

CLOSING THE ACCOUNTABILITY GAP

Views from autistic people, family carers
and professionals on the Scottish Government's
proposed Commissioner



Scottish
autism
WHERE AUTISTIC PEOPLE
ARE VALUED

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1. FOREWORDS

Rob Holland

Director,
National Autistic Society Scotland



Too often we hear from autistic people and families that do not have the support they need to live fulfilled lives on their terms. Despite many good laws, strategies and policies in Scotland, there remains a gap between the support people should receive and what they actually receive, whether in school, social care, healthcare or employment.

It's welcome therefore that the Scottish Government has committed to a commissioner, the first of its kind in the world, which can act as an agent for change, a powerful ally injecting more accountability into the system – so that people are no longer frustratingly passed pillar to post as they desperately seek help.

To do this though, the commissioner must have the appropriate legal 'teeth' and resources to do its job effectively and keep laser focused on the view of the community it is to serve.

I believe our report demonstrates an urgency to move forward with the Commissioner commitment. The longer the delay, the longer autistic people and families have to wait for real change.

Charlene Tait

Deputy Chief Executive,
Scottish Autism



All too often our organisation is confronted by the glaring lack of accountability in the systems that are meant to support autistic people in Scotland. In addition to the immeasurable human cost, we know that driving people into crisis is unsustainably expensive.

Along with other organisations, Scottish Autism is campaigning to introduce legislation that can be a catalyst for change. Not a panacea, but a vitally important first step in closing an accountability gap that is becoming a chasm. It is, of course, important to acknowledge there are differences of opinion as to how best to achieve change. However, there can be no argument that these issues do need addressed.

The commitment to establish a commissioner signals recognition of the specific needs of autistic people. Change is a process which will take many years, but this is a start in tackling the ingrained injustice that too many people in Scotland face.



David M. Nicholson

**Autism Campaigner,
Musician and Rural Activist**

It is abundantly clear to me that, whilst progress has been made when it comes to Autism, we have so much more to do. From those in rural areas of Scotland, to those who live in Scotland's towns and cities no autistic person should be left behind and their talents gone to waste.

It is therefore a great pleasure to read in the report that the overwhelming majority of respondents fully support the creation of a commissioner – a position that is much needed to ensure that government and public bodies are held accountable for the services they are supposed deliver. A position that can have the "teeth" to take real action where there are failings. A position that can be a real lever for helping Scotland become a country where every autistic person can have excellent support, lead happy and successful lives and contribute positively to society. That surely must be our ambition and one that needs to be fulfilled sooner rather than later.



Laura McConnell

Autism Campaigner

Despite the rising profile of autism, autistic people still struggle to access the same experiences, services, and rights as everyone else.

The biggest challenge we face as autistic people, is a culture of low expectations. There is an expectation that we are less capable and less worthy of the support we deserve to help us flourish in education, where we are often babysat by iPads or in bases. So, it is no surprise that autistic people are under employed.

This culture of low expectations also extends to our public services. When services are designed around the needs of neurotypical people, we are seen as too "difficult" or "complex" to include. Autistic people do not want to be included through kindness or charity because we are not outsiders, we are citizens of Scotland.

A commissioner for autistic people must hold policy makers and services to account, because when we are supported well, there is no reason that autism should be a barrier to anyone achieving all they are capable of.

2. INTRODUCTION

Partner Charities



National Autistic Society Scotland exists to transform lives, change attitudes and create a society that works for autistic people. We transform lives by providing support, information and practical advice for the 56,000 autistic adults and children in Scotland, as well as their family members and carers. We change attitudes and help create a society that works for autistic people by campaigning at a local and national level.



Scottish Autism was founded, in Alloa, in 1968. We exist to enable autistic people to lead meaningful lives, and to be recognised as valuable members of the communities in which they live. To this end, we have been providing support services and advocating for changes in practice for over fifty years. Our services include supported living, a national advice line, training and consultancy, and social enterprises – including a cafe and plant nursery. We also operate New Struan School, an independent day and residential school, which specialises in educating autistic learners.

We recognise that our organisations are part of a broader landscape of autism charities, third sector service providers and Autistic People's Organisations, and that there will be different views about how to proceed with legislation. We also recognise that learning disability organisations will make their own contributions to the national discussion on a Bill and a commissioner.

