



Values Into Action  
Scotland

# Universal Periodic Review

Joint Submission from The Scottish Commission for People with Learning Disabilities (SCLD) and Values into Action Scotland (VIAS)

March 2022

The Scottish Commission for People with Learning Disabilities (SCLD) – Established in 2001

Values into Action Scotland (VIAS) – Established in 2007

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# 1. Introduction

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*“Listen to our choices!”*

## UPR Focus Group Participant (November 2021)

- 1.1. Scotland is changing, and for people with learning disabilities (LDs)<sup>i</sup>. These changes could be significant in empowering them to live the life they want. While Scotland no longer has a universal approach to confining people with LDs in institutions, many people with LDs still face significant barriers to realising their human rights. These problems remain unchallenged in part because of the invisibility of this population and the devaluation they face.
- 1.2. In this report, SCLD and VIAS provide information on the human rights situation in the UK, focusing primarily on Scotland. We have included an assessment of the implementation of the 2017 recommendations and have highlighted significant human rights issues facing people with LDs and those who support them, and we make recommendations on how these should be addressed.
- 1.3. This report is informed by first-hand qualitative evidence from the 42 people with LDs and their supporters during our UPR focus groups in 2021. It draws from SCLD's survey on people with LDs and their families and carers' experience during the COVID-19 Pandemic and our experience over the 21 years of SCLD's operation.
- 1.4. Recommendations for change are listed at the end of each section/subsection.
- 1.5. Please see the annexes submitted alongside this report for more information on this submission's methodology, contributing organisations, and an Easy Read summary.

## 2. Progress made following the Universal Periodic Review Recommendations (2017)

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### 2017 Recommendations

#### Constitutional and Legislative Framework (A41)

Not implemented: 134.66, 134.65

In the process of implementation: 134.59

Partially implemented: 134.60, 134.63

#### Acceptance of international norms (A12)

Not implemented: 134.43-48

In the process of implementation: 134.12

#### Equality and Non-discrimination (B31)

Not implemented: 134.109, 134.106, 134.104.

Partially implemented :134.105, 134.101, 134.114.

### 2.1. Constitutional and Legislative Framework

*“Human rights are about choice, flexibility, and control. They are about getting your voice heard”*

UPR Focus Group Participant (November 2021)

- 2.1.1. In the UK, we are facing considerable weakening of the Human Rights Act to a Bill of Rights. The proposals made by the UK Government appear focused on the idea that many human rights cases are spurious and that human rights are dependent on ‘good behaviour.’ The reform aims to reduce the number of human rights cases on reserved matters such as economic rights, undermine the strength of the courts and increase deportations, all while purporting to protect freedom of speech and British democracy. This is deeply concerning for people with LDs in Scotland, given the inequitable negative impact of the reform on them and their lack of opportunity to engage in this process.
- 2.1.2. The lack of inclusion of people with LDs in this reform process is an issue SCLD has raised<sup>ii</sup>. The exclusion of people with LDs was illustrated in the UK Government's failure to produce and publish a suitable, Easy Read consultation document. As a result, a collective letter was sent to the Joint Human Rights Committee from over 205 organisations and individuals, including SCLD. Following this, one day before the UK's Government's Consultation on the Human Rights Act was due to close; a six-week extension was given for responses by those who required an accessible version. Had civil society and advocates not intervened, this would not have occurred.
- 2.1.3. The UK Government's current approach differs significantly from Scotland's human rights incorporation agenda. The difference is best illustrated in a paper from Dr Katie Boyle and Professor Nicole Busby on Human Rights and devolution:

*“It is apparent that, for some time, those in the devolved nations have fostered a receptive approach to human rights development with any obstruction in this respect being more likely to be confined to England.”<sup>iii</sup>*

2.1.4. These different approaches, the complexity of devolution agreements and legislative competency for devolved nations led to a supreme court challenge to The United Nations Convention on the Rights of the Child (Incorporation) (Scotland) Bill<sup>iv</sup>. The result has been a delay in the work of the Scottish Government (SG)<sup>v</sup> to implement the new United Nations Convention on the Rights of the Child Incorporation (Scotland) Bill, despite UPR recommendations<sup>vi</sup>.

2.1.5. Unlike the rest of the UK, Scotland has seen significant steps in aligning law to international treaties<sup>vii</sup>. This is best shown in Scotland's commitment to incorporate several conventions as part of a new Human Rights Bill for Scotland<sup>viii</sup>. The ongoing work on the new Human Rights Bill for Scotland has been based on wide-scale public and civil society engagement. The Convention on the Rights of Persons with Disabilities (UNCPRD) is to be incorporated as part of this Bill, and a lived experience board of people with LDs supports the Bill's development.

2.1.6. While SCLD welcomes these developments, SCLD remains cognisant that prior human rights work in Scotland, such as Scottish National Action Plan (SNAP) 1 made a minor impact on lived experience. Therefore, SNAP 2 and SNAP's leadership panel recommendations must be introduced and implemented promptly.

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| <ol style="list-style-type: none"><li>1. UK Government to take expert advice from the Human Rights Independent Review, British Human Rights Institutions, and civil society on the Human Rights Act Reform proposals, ensuring this process includes the voices of people with LDs throughout 2022</li><li>2. UK Government to follow SG in the incorporation of international human rights treaties</li><li>3. SG to continue incorporating international treaties, including the UNCPRD, through the new Human Rights Bill for Scotland and commit to enforceable and accessible remedies as part of this process</li><li>4. SHRC promptly introduce SNAP 2 with milestones and audit built in to evaluate impact</li></ol> |
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## 2.2. Acceptance of international norms

### Complaints Mechanisms

2.2.1. In Scotland, we have two National Human Rights Institutions, The Equality and Human Rights Commission (EHRC) and The Scottish Human Rights Commission (SHRC). They have powers to promote human rights, provide information, guidance, education on rights and monitoring of law, policies and practices, and powers to intervene in civil proceedings. However, for the SHRC, this has not extended to offering an advice service, representing individuals, or taking on their cases <sup>ix/x</sup>.

