



Briefing in support of Motion S5M-24199

'Further Support for Autism and Learning Disabilities'

(02.03.2021)

About this briefing

This briefing has been compiled by ENABLE Scotland, National Autistic Society Scotland and Scottish Autism and is to support the Members Business debate tabled by Alexander Burnett MSP **scheduled for last thing on Wednesday 3rd March**.

The motion notes the calls for a commissioner to protect and uphold the human rights of autistic people, people with a learning disability and families. This is the focus of the '[Our Voice Our Rights](#)' campaign which we as a coalition are advocating for along with partners.

The briefing includes information about autism and learning disability, key facts and figures together with details of our proposed Commissioner.

Key Points for the Debate

- There are at least 120,000 people with a learning disability and 56,000 autistic people in Scotland. With families and carers we estimate this population to be more than 700,000 Scottish citizens.
- The Scottish Government has had in place the well-intentioned 'Scottish Strategy for Autism' and 'Keys to Life' strategy for nearly 10 years, and put in place an extensive regulatory framework, both of which set out clear intentions to uphold the human rights of this population, and improve access to the indicators of a good life such as work, education, relationships, health, social care, housing, finances, and freedom from restrictions on liberty.
- Scotland also has an extensive regulatory framework in place to uphold the rights of autistic individuals and those who have a learning disability, for example, the Mental Welfare Commission, the Care Inspectorate, the Children's Commissioner, the Equality & Human Rights Commission, and the Scottish Human Rights Commission.
- However, despite these good intentions and existing regulators, this population continues to experience persistently poor outcomes as evidenced through data, independent research, and, critically, the experiences of individuals and families.
- MSP constituency caseloads will bear evidence day in and day out of how people's human rights are not upheld and too many people struggle to access support in education, work, healthcare and social care.
- MSPs will be directly involved in assisting many individuals and their families who are exhausted from fighting tooth and nail to get the much-needed support and status as equal citizens.
- The Scottish Government is currently **reviewing both the Keys to Life and the Autism strategies**, which creates an opportunity to introduce a more effective approach to lead and implement change through a new strategic vision and implementation model.
- **The Fraser of Allander Institute** is undertaking a year-long research project into the socioeconomic impact of persistently poor outcomes for people who have a learning

disability. Their interim report talks of ‘Scotland’s Invisible People’, and suggests that a radically different approach is neededⁱ.

- In December 2019, the **Independent Review of Learning Disability and Autism in the Mental Health Act**, commissioned by the Scottish Government, recommended that “a new commission be established with authority to promote and protect the human rights of autistic people and people with intellectual disability across all settings”ⁱⁱ.
- **The Cross Party Group on Autism** published a report, ‘The Accountability Gap’, in October last year. Of those who participated, 72% said they did not have enough support to meet their needs, 78% said that it was not easy accessing support locally, and 69% said they would feel less isolated with more support. 50% also said that they felt autism awareness among the general public had not improved, and 36% said they received no support within 12 months of receiving a diagnosis. The CPG’s report also made 10 recommendations, including a new Commissioner role for autistic peopleⁱⁱⁱ.
- The **pandemic** has had a disproportionate impact on this population. Building on existing persistent health inequalities, people with a learning disability are three times more likely to die from Covid-19 than the general population. 9 out of 10 autistic people reported negative effects to their mental health and increased loneliness and isolation.
- MSPs will be aware of the recent successful efforts of members of **the CPG on Learning Disability** to call for all people who have a learning disability to be called forward for Covid-19 vaccinations in Priority Group 6. The fact that this required such a national level of intervention, in spite of available evidence of existing persistent high mortality rates for this group, highlights the structural inequality and invisibility of this population in terms of public policy making.
- In the lead up to the **May Election** we are standing together with autistic people and people who have a learning disability to take a once in a generation opportunity and call on all the major political parties to commit to a Commissioner to ensure real change.
- The Commissioner would be the first of its kind in the world, established in law to champion the human rights of autistic people and people with a learning disability.
- They will be a powerful ally to whom people can turn if they are not getting the support they need and a powerful voice in the national debate.
- This is an opportunity for the Scottish Government and all political parties to demonstrate not only their commitment to upholding and defending human rights but also to ensuring that the voices of disabled people are listened to at all levels of society and government.
- We are asking the Government and all political parties to be brave and create a strong, robust defender and champion of the rights of autistic people and people with a learning disability.