In this report we seek to represent the communities with which we have actively engaged through surveys and consultation as well as the many experiences and stories we hear delivering social care services, branch meetings, an advice line, post diagnostic support and a range of community support activities.

About Autism

Autism is a lifelong neurodevelopmental condition characterised by differences and difficulties in communication and social interaction; sensory processing issues; and highly focused attention and interests, often accompanied by a preference for routinised and repetitive movements and activities.

Autism is clinically defined as 'Autism Spectrum Disorder'. However, many autistic people dislike this label and feel that they are disabled as much by societal barriers and a lack of acceptance and support as they are by their neurodevelopmental differences.

There are estimated to be around 56,000 autistic adults and children in Scotland. Around one third of autistic people are currently thought to have additional learning disabilities, though estimates of this number vary.

The autistic community is highly diverse. Some individuals may have high support needs throughout their life, be unable to communicate verbally, or require long term social care. Others will be professionals, parents and community leaders. It is important to recognise that too many autistic people face barriers to acceptance and support whatever their life trajectory.

A Mother and Daughter's Experience

Waiting two years to even see CAMHS made me realise an outer Scottish Island was not the place to be if your autistic child needs support. We reached rock bottom. Our location meant an emergency GP was our only option when we needed help. The advice I was getting was to keep reporting any concerns about an immediate risk of harm to the police, and eventually social services might help. It took an attempt on her own life for them to listen. Too little, too late.

Psychiatry 'lumped' her additional problems under the 'Autism umbrella'. Her OCD, Autism and CPTSD reached crisis point. After being turned away from the local doctors, my daughter was taken from her home by the police and social work to a bigger island with a hospital. During the next 48 hours she was held to the floor in the street by police officers, kept in a police van and taken to A&E. Social services and medical staff argued over whose responsibility she was. Nobody knew what to do.

We were told by police that she could not return home because there were 'inadequate resources' to support her. Eventually she was transferred to Aberdeen, but my daughter was now so overwhelmed that the next few days became the most dramatic of her life. She was restrained on multiple occasions and the arguments continued. The doctor said, 'I wouldn't have allowed her here had I known how mentally ill she was.'

Social services eventually found an emergency placement, where I had to leave my frightened and confused child. A month later she was moved again, further away still. There she remains in a trauma unit, hundreds of miles from home. And we are still on a CAMHS waiting list!

Her burning question: 'when can I come home?' Nobody has an answer. Every day I feel grief, anger and frustration. Nobody would listen to us. Every child and their family deserve to be listened to and not lied to. Support for families should be accessible to all. My daughter said, 'if I were unable to walk, people would build ramps. Why because I'm autistic am I left to struggle alone?'

We feel that a commissioner would help amplify our voice and represent our views. We need someone to fight for the support we deserve.

3. THE CASE FOR A COMMISSIONER

Autistic People and Families' Experiences

Many autistic people are excluded from opportunities and cannot participate fully in their communities because they don't get the support to which they are entitled as equal citizens. This includes support in early years, school and further education; social care provision; access to advocacy; good quality and appropriate housing; quality healthcare and access to mental health services; support to find a meaningful vocation, enter the labour market, or sustain a career; and good quality care in older age.

The Scottish Government and COSLA recognised these challenges and, in 2011, launched the ambitious and well-intentioned Scottish Autism Strategy. This ran until 2021. An independent review of the strategy concluded: "After ten years, valuable resources have been created and new and additional services delivered. However, real change for many autistic people, both in how they engage with services and in how they are supported to live productive lives, is not as evident".

The Accountability Gap, a report published by the Scottish Parliament's Cross-Party Group on Autism, also critiqued the 10 Year Autism Strategy. The report included a survey that found that 72% of respondents felt that they did not have enough support to meet their needs and 78% said it was not easy to access support locally. Fifty-three percent of respondents said that the Autism Strategy had made no difference to them.

We also know that many autistic children and young people are excluded from education. Research by Children in Scotland, National Autistic Society Scotland and Scottish Autism in 2018 found that 71% of respondents' children had missed school for a reason other than common childhood illness, with 81% not receiving support to catch up on work they had missed.

Clearly there is a gap between the support that people have a right to and the support they receive. A commissioner can work to close that gap by holding services and policy-makers to account for delivering better outcomes for autistic people.

