



National
Autistic
Society
Scotland

Scottish
autism
WHERE AUTISTIC PEOPLE
ARE VALUED



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New campaign calls on political parties to commit to the world's first Commissioner for autistic people and people with a learning disability in Scotland

ENABLE Scotland, National Autistic Society Scotland and Scottish Autism have today launched the 'Our Voice Our Rights' Campaign calling on the major political parties to commit to a Commissioner for autistic people and people with a learning disability at the forthcoming Holyrood election.

The 'Our Voice Our Rights' campaign aims to make Scotland the best country in the world for the 56,000 autistic people, the 120,000 people with a learning disability and their families in Scotland. A country where human rights are respected and upheld; everyone has equal access to the services and support they need throughout their lives; and where autistic people and people with a learning disability are active citizens and fully supported to fulfil their potential.

While there have been many ambitious and well-intentioned strategies over the years from Government and partners, and an extensive regulatory framework, the charities hear day in day out how too many people are struggling to access their human rights to education, work, a family life, healthcare, to high quality social care services, and to be free from discrimination in their communities.

Many individuals and their families are exhausted from fighting tooth and nail to get the much-needed support and status as equal citizens. A fight that sadly, they often lose, leaving many in crisis, something brought into sharp focus by the pandemic and the pressures on the system.

In the lead up to the Scottish Parliamentary Elections in May 2021 the three charities are standing together with autistic people and people who have a learning disability to say 'enough is enough' and calling on all the major political parties in Scotland 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 would be a powerful voice, improving access to services and advocating on people's behalf when they cannot and importantly helping people have the choice and control to live a good life, free from discrimination.

They would close the current gap – between what the law says and what actually happens in reality. They would lead improvements and importantly people would also have recourse when the system falls short and fails to deliver for them.

The charities have launched the campaign alongside autistic people, people with a learning disability and families including the broadcaster Stuart Cosgrove.

A website is now live with a series of videos featuring people from across Scotland making the case for change. People are also being encouraged to get involved and to contact the party leaders to call for a Commissioner for autistic people and people with a learning disability to be included in their election manifestos.

Quotes

[Picture 1]

Peter McMahon who has a learning disability and is a member of ENABLE Scotland said:

“We need a Commissioner for Learning Disability and Autism so that people who have a learning disability like me aren’t put on the back burner or forgotten about. With a Commissioner working with us we can improve access to services and speak up for people when they cannot. Most importantly we can help people live good lives with choice and control and free from discrimination. People with learning disabilities feel invisible, we don’t want to be the invisible people any more and feel a Commissioner would help us. “

[Picture 2]

Jason who is autistic said:

“People often think that autistic people are quirky or weird. I felt very self-conscious at school and so didn’t tell many people I was autistic as it only gave ammunition to bullies. My Asperger’s mean I look normal on the outside but I’ve so much that people don’t see and worry how people will react. I’d like to be actor but also one day own my own flat and have a relation. In many ways these are more challenging than acting. People in Scotland need to be more awareness, that would really help me feel more comfortable saying I’m autistic.”

[Picture 3]

Suzanne whose son Callum has a learning disability and autism said:

“Callum has a lot of challenges, he is constantly having to deal with sensory issues and sounds and he needs someone supporting him most of the time. It’s difficult for people to understand what he is saying and so we need to be with him when he is out to help as well as explain his compulsion to touch people.

When Covid hit a lot of the services withdrew leaving us to deal with health education and social work issues. Over time that has got better but we’re still not receiving the level of support we had before the pandemic.

I think there needs to be a lot more joined up thinking, sometimes we end up going from service to service – there needs to be someone holding the system together, someone at a national level I can go to if there is an issue. My hope is that when Callum leaves school he doesn’t end up sitting in a day centre all the time and that

there are opportunities for him. He loves buses and would love to be a bus driver. That may not be possible, but working or volunteering in and around buses would be amazing for him.”

[Picture 4]

Jan Savage, Director of ENABLE Scotland Charity and Membership said:

“The creation of a commissioner would do two things. It would be a symbolic appointment- a strong signal to this population that you matter, you are important to us all, and that we want to do better by you and with you.

Secondly, it would work alongside existing public bodies, their regulators and people who have learning disabilities themselves, to provide insight and accountability where things are not working well – and most importantly, lead the change. The simple truth is that for too long and too often we are not getting it right for people who have a learning disability. We need a new catalyst for change.”

[Picture 5]

Nick Ward, Director of National Autistic Society Scotland said:

“We believe a Commissioner would send a clear message that we as a country value autistic people, people with learning disabilities and their families and that Scotland is leading the way in making sure that people get the support they need and we create a more inclusive culture.

Day in day out we hear from autistic people and families locked in a battle to get access to desperately needed services, a battle which often leaves them frustrated and exhausted and even at crisis point. We believe a commissioner would make the difference: no one should have to fight to get the support they need, to be listened to or to have their human rights respected.”

[Picture 6]

Charlene Tait, Deputy CEO at Scottish Autism said:

“Despite Scotland already having existing well-intentioned policies and legislation in place, the human rights of autistic people and people with a learning disability are still being failed in numerous areas across education, health, social care, and community services. Covid-19 has further shone a light on this critical situation – Scotland can, and must, do better.