The case for a Commissioner

Autistic people and people who have a learning disability want their voices to be heard at every level of policy development within central and local government. We want services to work better so that people get the support they’re entitled to without battling the system endlessly. We want a system that cares sufficiently to get it right. We want people to feel valued and seen. And we want a bold solution for Scotland.

“Not only are [people who have learning disabilities] not visible in public debate, but the support they receive has receded in recent years and this has largely happened under the radar. Covid-19 has meant that much of the service infrastructure that was relied on has been taken away, and there are grave (and valid) concerns that their human rights are being curtailed... This is not a niche issue, and it is time people with learning disabilities received the attention they deserve.” – Fraser of Allander Institute, 2020^{iv}.

The below provides a summation of facts and figures highlighting the challenges and inequalities facing autistic people and people with a learning disability in Scotland. Occasionally, some of the figures are not Scotland specific and we have indicated so.

The number of autistic people and people with a learning disability in Scotland

- It is estimated that there are 56,000 autistic people in Scotland.^v
- There are an estimated 120,000 people with a learning disability in Scotland^{vi}.
- A third of autistic people also have a learning disability.
- Adding in families/carers we estimate there are over **700,000 people for whom autism and/or learning disability is part of daily life.**

Autism diagnosis

- A third of autistic people and families received no support following diagnosis^{vii}
- There are no up to date figures on waiting times for an autism diagnosis. However, data from 2014 showed that the average wait in Scotland was 331 days.^{viii}

Social care and social isolation

- 66% of autistic people in Scotland say that they feel socially isolated^x
- Less than 1 in 3 people with a learning disability can name at least one close friend^x
- 60% of children with a learning disability said they felt lonely at school.^{xi}
- Approximately 23,500 adults with a learning disability are *known* to local authorities meaning the majority do not receive any social care.^{xii}

Education

- There are almost 9500 autistic children in Scotland (0-16 years old)^{xiii}
- There are 15,324 school-age children and young people identified as having an additional support need resultant from a learning disability^{xiv}
- 34% of parents say their autistic child has been unlawfully excluded from school^{xv}
- 52% of children with a learning disability said they were not getting the right support at school.^{xvi}
- Over half of autistic young people said they did not receive enough information or support to transition from school.^{xvii}
- 41% of young people with a learning disability said they did not get support to help them make the transition from school. ^{xviii}
- There were 2,674 instances of seclusion and restraint in Scotland's schools in 2018. To date, there is no identified regulator of seclusion and restraint in non-residential school settings.^{xix}

Employment

- 22% of autistic people are in some kind of paid work.^{xx}
- 4.1% adults with learning disabilities known to local authorities are in employment^{xxi}
- In comparison to 45% of disabled people and 81% of non-disabled people in Scotland.^{xxii}

Health and mental health

- Autistic people die on average 16 years earlier than the general population (research from Sweden).^{xxiii}
- People with a learning disability die on average 20 years earlier than the general population (data from 2013).^{xxiv}
- Over 70% of autistic people have had a mental health condition^{xxv}
- Over half of autistic people said the process for getting mental health support took too long and was stressful.^{xxvi}
- Autistic adults who do not have a learning disability are 9 times more likely to die from suicide (research from Sweden).^{xxvii}

- Premature mortality was 12 times higher for children and young people with a learning disability ^{xxviii}

COVID 19 and people with a learning disability

- People who have a learning disability in Scotland are at greater risk of death - three times more likely to die than the general population from Covid-19. ^{xxix}
- People who have a learning disability in Scotland are at greater risk of infection – twice as likely as the general population to test positive for Covid-19. ^{xxx}
- People who have a learning disability in Scotland are at greater risk of becoming seriously ill as a result of Covid-19 – twice as likely to be hospitalised. ^{xxxi}