Policy and Legislative Reviews

Whilst we have an extensive and well-intentioned existing policy and legislative framework, the evidence suggests that the system all too frequently fails to uphold the human rights of autistic citizens and their families. Several recent reviews have pointed to these gaps and the need to ensure that autistic people and families' rights are promoted and protected.

The *Independent Review of Learning Disability and Autism in the Mental Health Act* (the Rome Review) recognised a wide range of legal deficiencies and 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"¹

Reviews into additional support for learning and mental health law have also highlighted the need for changes to our legislation to better promote and protect the human rights of autistic people.

Political and Government Commitments

In the lead up to the 2021 Scottish Parliamentary Election our two charities together with ENABLE Scotland campaigned for a commissioner to protect and promote the rights of autistic people and people with a learning disability. This was adopted into the manifestos of four of Scotland's political parties, including the Scottish National Party (SNP).

Following the election, the Scottish Government committed to the introduction of an *'Autism, Learning Disability, and Neurodiversity Bill'*.²

Through this Bill, it also promised to appoint a 'Commissioner' to uphold and protect the rights of autistic people and people with a learning disability.

¹ Andrew Rome, *Independent Review of Learning Disability and Autism in the Mental Health Act*, p.112-114.

² The Scottish Government, 2021-22 Programme for Government

When will it happen?

Despite having been announced in the 2021 Programme for Government, the Scottish Government has said that the consultation on the Bill will not begin until the second half of 2023.

This is, of course, disappointing and concerning not least because the longer this legislation is delayed, the more people miss out on much needed support.

People are already waiting too long for diagnosis and social care support, and too long for their rights to be upheld in education. We urge the Scottish Government to rethink this delay and bring the Bill forward sooner rather than later.

“I am concerned about the length of time this is projected to take before becoming law. I feel it suggests a lack of political will on the part of the government.”

Survey Respondent

What has the Scottish Government done so far?

In 2022, National Autistic Society Scotland and Scottish Autism each facilitated a series of engagement workshops for the Scottish Government, bringing together autistic people and families. The purpose of these workshops was to ensure that autistic people and families could voice their views and opinions on a commissioner early on. Other organisations also carried out similar workshops.

We welcome the recent announcement on the creation of a Lived Experience Advisory Panel which aims to drive the Scottish Government’s work.³ We are also pleased that the Scottish Government has delivered on its commitment to engage third-sector organisations, including both of our charities.

But, most importantly, the broader community of autistic people and families across Scotland *must* inform the development of the Bill and the role and remit of a future commissioner.

³ Scottish Parliament, Response to Written Question, S6W-10775

Jim's Perspective

People said that "I must be pleased that I now have a diagnosis". Wrong! I was bitter with myself and society in that I had spent the majority of my life feeling different and also at odds with society. I am extremely lucky, my wife is my social convener, keeps me on track. I would be lost without her.

Society is a nightmare. The social interaction that is expected of everyone – functions, dinners and even simple tasks like shopping. Most of all I hate the expected etiquette, noise, smells, bright lights, avoiding inconsiderate neurotypicals and idle chit-chat. When younger, I could mask most of my stress and anxiety, but as I get older, I find it increasingly more difficult to cope with the neurotypical world. I tend to stay in my house as going out makes me feel very tired.

I wonder if hermits are autistic?

I have to control how I accomplish things. I try and go shopping mid-week, either early morning or evening when shops are least busy. It doesn't always work, as there are situations when I have to go out when it is busy. I call this "being dragged into the neurotypical world".

The commissioner is critical to the integration of autistic people into society. In my opinion it is imperative that the commissioner is autistic. However, and this is equally important, the commissioner's team must be made up of autistic, disabled and neurotypical people.

The commissioner needs to get the message out to society about autism through seminars, adverts, posters and through education in schools, colleges and workplaces. But most importantly getting autistic people to go into these settings where they can give first-hand experiences of the issues they face and what neurotypical people can do to help. The commissioner's team should also support families and partners of autistic people, as invariably they end up struggling with their mental health.

But, most importantly, the commissioner's team is there to assist the autistic person with their issues and point them in the direction of support, on anything from employment and finance to health, day-to-day living and connecting with other autistic people.

