

Cross-Party Group on Autism

The accountability gap

A review of
the *Scottish
Strategy for
Autism*



Contents

4.	Foreword by the Co-Conveners
6.	Foreword by the Secretariat
7.	About the Cross-Party Group on Autism
9.	Introduction
10.	Methodology
11.	Executive summary
13.	Recommendations
15.	A Healthy Life
23.	Choice and Control
32.	Independence
41.	Active Citizenship
49.	Conclusion
50.	Recommendations
52.	Appendix A: CPG online survey
52.	Appendix B: 2019 survey from the National Autistic Society
59.	Appendix C: Non-MSP members of the CPG
60.	References

This report was written by National Autistic Society Scotland and Scottish Autism in their capacity as Joint Secretariat to the Cross-Party Group (CPG) on Autism. The views expressed in this report have been collated from survey submissions completed by organisations and individual members of the CPG and reflect discussions at designated CPG meetings.

October 2020

Foreword



Alexander Burnett MSP
Co-Convener



Annie Wells MSP
Co-Convener

We are pleased to present this report of the Scottish Parliament Cross-Party Group (CPG) on Autism's review of the *Scottish Strategy for Autism*.

The report was due to be published earlier this year but for very understandable reasons was delayed as we all focused on tackling the challenges of the COVID-19 pandemic.

The response to the review was fantastic. The four designated meetings, held between May 2019 and January 2020, provided the opportunity for lively debate, enthusiastic discussion, worthwhile contributions, and the sharing of views from a variety of different individuals and organisations. Similarly, our online survey received an outstanding response, with contributions providing us with detailed invaluable feedback.

We would like to thank all of our members who took part in the review, whether at our meetings or through the online survey. The views shared were, at times, incredibly passionate and direct, yet all have been contributed with a real desire to effect change.

This report seeks to document the views gathered through the course of the review, using the words of participants to detail the reality of day-to-day life for Scotland's autistic people. On the basis of what our members told

us, this CPG report has also sought to make a raft of recommendations for the Scottish Government to consider when discussing what may follow the current *Scottish Strategy for Autism*.

The CPG on Autism's review into the impact of the *Scottish Strategy for Autism* found that there is a widespread recognition that the

Strategy is well-intentioned and ambitious, and an overall acknowledgement that the Scottish Government introduced the Strategy with the genuine aspiration of improving life for Scotland's autistic people. It is clear that there are some genuine successes that provide models for future work.

After over eight years of the Strategy being in place, the majority of those who participated in our review still feel there has been limited impact in a variety of areas.

However, the majority view of the hundreds of people who have been involved in our review is that such ambition and aspiration has not been realised in practice, outwith sporadic areas of genuine progress. After over eight years of the Strategy being in place, the majority of those who participated in our review still feel there has been limited impact in a variety of areas, from diagnosis and post-diagnostic support to employment and transitions.



A number of reasons for this have been cited during the review. In particular, the review has found a number of concerns surrounding a lack of training for professionals, minimal funding for valued services such as the One Stop Shops, and a lack of accountability at local level, resulting in the Strategy's intended improvements never yet making it into practice.

It is clear that this issue of accountability, something raised consistently through all aspects of our review, is a particularly crucial concern that should be considered as a priority for both the Scottish Government and local government. As much as the content and ambition of the Strategy is to

be applauded, it has become clear through the review that there is a disconnect between what is expected to happen, as detailed in the Strategy, and what is actually happening in practice.

Within the context of the pandemic, we believe the report's recommendations are more important than ever for Scottish Government and its partners to consider when planning for 2021 and beyond.

We would like to conclude by again thanking all those who have contributed their experiences and time to this important review, and we are pleased to publish our findings in this report.

Alexander Barnett

Ann S. Wells

Foreword by the Secretariat

The impact of coronavirus has changed Scotland. While this review was conducted before the pandemic, we believe the findings are more important than ever and will help us build a positive future for autistic people and their families.