- 2.2.2. Additionally, we have The Children and Young People’s Commissioner for Scotland (CYPCS)<sup>xi</sup>. One of the most considerable advancements for the rights of people with LDs in Scotland comes from their investigation into restraint and seclusion in Scottish schools<sup>xii</sup>.
- 2.2.3. Despite this, people with LDs and those who support them do not feel enough action has been taken to improve their lives. Because of this, some<sup>xiii</sup> people with LDs, autism and those who support them called for an LD, Autism and Neurodiversity Commissioner<sup>xiv</sup> who has significant powers of investigation and enforcement. A commitment was then made to pursue this in Scotland’s Programme for Government 2021<sup>xv</sup>.
- 2.2.4. This is a significant development that SCLD believes has the potential to support the UPR recommendation to:
- “...allow individual complaints mechanisms under United Nations human rights treaties such as the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment.”<sup>xvi</sup>*
5. SG to develop LD, Autism and Neurodiversity Bill in conjunction with Scottish Human Rights Bill. This should include the creation/appointment of a commission/commissioner with powers to investigate complaints of human rights abuses. A wide representation of people with LDs should lead the development of a commissioner’s office/commission

6. Extend the powers of the SHRC to ensure the right to an effective remedy for human rights breaches is equally available in Scotland

## Gender Based Violence

*“They stabbed me in the neck. then the police asked me if I was doing foreplay; I didn’t even know what that meant”*

UPR Focus Group Participant (November 2021)

- 2.2.5. Since the 2017 recommendations, the issue of Gender Based Violence (GBV) has garnered significant attention. Despite the UK not yet implementing the recommendation to ratify the Istanbul Convention in Scotland, a £38 million investment was made in projects working to tackle GBV<sup>xvii</sup> and support the delivery of Scotland’s ‘Equally Safe Strategy’<sup>xviii</sup>.
- 2.2.6. However, there is still no robust dataset on women with LDs experience of GBV. Global rates of GBV tell us that 90% of women with LDs have been subjected to sexual abuse, with 68% experiencing sexual abuse before turning 18<sup>xix</sup>. A small-scale study conducted in Glasgow<sup>xx</sup> supports this, showing that 73% of the 62 participating disabled women had experienced domestic abuse, and 43% had been sexually assaulted<sup>xxi</sup>.
- 2.2.7. GBV was a significant concern that emerged from our UPR engagement sessions, with several women detailing their experiences and one woman saying,

*“I could have been like Sarah Everard<sup>xxii</sup>; I could have been dead”<sup>xxiii</sup>*

2.2.8. While research<sup>xxiv</sup> is clear that the intersectional experience of women with LDs places them at an increased risk, we have not seen widescale developments in focused support for this group. Instead, we have seen challenges in accessing support<sup>xxv</sup>. The life-threatening consequence of not accessing the right support is evidenced in the significant case review of the death of Miss A in North Lanarkshire in 2016<sup>xxvi</sup>.

7. SG to review appropriateness and effectiveness of adult support and protection referrals based on women with LD experiencing GBV and find alternative methods of support
8. SG support for an accessibility audit roll out for all GBV support services by 2023

## 2.3. Equality and Non-Discrimination

### Hate Crime

2.3.1. Since 2017, Scotland has made steps in advancing equality and non-discrimination through the Hate Crime and Public Order (Scotland) Act (2021)<sup>xxvii</sup>. Sections 14 and 15 of the Act are significant to people with LDs as they commit the SG to publish disaggregated figures on disability hate crimes. We now know that in over half of disability aggravated hate crimes, the perpetrator showed prejudice towards those with a LD (59%)<sup>xxviii</sup>. This is concerning given research<sup>xxix</sup> that found that people with LDs said they were not believed when they reported crimes. Even more worrying is that while the Bill did pass into law, there were widespread concerns that it would have a detrimental impact on individuals' freedom of speech, and there have been consistent threats to repeal the act<sup>xxx</sup>.

2.3.2. Following the Bill's entry into law and publication of the implementation overview of '*The Tackling Prejudice and Building Connected Communities Action Plan*'<sup>xxxi</sup>, we are awaiting the new SG strategy and plans to tackle hate crime.

9. SG to ensure the representation of LD in the development of the new strategy to tackle hate crime and representation on relevant advisory groups
10. UK Government and devolved nations to commission national guidance for media on reporting on LD
11. UK Government and devolved nations to develop awareness raising campaigns on the experiences of people with LD

## Data Collection

*“Without better data to underpin policy making, Scottish Government ambitions to improve the lives of adults with learning disabilities are unlikely to be realised.”*

Fraser of Allander (2021)<sup>xxxii</sup>

**2.3.3.** Robust data collection is critical to advancing equality and non-discrimination in Scotland. While there have been some advancements in data collection (i.e.hate crime), we are yet to see widespread improvements.

**2.3.4.** The lack of data collected on people with LD in Scotland was highlighted when we wanted how many people with LDs had died from Covid-19<sup>xxxiii</sup>. A lack of available data in Scotland resulted in an unacceptable delay in understanding how the crisis affected people with LDs. The death rate between January and August 2020 was not published until February 2021 and was based on Census data captured more than ten years ago. To date, we are still to see disaggregated data produced on the experience of people with LDs in basic health data and across social, economic, and political life. In terms of intersectional impacts, the data is even poorer<sup>xxxiv</sup>.

<p><b>12.</b> SG to examine approaches to build on existing data to enable understanding of the requirements of people with LDs throughout their life course and to build evidence on whether people can realise their human rights in line with Article 31 of the UNCRPD</p>
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### 3. Emerging Human Rights Violations Experienced by People with LDs Scotland

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**Failure to protect the right to life during the COVID-19 pandemic:** ECHR: Articles 1, 2, 13, 14, 15, 18; UN Ratified Treaties: ICCPR: Articles 4, 6 (2), 26. UNCRPD: Articles: 5, 10, 11, 25.

**Restrictions on independent living during the COVID-19 pandemic:** ECHR: Articles 1, 5, 8, 14, 15, 18; UN Ratified Treaties: ICCPR - Articles 8, 11, 14, 15, 17, 18; UNCRPD - Articles 9, 11, 19, 23, 30.