4. WHO WE HEARD FROM

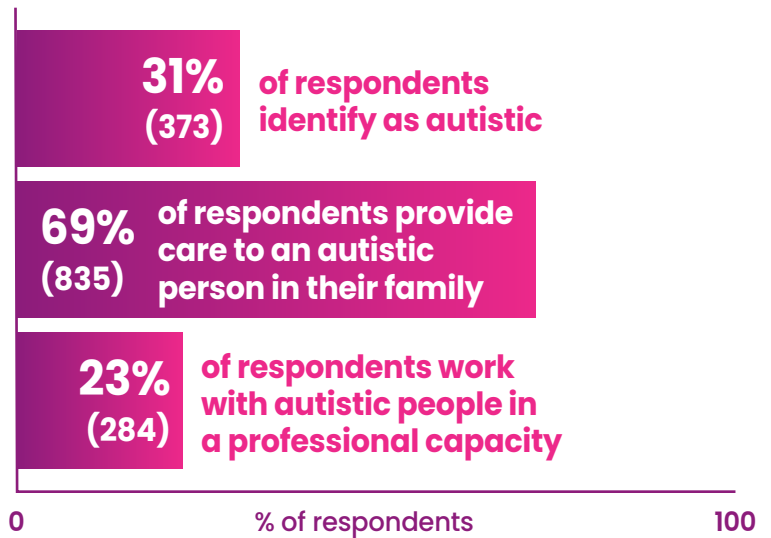
Over the summer of 2022 we launched a survey to ask the wider community their opinions on the proposal for a commissioner.

We heard from

1,215



autistic people, family carers, and professionals from across Scotland.⁴



One-quarter of the autistic people we heard from do not have a formal diagnosis.



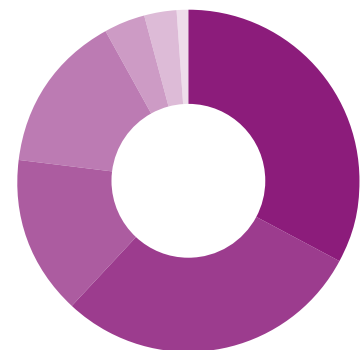
We heard from people in every local authority area



10% (83) of respondents identifying as family carers to autistic people are themselves autistic.

All age groups were represented, including teenagers and older people

- 33% (403) are 45-54
- 29% (354) are 35-44
- 15% (178) are 25-34
- 15% (178) are 55-64
- 4% (53) are 18-24
- 3% (40) are 65+
- 1% (9) are 16-17



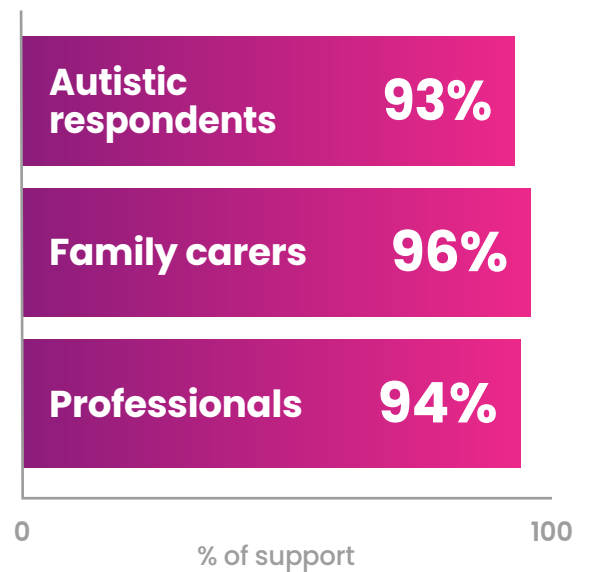
⁴ Throughout the report some percentage totals do not equal 100, as respondents were able to select multiple answers to some questions.

5. WHAT WE FOUND

Support for A Commissioner

96% of all respondents support creating a commissioner

1,166 autistic people, family carers, and professionals agree that the Scottish Government should establish a commissioner to promote and protect the rights of autistic people and people with learning disabilities.



Respondents gave many reasons for their support: experiences of workplace discrimination; difficulties accessing diagnosis; poor quality healthcare; lack of support in education; ongoing stigma; and many more.