“A Commissioner working across public bodies and existing regulators, to uphold and protect the rights of autistic people and people with a learning disability, would be a powerful champion for change. This new role, would ensure better access to additional support in the key areas where many individuals are being currently excluded and would mark a significant step forward towards a more inclusive Scotland.”

[Picture 7]

Broadcaster Stuart Cosgrove who has an autistic son said:

"This campaign has the capacity for real positive change - As a family we've been lucky in that Jack got his autism diagnosis early on as a child but like all parents I worry about what happens when he grows up and leaves school.

We of course want him to be independent, have his own place, a relationship, a job, all the usual things that parents hope for, but we also know those are likely to be challenging for him - he's going to need that bit extra help and support.

I believe by and large Scotland has a caring culture but establishing a Commissioner at a national level with a legal obligation to look into the different aspects of public life would make a huge difference. It would help Scotland lead the way to creating a society that fully includes and values autistic people."

ENDS

Notes to editors

For more information, please contact:

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Or

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For more information visit the campaign website which will go live with the campaign. Here you will find info about the concept of a Commissioner, videos from the autistic people, people with a learning disability and families involved in the campaign together with info on how people can take action:

www.OurVoiceOurRights.org

Or follow #OurVoiceOurRights on social media.

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.ⁱ
- There are more than 120,000 people with a learning disability in Scotlandⁱⁱ.
- A third of autistic people also have a learning disability.
- Adding in families/carers we estimate there are over 600,000 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 diagnosisⁱⁱⁱ

Social care and social isolation

- 66% of autistic people in Scotland say that they feel socially isolated^{iv}
- Less than 1 in 3 people with a learning disability can name at least one close friend^v
- 60% of children with a learning disability said they felt lonely at school.^{vi}
- Approximately 23,500 adults with a learning disability are *known* to local authorities meaning the majority do not receive any social care.^{vii}
- 705 adults with a learning disability are 'out of area' meaning that they do not live in their own community, due to lack of available support. 67 people are living in hospital because no appropriate accommodation and support is unavailable in their community. Of this group, 10% have been in hospital for more than 10 years, and 9% between 5-10 years.^{viii}

Education

- There are almost 9500 autistic children in Scotland (0-16 years old)^{ix}
- There are 15,324 school-age children and young people identified as having an additional support need resultant from a learning disability^x
- 34% of parents say their autistic child has been unlawfully excluded from school^{xi}
- 52% of children with a learning disability said they were not getting the right support at school.^{xii}
- There were 2,674 instances of children with a learning disability being secluded or physically restrained in Scottish schools in 2018^{xiii}

Employment

- Less than a third of autistic people are in some kind of paid work.^{xiv}
- 4.1% adults with learning disabilities known to local authorities are in employment^{xv}
- In comparison to 45% of disabled people and 81% of non-disabled people in Scotland.^{xvi}

Health and mental health

- Over 70% of autistic people have had a mental health condition^{xvii}
- Over half of autistic people said the process for getting mental health support took too long and was stressful.^{xviii}
- People who have a learning disability die twenty years younger than the general population^{xix}
- Children who have a learning disability in Scotland are 12 times more likely to die from preventable causes than other children.^{xx}

Housing

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

ⁱ P77, [Microsegmentation Analysis](#) (prevalence of autism is estimated at 1.035% of the population) Scottish Government, 2018

ⁱⁱ [ENABLE Scotland](#)

ⁱⁱⁱ *The Accountability Gap* – Report from the Cross Party Group on Autism (to be published in October 2020)

^{iv} *Too Much Information*, NAS Scotland 2016 (673 respondents)

^v ENABLE [Press Release](#) April 2020

^{vi} [IncludED in the Main?!](#) ENABLE Scotland 2017

^{vii} Learning Disability Statistics Scotland, 2019, SCLD & Statistics Scotland (2019)

^{viii} *Coming Home*, Scottish Government, 2018

^{ix} P19 [Microsegmentation Analysis](#), Scottish Government, 2018

^x ENABLE website

^{xi} *Not Included, Not Engaged, Not Involved*, NAS Scotland, Scottish Autism and Children in Scotland, 2018 (1,417 respondents)

^{xii} [IncludED in the Main?!](#) ENABLE Scotland 2017

^{xiii} [ENABLE Scotland](#) 2019

^{xiv} P113 of the [Microsegmentation Analysis](#), Scottish Government, 2018 puts employment at 31% with a small sample size (404 people). An NAS Report, *Too Much Information 2016*, puts the employment rate at 32%. This is a larger sample size but UK wide.

^{xv} Learning Disability Statistics Scotland, 2019, SCLD & Statistics Scotland (2019)

^{xvi} *A Fairer Scotland – Employment Action Plan*, Scottish Government 2018

^{xvii} *P6 Personal tragedies, public crisis* – Autistica UK, 2017(based on Swedish research)

^{xviii} *The Accountability Gap* – Report from the Cross Party Group on Autism (to be published in October 2020)

^{xix} [Life expectancy of people with learning disabilities | Research projects | Scottish Learning Disabilities Observatory \(sldo.ac.uk\)](#)

^{xx} [Mortality rates for children and young people with learning disabilities](#), Scottish Learning Disabilities Observatory, (2020)

^{xxi} Learning Disability Statistics Scotland, 2019, SCLD & Statistics Scotland (2019)

^{xxii} *Ibid*