**Failure to ensure equal recognition in the law:** ECHR: Articles 1, 8, 10, 13, 14, 18; UN Ratified Treaties: ICESCR: Articles 1, 2(2), 4, 5; ICCPR: Articles 9(1), 16, 17, 18, 19, 23, 26; UNCRPD: Articles 12, 14, 19, 21.

**Failure to respect liberty:** ECHR: Articles 1, 3, 5, 6, 8, 13, 14, 18; UN Ratified Treaties: ICESCR: Articles 1, 2(2), 4, 5, 10, 12, 13; ICCPR: Articles 2, 5(1), 7, 9(1), 9(4), 9(5), 10(1), 12(1), 16, 17; UNCRPD: Articles 12, 14, 19, 21, 28.

**Failure to protect from torture, cruel, inhuman, or degrading treatment or punishment:** ECHR: Articles 1, 3, 8, 13, 14, 17, 18; UN Ratified Treaties: ICCPR Articles 2(2), 5, 9(5), 10, 12, 15, 17; UNCAT: Articles 2, 10, 11, 12, 13, 14, 16; UNCRPD: Articles 10, 14, 15, 16.

**Failure to provide an adequate standard of living and social protection:** ECHR: Articles 1, 13, 14, 17; UN Ratified Treaties: ICESCR: Articles 2, 3, 5, 6, 7, 8, 9, 10 (3), 11, 12, 13; UNCRPD: Articles: 19, 20, 24, 25, 26, 27, 28.

#### 3.1. Failure to Protect the Right to Life during the COVID-19 Pandemic

*“Underneath all that is fear: fear of losing him to the virus if he got it - fear of death; fear of challenges to nursing him as he would be so frightened in the main hospital, he wouldn't tolerate an IV drip or a mask; fear of virus causing damage to his lungs, the heart if he got it badly...”*

Parent/Carer's response to SCLD COVID-19 Survey (2020)<sup>xxxv</sup>

3.1.1. People with LDs have experienced significantly higher death rates from COVID-19 than the general population<sup>xxxvi</sup>. Data from Scotland<sup>xxxvii</sup> is clear that people with LDs were at least three times more likely to die from COVID-19 than the general population.

3.1.2. Given the increased risk COVID-19 presented for people with LDs, a significant source of anxiety was clinical decision making and access to life-saving medical interventions. During the initial stages of the pandemic, people with LDs were among those being pressured to sign Do Not Resuscitate (DNRs), and in other cases, found that DNRs had been applied to case records without discussion<sup>xxxviii</sup>. The Scottish Parliament's Equality and Human Rights Committee<sup>xxxix</sup> and the House of Commons Health and Social Care Committee<sup>xl</sup> acknowledged that although there was never national NHS guidance for applying DNR



notices to people with LDs, notices were issued inappropriately for some individuals, thus infringing on their right to life.

- 3.1.3. Therefore, it is unacceptable that the Terms of Reference<sup>xli</sup> for Scottish COVID-19 Public Inquiry omits a focus on disproportionately impacted equalities groups<sup>xlii</sup>. It is also disappointing that the Terms of Reference do not extend to examining the devaluing of people with LDs lives through political and media messaging that stated that the pandemic would only impact the ‘vulnerable’<sup>xliii</sup>.

**13.** UK and devolved nations' inquiries into the handling of the COVID-19 pandemic should include evidence sessions from people with LDs

**14.** UK including devolved nations, to conduct inquiries into political and media messages surrounding the COVID-19 Pandemic

### 3.2. Restrictions on Independent Living during the COVID-19 Pandemic

*“I’m worried that if I don’t get back to my groups soon, what is going to become of me? I’m going to be a nobody and lost and very upset.”*

Individual response to SCLD’s COVID-19 Survey (2020)<sup>xliv</sup>

- 3.2.1. According to a UK wide longitudinal study<sup>xlv</sup>, over a quarter (27%) of people with LDs and 58% of people with more severe<sup>xlvi</sup> LDs used day services before the pandemic started. This study found that in December 2020, almost all day, respite and community services had stopped. By August 2021, a third of people with LDs (32%) and almost half of those with more severe LDs (48%) had not returned to their day service, either in person or online. By 2021, a quarter of people with LDs and over half of carers of people with more severe LDs said they were receiving less support than before the pandemic started. This reduction in services significantly impacted individuals, with 58% of respondents to an SCLD survey saying they were lonelier than before COVID-19<sup>xlvii</sup>.
- 3.2.2. When services stopped, many people with LDs were encouraged to access support online. However, official statistics show that disabled people are more than four times as likely never to have used the internet<sup>xlviii</sup>. SCLD’s survey showed that only 33% of people with a LD had used social media in the earlier weeks. According to ONS (Office for National Statistics), this compares to 59% of disabled people and 71% of non-disabled people<sup>xlix</sup>.
- 3.2.3. Given the elevated levels of digital exclusion faced by people with LDs during this time, SCLD welcomes the commitment from the SG Technology Enabled Care Team to work with SCLD on showcasing the value and impact of technology enabled care.

- 15.** Scottish Government to ensure the new National Care Service places human rights compliance at its centre as recommended by the Independent Review of Adult Social Care in Scotland<sup>i</sup>
- 16.** The UK and devolved nations to report on learning disability support services' re-mobilisation and uptake by 2023/24

### 3.3. Failure to ensure Equal Recognition in the Law

*"I have another pal [friend] who's on guardianship order from her cousin. Her cousin goes wherever she goes, she's got no privacy, no say, and she doesn't ken [know] when she's gonna get off it."*

UPR Focus Group Participant (November 2021)

- 3.3.1.** The Scottish Mental Health Law Review (SMHLR)<sup>ii</sup> is currently consulting on proposals made by its Executive Team for changes to mental health and incapacity law in Scotland. However, any changes proposed for people with LDs must address the recommendations outlined in the earlier Independent Review of LD and Autism in the Mental Health Act (IRMHA)<sup>iii</sup>, including issues relating to the inclusion of learning disability within the definition of a mental disorder.
- 3.3.2.** In addition, under the Adults with Incapacity (AWI) Act, the least restrictive option is required; however, this is often not reflected in lived experience. People with LD who took part in SCLD's UPR consultation events told us that guardianship orders entail a serious restriction on their choice, autonomy, and privacy. This is concerning given that people with LDs represent 45% of all welfare guardian orders under the AWI Act<sup>liii</sup>. Furthermore, concern has been expressed about the lack of automatic, periodic judicial scrutiny of guardianship in relation to indefinite orders, which apply to 5% of people with LDs<sup>liv</sup>.
- 3.3.3.** Pre-existing concerns regarding guardianship have been heightened during the pandemic. Recent research<sup>lv</sup> found that people had been moved during this time without the protection of legal authority and expressed significant concern that these cases may also constitute Article 5 deprivation of liberty and a breach of the European Convention on Human Rights (ECHR). The same report also cited endemic examples of poor practice, including a lack of understanding of the law, limited knowledge of good practice, confusion over the nature of placements and misunderstanding over power of attorney.