COVID 19 and autistic people

- 9 in 10 autistic people worried about their mental health during lockdown; 85% said their anxiety levels got worse. ^{xxxii}
- Autistic people were 7 times more likely to be chronically lonely than the general population*; and 6 times more likely to have low life satisfaction** (comparisons using ONS data). ^{xxxiii}
- 1 in 5 family members responding to the survey had to reduce work due to caring responsibilities. ^{xxxiv}
- 7 in 10 parents say their child has had difficulty understanding or completing school work and around half said their child's academic progress was suffering. ^{xxxv}

Institutional hospital care and out of area placements for those with complex needs

- 705 people were 'out-of-area' in Scotland. ^{xxxvi}
- 453 were identified as being out of area not through choice.
- A further 67 people were classified as delayed discharge, that is to say they were unable to return to their local communities because appropriate accommodation and support was unavailable.
- 22% had been in the hospital for more than 10 years and 9% for 5-10 years.
- The 2018 Mental Health and Learning Disability Inpatient Census showed that 28% of patients in learning disability wards were delayed discharges that is to say there were not appropriate community care services.

Housing

- 31% of people with a learning disability known to local authorities live with a family carer. ^{xxxvii}
- Of this number 77% are living with a parent carer ^{xxxviii}

Funding and autism

- The incremental annual national 'cost' of autism was estimated at £2.2 billion. ^{xxxix}
- Services supporting autistic people account for more than half of this (56%) costing more than £1.2 Billion per year. ^{xl}
- The remaining cost (close to a billion) is lost to individuals and the state mainly due to the low employment rate. ^{xli}
- The incremental lifetime cost for autistic people with and without a learning disability was estimated at £1.6 million and £0.89 million respectively. ^{xlii}

These key statistics present a persistently poor picture for autistic people and people who have a learning disability in Scotland. That's why, together, we're calling for a Commissioner - the first of its kind in the world, to be established in law to champion the human rights of autistic people and people with a learning disability. The Commissioner's role would be to strive for better outcomes: introducing accountability in public services, and promoting the rights of autistic people, people with a learning disability and their families to have the choice and control to live a good life, free from discrimination.

They would close the current accountability gap – between what the law prescribes and what actually happens in reality – so that public bodies can be better supported to deliver better outcomes for all autistic people and people who have a learning disability. In order to inform ongoing quality improvement, they would also give autistic people, people with a learning disability and their families access to recourse when the system falls short.

The Commissioner would ensure that autistic people and people with a learning disability design and benefit from the services and support to which they are entitled, ensuring that they have an equal stake in Scotland's future.

As previously mentioned, while some of the injustices facing both people with a learning disability and autistic people are shared, others are distinct. The Commissioner would be mindful of this, taking time to engage with and involve autistic people and people with a learning disability to fully understand the different issues in order to act effectively.

A proposed structure for a Commissioner

The responsibilities, powers and functions of the Commissioner would be set out in law together with reporting mechanisms. This would require an Act of Parliament.

As a model, we have looked to some of the statutory levers and powers that the Children and Young People's Commissioner has in statute and suggest the following as a starting point for a Commissioner.

Six Principle Functions

We would suggest that the Commissioner have six principle functions set out in law.

****Function 1 - Promoting human rights***

The Commissioner should act as a champion by promoting human rights and acting as a powerful spokesperson in the national discourse. In addition to providing information and guidance on rights the Commissioner should proactively work with statutory agencies to promote and embed rights-based thinking in daily activity.

****Function 2 – Involving autistic people and people with a learning disability***

In developing a strategy and programme of work to improve access to the human rights of this population, the Commissioner must involve autistic people, people with a learning disability, families, charities, other statutory agencies and other relevant organisations in a meaningful way.

****Function 3 – Conducting formal investigations***

The Commissioner should have the power to conduct formal investigations where they believe that a particular group of people are being disadvantaged or their rights are being abused. It could also look to conduct an investigation looking at a particular area of life or policy, such as health inequalities, access to mental health services, housing and so on.

****Function 4 – investigating individual cases***

The Commissioner should have the power to investigate individual cases where someone is seeing their rights abused or they are unfairly being denied a service. Other agencies and charities could also refer cases to the Commissioner.