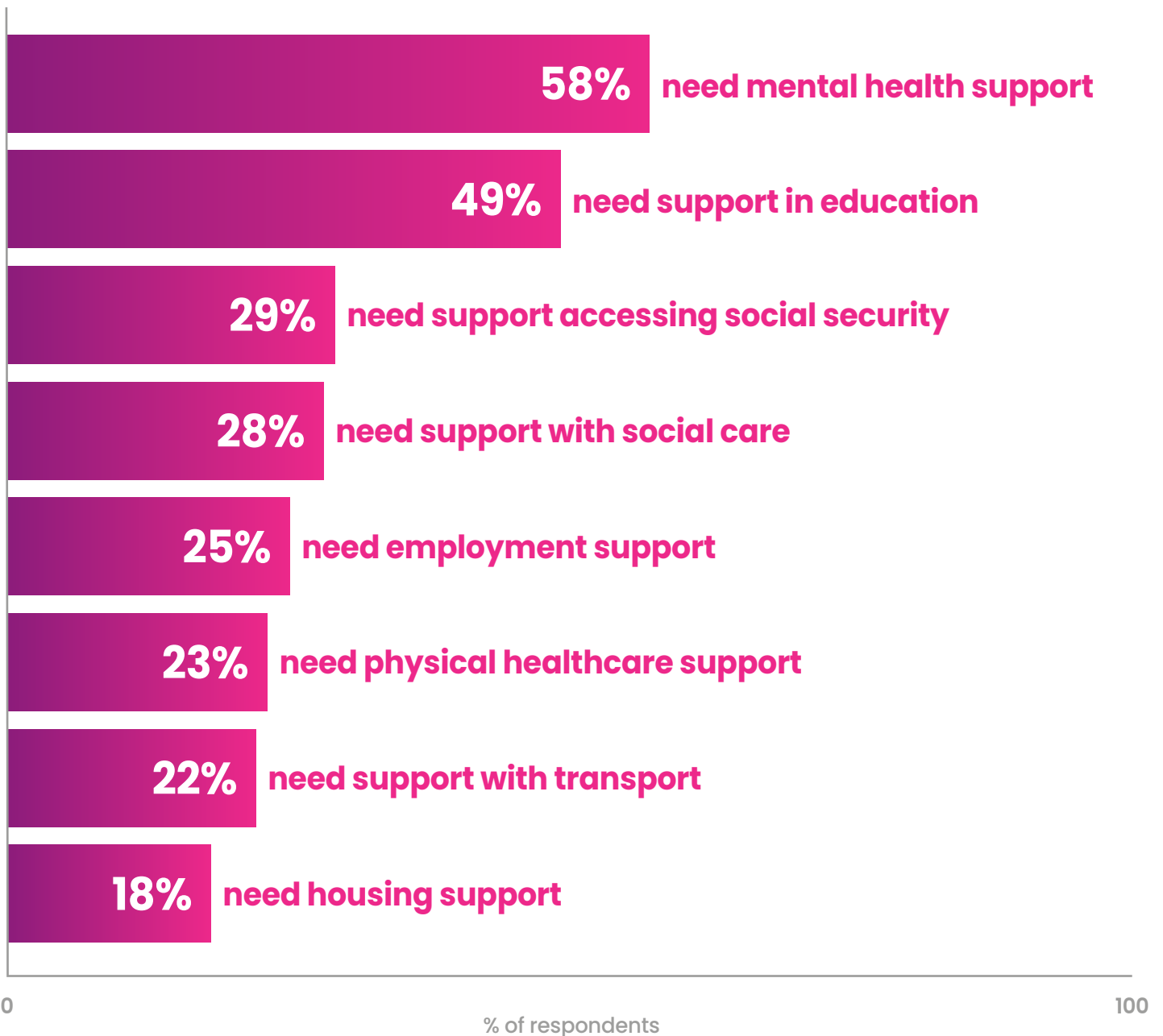
It's about time this was in place to hold everyone accountable.

This is very much needed because autistic people, particularly children, are being utterly failed in Scotland and lots of people are in complete denial about it.

It must have real teeth and powers to achieve meaningful and sustainable systemic change.

I think it will give a strong voice to people without their own.

Where Support Is Needed



It is clear that autistic people need support in many different areas of their lives, from health and education to employment and transport. That is why it is so important that the commissioner's remit cuts across all the relevant policy areas within national and local government, and takes a whole life view encompassing the array of different needs from childhood to older age.

Mental Health

All groups of respondents – autistic people, family carers, and professionals – were more likely to require support with mental health than anything else.

58% of all respondents need mental health support either for themselves or someone they care for.