- 17.** SG to respond to the IRMHA recommendations as part of the ongoing SMHLR and explore connections with the Scottish Human Rights Bill and the LD, Autism and Neurodiversity Bill
- 18.** SG to explore embedding a UNCRPD compliant national supported decision framework as part of the ongoing SMHLR. This should be considered alongside appropriate safeguards to ensure that the rights, will and preferences of people with LDs are respected

### 3.4. Failure to Respect Liberty

*“It’s about having the right to live and be supported in your community. Not having to worry that if you have a crisis and end up in the hospital, you will be stuck there.”*

UPR Focus Group Participant (November 2021)

3.4.1. ‘The Coming Home report’ showed 67 people with LDs and complex needs were subject to a delayed discharge. Of these, 22% had been in hospital for more than ten years and another 9% for five to ten years<sup>lvi</sup>. An earlier report found that 32% of people in LD wards were delayed discharges<sup>lvii</sup>. The latest Mental Health and LD Bed Census showed 54 delayed discharges in LD specialities, with an average length of delay totaling just under four years<sup>lviii</sup>.

3.4.2. ‘The Coming Home report’ also identified 705 people living in Out of Area Placements (OAPs), 45% being out-of-area for more than ten years. One hundred nine people had not chosen their OAP and were identified as a priority to return. There were also 79 people placed outside of Scotland<sup>lix</sup>. The main reasons detailed by Health and Social Care Partnerships were lack of funding, service provision and/or suitable accommodation<sup>lx</sup>.

3.4.3. Living in a hospital setting without clinical need or being placed out of area without choice is an excessive restriction on liberty and the right to home life. Institutional living also risks exacerbating individuals’ mental distress and ill health, while closed cultures risk infringing the right to freedom from inhuman and degrading treatment. The aforementioned reports evidence a range of areas where rights are restricted, including access to the community.

3.4.4. One of the main reasons community access is denied to people with profound and multiple learning disabilities (PMLD) is the lack of fully accessible, Changing Places Toilets (CPTs)<sup>lxi</sup>. Most recent figures state that there are 246 CPTs in Scotland and 1692 in the UK, with the SG committing 10 million in funding for expansion in Scotland.

3.4.5. The ongoing institutionalisation of people with LDs illustrates a failure to meet the standards set out in UNCRPD Article 19. It demonstrates the gap identified in General Comments Number 5 of an:

*“...inadequacy of social support and protection schemes for ensuring living independently within the community”<sup>lxii</sup>.*

3.4.6. In 2021, we saw £20 million of funding allocated to Integration Authorities to fulfil the vision that OAPs and hospital stays are significantly reduced by 2024<sup>lxiii</sup>. This was followed by a report from the working group on complex care and delayed discharge<sup>lxiv</sup>, outlining the implementation framework.

**19.** SG and local areas to ensure the implementation and monitoring of recommendations within the ‘Coming Home Implementation Framework’ by 2024 while investing in and promoting high quality social supports, including CPTs, to allow people to move out of hospitals and out of area placements

### 3.5. Failure to Protect from Torture, Cruel, Inhuman, or Degrading Treatment or Punishment

*“Restraining and secluding Ben, locking him in rooms at school, has done untold damage to Ben and nearly so nearly broken us as a family.”*

Case study (2020)<sup>lxv</sup>

- 3.5.1. A joint report by PABBS and CBF<sup>lxvi</sup> highlighted accounts of restrictive practices from family carers for 720 children and young people in the UK with a range of learning and developmental disabilities. This reported that 86.5% of restraints on children and young people resulted in physical injuries.
- 3.5.2. In 2018, CYCPS conducted a Scotland-wide investigation into the use of restraint and seclusion, which identified 2,674 incidents relating to 386 children<sup>lxvii</sup>. The investigation also found that ten local authorities failed to record all incidents, and a further four did not record any. CYCPS found that the availability and content of local guidance on restraint and seclusion varied significantly, as did access to training standards in supporting children who have communication challenges and resulting behaviours that may be viewed as ‘challenging’<sup>lxviii</sup>.
- 3.5.3. Evidence also suggests that antipsychotic medications are used to manage ‘challenging behaviour.’ Research also found that adults with LDs are prescribed antipsychotic drugs at much higher rates than reported rates of psychosis among people with a LD<sup>lxix</sup>. These drugs are found to be frequently prescribed to people with LDs on a long-term basis despite significant side effects<sup>lxx</sup> and with no evidence of effectiveness beyond sedation<sup>lxxi</sup>. There are concerns that these are frequently administered on a compulsory basis, often in the absence of appropriate structures for supported decision-making.
- 3.5.4. As a result of these findings, Restraint Reduction Scotland (RSS) was established in 2020 and aims to eliminate the misuse of restrictive practices, including physical, chemical, environmental, and mechanical restraints and seclusion<sup>lxxii</sup>.

- 20.** UK and SG to embed national human rights-based legislative standards, guidance, and monitoring of restrictive practices across all settings
- 21.** SG to establish a clinical review of prescribing practice in psychotropic medication, which makes recommendations on developing a national human rights-based approach
- 22.** SG to explore the role of a new LD, Autism and Neurodiversity Commissioner, in monitoring restrictive practices in all relevant settings

### 3.6. Failure to Provide an Adequate Standard of Living and Social Protection

3.6.1. A considerable concern for people with LDs is a failure of the Scottish Government, local authorities, and public bodies to support people with LDs to realise their right to an adequate standard of living and social protection in line with Article 28 of the UNCRPD. This was discussed in relation to several interconnected rights listed below.