****Function 5 - Promote good practice and lead quality improvement***

The Commissioner should promote good practice among statutory agencies and the Third Sector, and monitor improvements in key outcomes which demonstrate the achievements of human rights. In determining what is good practice the Commissioner should consult with Government, statutory agencies, other stakeholders as well as autistic people, people with a

learning disability and families. Due to the unique nature of the office they would also be well positioned to identify good practice internationally and share it appropriately. The Commissioner would also have a leadership role, working across public bodies to lead positive change.

****Function 6 – Advocating the rights of those in delayed discharge or inappropriate residential care settings***

The Commissioner should have a specific role in monitoring and advocating for the rights of individuals who are in delayed discharge or long-term residential settings, with a view to reducing this. This population was identified by the Scottish Government's 'Coming Home' report in 2018, and was prioritised in the recent Independent Review of Adult Social Care as requiring urgent attention and a national approach to funding, decision making, and monitoring. The Scottish Government's recent announcement^{xliii} of a new £20m Community Living Change Fund to be available to health and social care integration authorities to design community-based support for people with complex needs who, in the past, have endured long stays in a hospital setting or had to seek care outside of Scotland is very welcome. The Commissioner would work alongside integration authorities to lead a process of ensuring that the voice of the person leads decision-making.

Indicative cost of the Commissioner's Office

MSPs should note that public funding is already invested in a number of bodies to conduct research and promote good practice in upholding the rights of autistic people and people who have a learning disability. This means public finances are already being spent on research, collecting data, and promoting best practice, and there is potentially a role to explore in repurposing some of this to include a formal role in upholding rights.

This would align with the budgetary scale of other similar bodies: namely the Children's Commissioner which has an annual budget of £1.3 million and employs 14 people, and the Mental Welfare Commission (MWC) which has an annual budget of £4.8 million and employs over 50 people. Much of the resource is focused on visiting individuals (1400 people were visited in 2018/19).

We would expect that our proposed Commissioner would fall in between. We would expect it to need resource to provide advice to individuals and families (something the Children's Commissioner does not do to a great extent) but less resource than the MWC as it will not be carrying out extensive fieldwork.

When considering that the incremental cost of support for a single autistic person ranges from £0.9m to £1.6m across the person's lifespan, and that the costs of services for autistic people alone is over £2 billion per year^{xliiv}, the cost of a Commissioner - who would undoubtedly make services work more effectively - would be nominal.

About autism and learning disability

About autism

Autism is a lifelong developmental disability that affects how people perceive the world and interact with others.

Autistic people see, hear and feel the world differently to other people. If you are autistic, you are autistic for life; autism is not an illness or disease and cannot be 'cured'. Often people feel being autistic is a fundamental aspect of their identity.

Autism is a spectrum condition. All autistic people share certain difficulties, but being autistic will affect them in different ways. Some autistic people also have learning disabilities, mental

health issues or other conditions, meaning people need different levels of support. All people on the autism spectrum learn and develop. With the right sort of support, all can be helped to live a more fulfilling life of their own choosing.

About learning disability

A learning disability is a significant, lifelong condition that starts before adulthood, which affects a person's development and which means that they may need help to understand information, learn skills and live independently.

Having a learning disability means a person may take longer to learn things and often needs support to develop new skills, be aware of risk, understand complicated information and interact with other people. Some people who have other conditions, such as Down's syndrome, and some people who have autism or dyspraxia also have a learning disability.

The level of support a person needs depends on the individual. In the UK we have used the terms profound, severe, moderate and mild to describe people who have a learning disability.

But all of this is only part of a description. It does not capture the whole person, and everything they are – a friend, a family member, a community activist, a student, a parent, an employee or employer for example. It is essential that we keep in mind all of these possibilities and support individuals who have a learning disability to be equal members of society, and to realise their full potential and goals in life.