Previous research tells us that autistic people are far more likely to face mental health challenges during their life than non-autistic people.⁵ Like autistic people, family carers are also more likely than the general population to experience poor mental health. It is therefore vital that autistic people and their families can access the mental health support they need, without having to fight for it and without being dismissed.

CAMHS is woefully unsuitable for our children [...] they are constantly told they are not anxious enough and discharged causing even worse mental health issues.

The stress of coping on my own as a single parent in poverty to care solely for my daughter who was suicidal has impacted my mental health.

I am an autistic adult who also has ADHD [...] I had a terrible experience with NHS mental health care, with them being dismissive and honestly I felt like it did more damage than good.

⁵ National Autistic Society, How to adapt mental health talking therapies for autistic children and adults, August 2021

Education

We know that autistic learners too often find themselves excluded from education because their needs are not met. Many autistic children and young people are not attending school at all, and many more are only attending on a part-time basis.

Our charities regularly hear from families about autistic learners who are not accessing their right to education because the support just isn't there, even though they already have a legal right to such support.

My son has missed over 2 years of school as they "cannot accommodate his needs" claiming not [to] have space in the school for a quiet zone as the school is overcrowded.

My son spends much of his day being taken out of the class and put in the soft playroom. This in no way is preparing him for being sent off to a mainstream high school in 2 years' time! Our children are being failed by the lack of provision. This is not getting it right for every child!

49% of all respondents identified a need for support in education either for themselves or for someone they care for.

I have had to home-school my daughter as no other option [is] available to us other than mainstream school. I have had to give up my full-time job to do this yet get no funding for my daughter's home-schooling education.

As a teacher I have sat with parents who are stressed, tired, dispirited, heartbroken and yes, angry at the hoops they have to jump through for their child.

The Role of a Commissioner

We know there is a gap between the support and services that autistic people and families have a right to access and what they get in reality.

Respondents identified holding local authorities and service providers to account as the most important priority for the commissioner.

When asked to rank the proposed duties of the commissioner in order of priority, respondents prioritised the functions of the commissioner as follows:

1. Hold local authorities and service providers to account
2. Hold Scottish Government Ministers to account
3. Promote understanding of autism to the wider public
4. Support individuals and families to address issues and make complaints
5. Gather data on meeting autistic people's needs

If the Commissioner is to be effective, it is crucial that the role has the proper powers and resources to ensure autistic people and families' rights are upheld.

Holding service providers to account and ensuring a consistent approach across the country.

The appointment of a commissioner needs to happen urgently and the priorities listed above acted on immediately, not in a few years.

Local authorities continually evade giving the support to autistic people that they are entitled to, using the excuse of lack of funding, resources or even still Covid-19. They need someone to hold them to account and tell them they cannot do this.

Neurodiversity

Since the term 'neurodiversity' has been added to the proposed Bill, we wanted to find out if people identified with the term.

Society is made up of people whose brains work in a wide range of different ways.

The concept of 'neurodiversity' was coined to validate the variety of ways in which people think, communicate and act – whether they belong to the 'neurotypical' majority or 'neurodivergent' minorities such as autistic people.

Neurodiversity was conceived by autistic scholars and advocates as a way of recognizing neurodevelopmental differences in the population and valuing the inclusion of those who might depart from 'neurotypical' ways of thinking or acting – such as autistic people, or those with ADHD, dyspraxia and other minority neurodevelopmental profiles. Sometimes people belonging to these minority groups refer to themselves as 'neurodivergent'.

Our findings show that survey respondents are very familiar with the concept of neurodiversity, and that a significant majority either identify as neurodivergent or have family members who do.

90.8% of all respondents have heard of 'neurodiversity'.

Only **27%** of all respondents come from families where no one identifies as 'neurodivergent'.

We often experience professionals, policy-makers and campaigners using the term in different ways, departing from the definition that was originally championed by autistic thinkers.

'Neurodiverse' is a word describing whole groups or populations that include people with different neurotypes, and which may also include the 'neurotypical' majority. The term is occasionally misunderstood as a collective term for neurodevelopmental conditions, or a label for individuals, but this is not how the term was originally conceived.

A neurodiversity affirmative society is one in which those from minority neurotypes such as autistic people are recognized, valued and given the support that they need to be fully included and pursue the life of their choice.

Our organisations are committed to the vision of a neurodiversity affirmative society. We believe that for this to be achieved the needs of specific minorities, such as autistic people, need to be understood and met for their rights to be fulfilled.