#### Education

*“I got very little support [at school] ...budgets seemed to be cut every month.”*

UPR Focus Group Participant (November 2021)

3.6.2. People with LDs’ experience of poverty relates to economic exclusion, low levels of support and limited life choices. This often begins at an early age due to a lack of early years (ELC) provision for children and young people with LDs and extends into educational opportunities throughout their childhood, teenage years, and young adulthood. For example, SCLD’s research<sup>lxxiii</sup> examining ELC provision for children with LDs in Scotland illustrated a complex, fragmented system that can lead to children and young people with LDs missing out on funded ELC places. These barriers continue into school education, as Enable found that 52% of 116 children and young people with LDs said they were not getting the right support at school.

**23.** SG to ensure the first phase of the rollout for free ELC provision for 1- and 2-year-olds to include children and young people with LDs; uptake should be monitored and enforced through the UNCRC Children’s Scheme

#### Transitions

*“Everyone tells me what I have to do, and I don’t like it.”*

UPR Focus Group Participant (November 2021)

3.6.3. These negative experiences often continue as children and young people with LDs transition into adulthood. Research<sup>lxxiv</sup> has found that people with LDs expressed widespread dissatisfaction with their transition planning. This is supported by a study from ARC Scotland and the Scottish Transitions Forums<sup>lxxv</sup>, which shows that children with additional support needs experienced a significant gap between their ambitions and reality in the transitions process. However, progress in improving transitions is underway with the Disabled Children and Young People (Transitions to Adulthood) (Scotland) Members’ Bill accepted into parliament towards the end of 2021<sup>lxxvi</sup>.

**24.** SG and local authorities to support the implementation of the Disabled Children and Young People (Transitions to Adulthood) (Scotland) Bill through the resourcing of local area transitions workers' to support children and young people to access support and achieve their goals

## Employment

*"I have been for numerous interviews; the employers don't take my documents; that tells me straight away I'm not getting the opportunity."*

UPR Focus Group Participant (November 2021)

3.6.4. Best evidence states that only 4.1% of adults with LDs in Scotland were employed<sup>lxxvii</sup>. This, in part, is the result of poor educational opportunities and transition planning alongside negative assumptions made about people with LDs. These low levels of employment can prevent this population from establishing economic security.

**25.** SG to review the current supported employment programmes on offer in each part of Scotland for people with LDs

## Social Care Charges and Adult Disability Payments

*"Care charges are against people's human rights."*

UPR Focus Group Participant  
(November 2021)

*"Just when you get used to one benefit, it changes to another...they need to realise that we get confused."*

UPR Focus Group Participant  
(November 2021)

3.6.5. As part of the UPR engagement sessions, people with LDs highlighted that care charges and barriers in accessing disability payments stopped them from being able to live the life they chose.

3.6.6. These concerns are supported by research<sup>lxxviii</sup> that highlighted that local authority thresholds for accessing social care have risen over the past decade. People with LDs increasingly must be assessed as having a 'critical' need to be eligible for Self-Directed Support. The same report highlighted that additional care charges for individuals varied from area to area and are subject to frequent increases.

3.6.7. Meanwhile, in Scotland, the Adult Disability Payment has replaced PIP (Personal Independence Payment). While the move of disability payments to Scotland is positive, some



have criticised the continued focus on isolated ‘activities’ within the eligibility criteria for creating additional barriers to people with LDs in accessing these payments<sup>lxxix</sup>.

**26.** UK Government and devolved nations to end care charges

**27.** SG to seek to design a progressive, rights-based approach to disability assistance that is less deficit-focused and takes greater account of the social and structural barriers which infringe on people with LDs right to independent living and equal participation in society

## 4. Conclusion

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- 4.1. People with LDs in Scotland and across the UK experience denials of their human rights daily. This includes violations of their right to life, barriers to accessing justice, the use of restrictive practices and being denied the opportunity to make decisions for themselves. These issues are likely to be further exacerbated by the proposed reform of the UK Human Rights Act, which we fear the Scottish Human Rights Bill will only be able to mitigate. Therefore, member states must ask the UK Government to listen to people with LDs<sup>lxxx</sup> and abandon their regressive approach to human rights. Instead, follow the positive example shown in Scotland to incorporate international human rights treaties, critically the UNCRPD.
- 4.2. In Scotland, poor data collection is a central issue behind many concerns raised in this report as it leaves people with LDs invisible in legislation, policy, and practice. This invisibility enables exclusion and, in turn, human rights abuses. No clearer example of the consequences of this invisibility exists than the murder of Margaret Fleming<sup>lxxxi</sup>. Margaret was missing for over 17 years before her disappearance, and her subsequent death was ever reported. SCLD and VIAS, therefore, urge the member states to make people with LDs visible in this UPR reporting cycle and future recommendations.

**ENDS**

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<sup>i</sup>Learning disability/disabilities has been abbreviated to LD/LDs due to this document’s word count

<sup>ii</sup>[SCLD \(2022\)](#)

<sup>iii</sup>[Boyle and Busby \(2021\)](#)

<sup>iv</sup>[Supreme Court \(October 2021\)](#)

<sup>v</sup>Scottish Government abbreviated to SG throughout the main body of the report

<sup>vi</sup>UPR Recommendations (2017) A41:134.59/60/65

<sup>vii</sup>UPR Recommendations (2017): A: 41:134.63

<sup>viii</sup>[National Taskforce for Human Rights Leadership Report \(2021\)](#)

<sup>ix</sup>[The Scottish Commission for Human Rights Act \(2006\)](#)

<sup>x</sup>[Equality and Human Rights Committee \(2018\)](#)

<sup>xi</sup>[The Children and young Peoples Commissioner for Scotland](#)

<sup>xii</sup>[The Children and Young People's Commissioner Scotland \(2020\)](#)

<sup>xiii</sup>This was a campaign led by Enable Scotland, Scottish Autism and the National Autistic Society Scotland. It should be noted it is not an approach welcomed by all people with learning disabilities in Scotland