Further information

For further information contact **Jason Henderson**, Public Affairs Officer at National Autistic Society Scotland at: jason.henderson@nas.org.uk or **Jan Savage**, Director of Campaigns and Membership at ENABLE Scotland at jan.savage@enable.org.uk

Where the figures come from (End notes)

- ⁱ [Scotland's Invisible People](#) - Fraser of Allander Institute, September 2020
- ⁱⁱ [The Independent Review of Learning Disability & Autism in the Mental Health Act](#), December 2019.
- ⁱⁱⁱ [The Accountability Gap](#) – Cross Party Group on Autism, October 2020
- ^{iv} [Scotland's Invisible People](#) - Fraser of Allander Institute, September 2020
- ^v P77, [Microsegmentation Analysis](#) (prevalence of autism is estimated at 1.035% of the population) Scottish Government, 2018
- ^{vi} ENABLE Scotland estimate <https://www.enable.org.uk/what-is-a-learning-disability/>
- ^{vii} *The Accountability Gap* – Report from the Cross Party Group on Autism (published October 2020)
- ^{viii} *Autism ACHIEVE Alliance. Autism spectrum disorders: Waiting for assessment. (2014)*
- ^{ix} *Too Much Information*, NAS Scotland 2016 (673 respondents)
- ^x ENABLE [Press Release](#) April 2020
- ^{xi} [IncludED in the Main?!](#) ENABLE Scotland 2017
- ^{xii} Learning Disability Statistics Scotland, 2019, SCLD & Statistics Scotland (2019)
- ^{xiii} P19 [Microsegmentation Analysis](#), Scottish Government, 2018
- ^{xiv} ENABLE website
- ^{xv} *Not Included, Not Engaged, Not Involved*, NAS Scotland, Scottish Autism and Children in Scotland, 2018 (1,417 respondents)
- ^{xvi} [IncludED in the Main?!](#) ENABLE Scotland 2017
- ^{xvii} *The Accountability Gap* – Report from the Cross Party Group on Autism (published in October 2020)
- ^{xviii} [IncludED in the Main?!](#) ENABLE Scotland 2017
- ^{xix} [No Safe Place: Restraint and Seclusion in Scotland's Schools](#) – Children & Young People's Commissioner Scotland (December 2018).
- ^{xx} [Office for National Statistics](#), data from 2020.
- ^{xxi} Learning Disability Statistics Scotland, 2019, SCLD & Statistics Scotland (2019)
- ^{xxii} *A Fairer Scotland – Employment Action Plan*, Scottish Government 2018
- ^{xxiii} *P3 Personal tragedies, public crisis* – Autistica UK, 2017 (based on Swedish research)
- ^{xxiv} [Keys to life](#) (2013)
- ^{xxv} *P6 Personal tragedies, public crisis* – Autistica UK, 2017(based on Swedish research)
- ^{xxvi} *The Accountability Gap* – Report from the Cross Party Group on Autism (to be published in October 2020)
- ^{xxvii} *P3 Personal tragedies, public crisis* – Autistica UK, 2017(based on Swedish research)
- ^{xxviii} [Mortality rates for children and young people with learning disabilities](#), Scottish Learning Disabilities Observatory, (2020)
- ^{xxix} [The impact of COVID -19 on people with learning/intellectual disabilities in Scotland](#) - Scottish Observatory for Learning Disabilities, (February 2021)
- ^{xxx} Ibid
- ^{xxxi} Ibid
- ^{xxxii} [Left Stranded](#) – National Autistic Society, October 2020
- ^{xxxiii} Ibid
- ^{xxxiv} Ibid
- ^{xxxv} Ibid
- ^{xxxvi} [Coming Home: complex care needs and out of area placements](#), Scottish Government (2018)
- ^{xxxvii} Learning Disability Statistics Scotland, 2019, SCLD & Statistics Scotland (2019)
- ^{xxxviii} Ibid
- ^{xxxix} This includes the cost of service provision but also the loss in income to the individual and state (predominately from a low employment rate). P22 [Microsegmentation Analysis](#), Scottish Government, 2018.
- ^{xl} P166 [Microsegmentation Analysis](#), Scottish Government, 2018
- ^{xli} Ibid
- ^{xlii} P22 [Microsegmentation Analysis](#), Scottish Government, 2018
- ^{xlii} Backing for Feeley Review recommendations – gov.scot (www.gov.scot)
- ^{xlii} [Microsegmentation Analysis](#), Scottish Government, 2018