We did not ask survey respondents how they think the commissioner role should address neurodiversity, but the scope of the Bill and the commissioner's remit in relation to neurodiversity clearly needs to be part of the national conversation.

Nicola and Alex's Experience

Our son Alex is clever, loves drawing and has an impressive vocabulary. We could see that he had some differences from other children, but they were never concerning. So, it was a shock when, in P1, the school asked us to come in for a chat. An Educational Psychologist observed Alex, and we were referred to CAMHS (Child and Adolescent Mental Health Services).

We continued in this fashion, making little progress on the CAMHS waiting list, until Covid hit halfway through P3. At this point, we started home-schooling and Alex's difficulties became more apparent. We decided to seek out support ourselves and eventually travelled to Newcastle for a private assessment. This resulted in a diagnosis of ASD with Associated Language Disorder. It was a huge shock, but we were reassured that we would now get the help we needed.

Alex's school was very supportive and quickly completed the applications to the council. Our optimism, however, was short-lived. At the start of P5, the council failed to put regular support in place and the ASD Outreach Worker left the role and was not replaced. Our amazing Pupil Support Teacher continued to work with Alex, but he was still struggling.

He is now in P6 and, having been on the waiting list for Speech Therapy for almost two years, we found a private therapist over the school holidays. This was positive, but the expense meant we couldn't continue the sessions. On the advice of his teacher, we also recently sought an ADHD assessment, which resulted in a diagnosis of combined type ADHD. Once again this was paid for at our own expense.

Our experience has been prolonged, frustrating, and confusing. After six years we are finally getting some clarity on Alex's support needs. But it is upsetting to have lost critical years that could have been used to make his school experience easier. We have been left to navigate the system on our own, learning as we go and funding everything ourselves. And still we have not heard from CAMHS.

It is clear resources are stretched and children like Alex are being failed by the services that are meant to help them. Support for young autistic people involves different professions and, because each autistic person is individual, the journey cannot ever be linear. But it can be easier. We feel that a commissioner for autistic people could help to create a more joined up system that prioritises individuals' needs, and fights for recognition of the autistic community.

6. PROPOSED ROLE AND PRINCIPLES OF A COMMISSIONER

In thinking through what the role and principles of the commissioner's remit might look like, and reflecting on the results of the research, we look to the Children and Young People's Commissioner as an established model of good practice. The below is not an exhaustive list, but it sets out the key things which we believe, if incorporated into legislation, will give a commissioner the appropriate legal powers to lever real change.

The role of the commissioner should be:

1. Consulting and involving autistic people and people with a learning disability
2. Promoting human rights
3. Conducting formal investigations
4. Investigating individual cases
5. Promote good practice

The commissioner should...

- Be subject to a series of interviews prior to their assuming the role, conducted by a panel comprised of autistic people, people with a learning disability and families.
- Be approved by The Scottish Parliament and report annually to The Scottish Parliament on its work.
- Be fully independent of Government.
- Publish an annual Strategic Plan – co-produced with and scrutinised by autistic people, people with learning disabilities and families.
- Make public all its financial accounts.

APPENDIX A: METHODOLOGY

In designing our survey, we sought the views of a Leadership Group of autistic people. Across several sessions, we discussed:

- Format
- Content
- Audience

The survey comprised of eight questions, including key demographic questions. Some questions allowed respondents to select more than one answer, so percentage totals do not always equal 100. Moreover, respondents had the opportunity to input into 'free-text' boxes if they wished.

Survey Questions:

- **Place a mark next to all of the statements that apply to you.***
 - Six statements were made available, each outlining different 'relationships' to autism. All respondents were able to mark as many as was relevant to them.
- **Where do you live in Scotland?**
- **How old are you currently?**
- **We know that many autistic people and families require regular help and support. If this applies to you, or your family, in what areas do you require support?***
- **Do you support creating a commissioner?**
- **What do you think should be the most important priorities for a commissioner?**
- **Are you familiar with the term 'neurodiversity'?**
- **Do you, or a member of your family, identify as 'neuro-divergent'?***

The survey opened on 20th June 2022, running until 21st August 2022.

Data is important; however, the lived experiences and stories of autistic people and their families are equally, if not more, valuable. Around one-third of all respondents left some form of written contribution and some of these contributions feature in the report.

* Respondents could select multiple answers.