<sup>xiv</sup>[Enable \(2021\)](#)

<sup>xv</sup>[Scottish Government \(2021\)](#)

<sup>xvi</sup>UPR Recommendations (2017) A:12 134.12

<sup>xvii</sup>[Scottish Government \(August 2021\)](#)

<sup>xviii</sup>[Scottish Government \(2018\)](#)

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- xix [United Nations General Assembly \(2017\)](#)
- xx [Glasgow is the most populous city in Scotland](#)
- xxi [Wise Women \(2015\)](#)
- xxii [Sarah Everard was a woman from London who was murdered by a member of the metropolitan police after falsely arresting her in 2021](#)
- xxiii [UPR Focus Group Participant: \(November 2021\)](#)
- xxiv [McCarthy et al \(2015\)](#)
- xxv [Engender \(2018\)](#)
- xxvi [North Lanarkshire Adult Protection Committee \(2016\)](#)
- xxvii [Hate Crime and Public Order \(Scotland\) Act \(2021\)](#)
- xxviii [Scottish Government \(February 2021\)](#)
- xxix [Wiseman and Watson \(2021\)](#)
- xxx [Herald \(2021\)](#)
- xxxi [Scottish Government \(2021\)](#)
- xxxii [Fraser of Allander \(2021\)](#)
- xxxiii [In England, the death rates of people with learning disabilities from Covid-19 were reported from two sources: a targeted piece of work by the Office for National Statistics using information on \[care home deaths reported to the Care Quality Commission\]\(#\), and a weekly update of \[Covid-19 deaths reported to the Learning Disability Mortality Review \\(LeDeR\\)\]\(#\).](#)
- xxxiv [Scottish Government \(2017\)](#)
- xxxv [SCLD \(2020\)](#)
- xxxvi [Public Health England \(2020\)](#)
- xxxvii [SLDO \(2020\)](#)
- xxxviii [The Christian Institute \(2021\) – Of the 2,048 social care providers who submitted information to the Care Quality Commission \(England\), 508 stated that DNRs had been applied without the agreement of the person, their relative or carer between 17 March and 21 December 2020. This amounts to more than five per cent of all DNRs put in place by respondents.](#)
- xxxix [Scottish Parliament EHRC Committee \(2021\)](#)
- xl [House of Commons Health and Social Care Committee \(2021\)](#)
- xli [Scottish Government \(2021\)](#)
- xlii [The National \(2022\)](#)
- xliii [SCLD \(2020\)](#)
- xliiv [SCLD \(2020\)](#)
- xlv [UKRI \(2021\)](#)
- xlvi [See Challenging Behaviour Foundation for Definition of Severe Learning Disability. This definition uses medical diagnosis. The language of severe learning disability terminology is from the UKRI report.](#)
- xlvii [SCLD \(2020\)](#)
- xlviii [Office for National Statistics \(2019\)](#)
- xlix [Office for National Statistics \(2019\)](#)
- i [Scottish Government \(2021\)](#)
- ii [Scottish Mental Health Law Review \(2022\)](#)
- iii [Independent Review of LD and Autism in the Mental Health Act \(2019\)](#)
- iiii [Mental Welfare Commission \(2018\)](#)
- liv [Mental Welfare Commission \(2018\)](#)
- lv [Mental Welfare Commission \(2021\)](#)
- lvi [Scottish Government \(2018\)](#)
- lvii [Mental Welfare Commission \(2016\)](#)
- lviii [Scottish Government \(2019\)](#)
- lix [Scottish Government \(2018\)](#)
- lx [Scottish Government \(2018\)](#)
- lxi [SCLD \(2022\)](#)
- lxii [UNCRPD Committee \(2017\)](#)
- lxiii [Scottish Government \(2022\)](#)
- lxiv [Scottish Government \(2022\)](#)
- lxv [PABBS & CBF \(2020\)](#)
- lxvi [PABBS & CBF \(2020\)](#)
- lxvii [The Children and Young Peoples Commissioner Scotland \(2018\)](#)
- lxviii [Enable Scotland \(2019\)](#)
- lix [Scottish Learning Disabilities Observatory \(2020\)](#)
- lxx [Tyler & Cooper \(2014\)](#)
- lxxi [Scottish Learning Disabilities Observatory \(2020\)](#)



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- lxxii [Restraint Reduction Scotland \(2021\)](#)
- lxxiii [SCLD Report \(to be published\)](#)
- lxxiv [Fraser of Allander institute \(2021\)](#)
- lxxv [Arc Scotland and the Scottish Transitions Forums \(2017\)](#)
- lxxvi [Scottish Parliament \(2021\)](#)
- lxxvii However, the employment status of more than 50% of adults within this dataset is unknown. (LDSS, 2019)
- lxxviii [SDS \(Self Directed Support\) Scotland and The Alliance \(2020\)](#)
- lxxix [SCLD \(2019\)](#)
- lxxx [British Institute of Human Rights \(2022\)](#)
- lxxxi [Inverclyde Council \(2020\)](#)

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## Annexe 1: Full list of Recommendations

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1. UK Government to take expert advice from the Human Rights Independent Review, British Human Rights Institutions, and civil society on the Human Rights Act Reform proposals, ensuring this process includes the voices of people with LDs throughout 2022
2. UK Government to follow SG in the incorporation of international human rights treaties
3. SG to continue incorporating international treaties, including the UNCRPD, through the new Human Rights Bill for Scotland and commit to enforceable and accessible remedies as part of this process
4. SHRC promptly introduce SNAP 2 and with milestones and audit built in to evaluate impact
5. SG to develop LD, Autism and Neurodiversity Bill in conjunction with Scottish Human Rights Bill. This should include the creation/appointment of a commission/commissioner with powers to investigate complaints of human rights abuses. A wide representation of people with LDs should lead the development of a commissioner's office/commission
6. Extend the powers of the SHRC to ensure the right to an effective remedy for human rights breaches is equally available in Scotland
7. SG to review appropriateness and effectiveness of adult support and protection referrals based on women with LD experiencing GBV and find alternative methods of support
8. SG support for an accessibility audit roll out for all GBV support services by 2023
9. SG to ensure the representation of LD in the development of the new strategy to tackle hate crime and representation on relevant advisory groups
10. UK Government and devolved nations to commission national guidance for media on reporting on LD
11. UK Government and devolved nations to develop awareness-raising campaigns on the experiences of people with LD
12. SG to examine approaches to build on existing data to enable understanding of the requirements of people with LDs throughout their life course and to build evidence on whether people can realise their human rights in line with Article 31 of the UNCRPD
13. UK and devolved nations' inquiries into the handling of the COVID-19 pandemic should include evidence sessions from people with LDs
14. UK, including devolved nations, to conduct inquiries into political and media messages surrounding the COVID-19 pandemic

