ However, it is important that we manage expectations about what can be undertaken by the Scottish Government with the devolved powers and how far things can be improved. The system is complex and there will be two systems, with different expectations and cultures. There will therefore need to be ongoing coordination with Westminster and reserved powers and benefits. Improvements need to be made but in a well managed way, taking the time to get things right. The system is already complex and there will be two systems, with different expectations and cultures. Any changes to social security should ensure there is no detriment to existing benefits.

■ Reform of social security in Scotland must address the failure of the benefits system to adequately compensate disabled people for the extra financial costs they face. The changes to the system in recent years have undermined disabled people’s right to live independently and their right to family life in contravention of articles 19 of the UN Convention on the Rights of People with Disabilities (UNCDP) and Article 8 of the United Nations Convention on Human Rights (UNCHR). This affects disabled people, carers and others around them and the wider society and economy.

■ Greater automatic entitlement should be built into the social security system as this would assist people to access the support they are entitled to, and would save some resource and also the impact on people, compared to the current system.

■ Assessments should be more personalised to a persons condition and avoiding irrelevant questions.
There is also an opportunity for social security to be better coordinated with other systems of support and referral, such as the Welfare Fund; and signposting people to other forms of advice and support.

Other opportunities for a better approach would be clear and respectful communications about the changes being made and the culture throughout the social security system being introduced.

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.

Recommendation:
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.

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:
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 resources 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. Recognise that this is one of they key added value elements of the third sector. 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.
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 and gaining 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 meet other people in a different environment. The chance to take part in activities was particularly welcomed.

The impact of different people attending particular services can challenge integration and meeting different people; but on the other hand, a downside 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.

Recommendation:
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.

Recommendation:
DAS calls on the Scottish Government and local authorities to continue and extend its support for the third sector as civil society has a vital role in helping people across society but particularly the most vulnerable. There should also be greater incentives for partnerships; longer awards of funding; and increased support for third sector organisations to work with public bodies to build sustainability plans.
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 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 1 in 5 campaign. Some DAS members are likely to access this fund to support people with disabilities 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.

**Recommendation:**
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 needs to be accountability and clear responsibility, with objectives and timelines, for 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:**
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:**
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.
Notes

1 http://www.gov.scot/Topics/People/Equality/disability

2 http://www.scope.org.uk/campaigns/extra-costs/what-are-costs


4 Scottish Government hate crime statistics and press release (2013-14)


7 http://www.gov.scot/Topics/People/Equality/disability


10 http://www.gov.scot/Publications/2016/10/9964/downloads

11 http://www.un.org/disabilities/convention/conventionfull.shtml The UNCRDP is an international human rights treaty of the United Nations intended to protect the rights and dignity of persons with disabilities. Parties to the Convention are required to promote, protect, and ensure the full enjoyment of human rights by persons with disabilities and ensure that they enjoy full equality under the law. The Convention has served as the major catalyst in the global movement from viewing persons with disabilities as objects of charity, medical treatment and social protection towards viewing them as full and equal members of society, with human rights.


13 http://www.scope.org.uk/campaigns/extra-costs/what-are-costs


16 https://beta.gov.scot/groups/independent-advisory-group-on-hate-crime/


https://theharderthit.wordpress.com/

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http://inclusionscotland.org/access-to-politics-project-launches/

http://inclusionscotland.org/information/employability-and-civic-participation/access-to-politics/aefs/

http://www.gov.scot/Topics/People/Equality/DataGrid/Disability/DisabLab

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RNIB, My Voice, 2015


https://blogs.gov.scot/developing-young-workforce/

http://www.gov.scot/Publications/2016/07/2799

https://www.skillsdevelopmentscotland.co.uk/media/40691/2869_sds_equalities_action_plan_digital_v7.pdf


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