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15. Scottish Government to ensure the new National Care Service places human rights compliance at its centre as recommended by the Independent Review of Adult Social Care in Scotland
  16. The UK and devolved nations to report on learning disability support services' re-mobilisation and uptake by 2023/24
  17. SG to respond to the IRMHA recommendations as part of the ongoing SMHLR and explore connections with the Scottish Human Rights Bill and the LD, Autism and Neurodiversity Bill
  18. SG to explore embedding a UNCRPD compliant national supported decision framework as part of the ongoing SMHLR. This should be considered alongside appropriate safeguards to ensure that the rights, will and preferences of people with LDs are respected
  19. SG and local areas to ensure the implementation and monitoring of recommendations within the '*Coming Home Implementation Framework*' by 2024 while investing in and promoting high quality social supports, including CPTs, to allow people to move out of hospitals and out of area placements
  20. UK and SG to embed national human rights-based legislative standards, guidance, and monitoring of restrictive practices across all settings
  21. SG to establish a clinical review of prescribing practice in psychotropic medication, which makes recommendations on developing a national human rights-based approach
  22. SG to explore the role of a new LD, Autism and Neurodiversity Commissioner, in monitoring restrictive practices in all relevant settings
  23. SG to ensure the first phase of the rollout for free ELC provision for 1- and 2-year-olds to include children and young people with LDs; uptake should be monitored and enforced through the UNCRC Children's Scheme
  24. SG and local authorities to support the implementation of the Disabled Children and Young People (Transitions to Adulthood) (Scotland) Bill through the resourcing of local area transitions workers' to support children and young people to access support and achieve their goals
  25. SG to review the current supported employment programmes on offer in each part of Scotland for people with LDs
  26. UK Government and devolved nations to end care charges
  27. SG to seek to design a progressive, rights-based approach to disability assistance that is less deficit-focused and takes greater account of the social and structural barriers which infringe on people with LDs right to independent living and equal participation in society.

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## Annexe 2 – Methodology

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Between November and December 2021, SCLD held three engagement events to hear the views of people with learning disabilities and those who support them on what should be included in our submission to the UPR. This included:

- 1) Public event for people with LD and those who support them
- 2) Small focus group of SCLD Expert Group members
- 3) Focus groups as part of an Assembly<sup>lxxxi</sup> meeting supported by VIAS.

All three sessions aimed to gather qualitative data to inform our joint submission to the UPR. At these events, we engaged 42 people with LD and those who support them from across Scotland.

The first was a public event attended by a mixed group, including those with lived experience. Forty-three people signed up for this event, and 24 people attended on the day. Eighteen people stayed to participate in smaller focus groups in the second part of the meeting. Participants were a mix of people with LD and those who support them.

Our expert group session included three people with learning disabilities. Fifteen people with LDs took part in a focus group discussion at an Assembly meeting coordinated by VIAS.

Each engagement event took place online and followed a similar structure that included:

- An introductory presentation about the Universal Periodic Review
- A tour of SCLD's app '*Human Rights Town*<sup>lxxxi</sup> to help focus group participants understand the concept of rights
- Break-out room discussions in which participants were asked to venture around their own human rights town and discuss critical issues<sup>lxxxi</sup>.

Facilitators of these events used a semi-structured interview technique, listening to the issues raised by focus group participants and adapting questions to the relevant topics.

Following the public engagement event, we amended this approach. At the second engagement event, the facilitator asked the group of 3 people to produce four issues of importance to them and recommendations they would want to make. A similar approach was taken at the engagement event with the Assembly.

Following this, staff at SCLD conducted a content analysis of the notes and recordings taken of each focus group discussion. From this, we were then able to identify several key issues.

In December 2021, SCLD hosted a meeting of key stakeholders and trusted advisers. This included members of our Human Rights Town App Development Group, PAMIS<sup>lxxxi</sup> and VIAS. At this meeting, we discussed the critical issues raised during the focus groups and allowed

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stakeholders to have the opportunity to prioritise issues to be included in this submission collectively.

SCLD, alongside our advisers and stakeholders, based what we would focus on in this report based on the most serious rights infringements facing people with learning disabilities in Scotland. We prioritised issues using a traffic light system. The most severe human rights violations were red, for example, failing to respect the right to life during the COVID-19 pandemic.

This report is primarily based on issues that people with learning disabilities and those who support them told us about at UPR engagement events. We have supplemented this with additional evidence and research presented in this report. Quotes from participants across the three engagement events are highlighted throughout this report.

For the section on people with learning disabilities experience during the Covid-19 pandemic, we have used quotes from the SCLD survey of 127 people with learning disabilities and 223 of their carers and supporters during the initial stages of the COVID-19 pandemic<sup>lxxxi</sup>. For the section on restraint and seclusion, we have used a quote from a PABBS and CBFreport to examine case study data from family carers on restrictive interventions in schools, such as restraint and seclusion.

As part of the UPR reporting process, SCLD will share this report with the relevant UK and Scottish Government officials to highlight these issues and ask they be addressed. This will support a range of our ongoing work, including:

- SCLD's response to the human rights act reform<sup>lxxxi</sup>
- The development of a new Human Rights Bill in Scotland,
- The ongoing Scottish Mental Health Law Review and the development of an LD, Autism and Neurodiversity Commissioner Bill

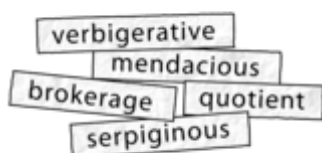
## Annexe 3 - Easy Read Summary



This report is by the Scottish Commission for People with Learning Disabilities in partnership with Values into Action Scotland



This report is for us to tell the **human rights council** if we think the UK is helping people with learning disabilities get their human rights



Difficult words in this Easy Read are in red



You can find out what the difficult words mean by looking at the end of this Easy Read



In this report we said



That people with learning disabilities in Scotland and across the UK don't always get their human rights



We said there are lots of problems that stop people with learning disabilities from getting their human rights

This includes



The UK government wanting to change the human rights act to a bill of rights

This will take away protections from people with learning disabilities



We said it was a problem that people with learning disabilities had not been asked what they thought about these changes



We said that the UK government should listen to what **human rights defenders** and people with learning disabilities say about changing the law



We said that people with learning disabilities in Scotland do not feel enough has been done to make sure they get their human rights



We said some people with learning disabilities and autism have asked for a learning disability, autism and neurodiversity commissioner or commission



We said that a commission or commissioner should have powers to investigate abuses of human rights and help people with their legal cases and that people with learning disabilities should help lead the commissioner



We also said the Scottish human rights commission should have more legal powers





We said that women with learning disabilities had told us they experience **gender based violence**



We said that women told us when they reported violence against them they got referred to adult support and protection



We said the Scottish government should look at if adult support and protection was helping women with learning disabilities who had experienced violence



We said the Scottish government should support the rollout of an **accessibility audit** for gender based violence support services



We said we now know more about people with learning disabilities experience of hate crime in Scotland



We said the Scottish government should make sure people with learning disabilities are involved in the development of a new hate plan and should be

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represented in **advisory groups**



We said there should be guidance on how the media reports on people with learning disabilities



We said there should be a national awareness raising campaign on the experiences of people with learning disabilities

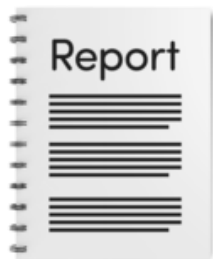


We said there was no **data** about the experiences of people with learning disabilities

We said the Scottish government should look at what improvements they can make to data about people with learning disabilities



We said that during the COVID-19 **pandemic** the UK and Scottish governments had failed to protect people with learning disabilities from the virus and this meant a lot of people had died



We said that reviews looking into the pandemic should ask people with learning disabilities about their experiences



We said there should be an investigation about the things politicians and the media said about the pandemic



We said that people with learning disabilities lost their support during the pandemic



We said that the UK and Scottish governments should report on how many people now have the same support as they did before the pandemic



We said that many people with learning disabilities are not allowed to make their own decisions because of **guardianship orders**



We said the Scottish government should create a supported decision making framework as part of the Scottish mental health law review



We said that many people with learning disabilities lived in a hospital or far away from their families in out of area placements



We said the Scottish government should make sure nobody with a learning disability should have to live in a hospital and people with learning disabilities need good support to live in their communities



We said people with learning disabilities across the UK had experienced restraint and seclusion



We said the UK and Scottish governments should have laws to make sure that restraint and seclusion do not happen and that people should **monitor** how often it happens



We said the new learning disability, autism and neurodiversity commissioner in Scotland could have a role in monitoring the use of restraint and seclusion



We said that people with learning disabilities did not always get their rights to



Education



Support during transitions



Employment



Social care and social security





We said that to help make things better



The Scottish government should include children and young people with learning disabilities in the rollout of early years places



The Scottish government and local authorities should fund local area transitions workers



The Scottish government should look at what employment support programmes are available to people with learning disabilities in every different part of Scotland



The UK and Scottish governments should end care charges





The Scottish government should create a human rights based approach to disability assistance

This Easy Read is a summary of the main points we made in our report

It does not cover everything we said

If you have any questions about this report and everything we said you can contact Oonagh Brown



Oonaghs email is

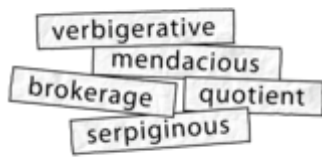
Oonagh.b@sclد.co.uk

You can also reach Oonagh by calling the SCLD office on 0141 248 3733



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## Difficult words



**Human Rights Council** is part of the United Nations

It is made up of different countries from all over the world



**Human Rights Defenders** promote and protect human rights



**Gender Based Violence** means someone harming you because of your gender



An **accessibility audit** helps organisations find out how accessible they are



**Advisory Groups** give advice to different organisations and government





**Data** means numbers or facts that give you information



A **pandemic** is when there is an outbreak of a disease across the world like COVID-19



A **guardianship order** is when a court says a person can make decisions on behalf of someone they think cannot make decisions for themselves



To **monitor** means to check up on something

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## Annexe 4 – Organisational information

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**SCLD** is committed to finding new and better ways to improve the lives of people with learning disabilities. SCLD offers support, information, and new ideas about learning disability in Scotland. We work to defend the human rights of people with learning disabilities in Scotland. We work as a partner to the Scottish Government in the delivery of Towards Transformation, the autism and learning/intellectual disability transformation plan, which sets out to ensure that progress is made in transforming Scotland for autistic people and people with learning disabilities.

At the Scottish Commission for People with Learning Disabilities, our values are the foundation of what we do. They combine with our human-rights based approach and our policy of safeguarding. As an organisation, we are:

- **Respectful:** We respect people with learning disabilities, one another, and everyone we come into contact with
- **Inclusive:** We are a place where everyone belongs, no matter who they are or what barriers they face
- **Collaborative:** We value working with others. Everyone has something to give, and everyone is given the opportunity for their voice to be heard.
- **Pioneering:** We are not afraid to take risks or to enable people with learning disabilities to take risks

**VIAS** believe in a Scotland, where people with learning disabilities or autism have the same opportunities as everyone else and are supported to achieve these goals, whether to work, live where they want, or have a relationship. Employing people with learning disabilities and autism VIAS provides consultancy, training and service evaluations. VIAS coordinates The Assembly, which is made up of a growing number of individuals who support and facilitate accessible politics and active political engagement for Scotland's community of people with learning disabilities and/or autism.