There is a huge opportunity now to change how autistic people are supported in Scotland. The virus has taken a terrible toll on many but it has also exposed how the old ways of doing things need not be the way forward for the future. This potential for change has been grasped by the Scottish Government and over the course of the pandemic, we saw a shift in how they worked not just with our charities but also with other stakeholders to ensure that autistic people and their families were supported as much as possible during these tough times. We thank them for that and believe that this cooperation and partnership can provide the basis for new and much-needed change.

This report is hard-hitting, there is no getting around it. It demonstrates loudly and clearly that autistic people and their families still have to fight for their rights, fight for the correct support and fight for access to the services that they are entitled to. It isn't right and our organisations will continue to campaign until autistic people and their families don't need to fight any longer. What comes across clearly is that there is still significant work to do to achieve that goal, but the report makes concrete and realistic recommendations to move us towards it.

We know that the financial situation facing local government is very challenging. Increased and sustainable funding is undoubtedly an important part of the answer. We also know that there is an accountability gap between

the positive policy positions of the Scottish Government and the realisation of those policies at a local level. People don't feel any difference. Sadly, well-intentioned policy is not enough and so we have proposed the creation of an autism commissioner, an office which could act as a human rights champion for autistic people, that could work with councils and health boards and where, if necessary, could ensure that autistic people's rights are upheld. This would be the first such commissioner in the world and we want to work with the Scottish Government, COSLA and other stakeholders to make it happen.

The Scottish Government Autism Policy Team have shown real willingness to work with us to achieve better outcomes for autistic people and their families. We thank them for that. This report provides us with a signpost of how we can start down that path together, working in partnership to make Scotland the best place in the world for autistic people and their families. This report shows we have a long way to go, but together we believe we can achieve it.



Charlene Tait
Deputy Chief Executive
Scottish Autism



Nick Ward
Director
National Autistic
Society Scotland

About the Cross-Party Group on Autism

The Cross-Party Group (CPG) on Autism has a large membership comprising of individuals, organisations and professionals from across Scotland, all with a particular interest in autism. The group aims to look at key issues related to the topic of autism in Scotland.

Purpose of the group:

- to act as a channel of communication between the Scottish Parliament and autistic people, their families and carers, professionals and organisations
- to raise awareness and promote the interests of autistic people, their families and carers, and to influence Scottish Government policy
- to provide opportunities for MSPs to learn about the latest Scottish and international autism research and to learn about the needs of autistic people in Scotland, including the views of both autistic people and the wider community.

Alexander Burnett MSP
Co-Convenor

Annie Wells MSP
Co-Convenor

Bill Bowman MSP
Member

Jeremy Balfour MSP
Member

Alex Cole-Hamilton MSP
Member

Oliver Mundell MSP
Member

Daniel Johnson MSP
Member

Fulton MacGregor MSP
Member

Mark McDonald MSP
Member

Johann Lamont MSP
Member

The Secretariat to the Cross-Party Group on Autism is provided by:



The National Autistic Society Scotland

is here 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.

Since 1962, autistic people have turned to the National Autistic Society Scotland at key moments or challenging times in their lives, be it getting a diagnosis, going to school or finding work. We change attitudes by improving public understanding of autism and the difficulties many autistic people face. We also work closely with businesses, local authorities and government to help them provide more autism-friendly spaces, deliver better services and improve laws.

Scottish Autism

is an organisation dedicated to enabling autistic people to lead happy, healthy and fulfilling lives. Established in 1968 by a group of parents, we are now the largest provider of autism-specific services in Scotland and a leading authority and advocate for good autism practice.

We exist to help those diagnosed as autistic to lead meaningful and fulfilling lives and be recognised as valued members of the community they live in. We also seek to share our knowledge and expertise with parents, carers and other professionals in order to support the development of skills and strategies needed to provide the best care and support for autistic people.

What is autism?

Autism is a lifelong disability which affects how people communicate and interact with the world. There are approximately 56,000 autistic adults and children in Scotland.

All autistic people have difficulties with communication and social interaction. These can include not being able to speak, delays in processing information or difficulty holding conversations and making friends. Autistic people also engage in repetitive behaviours, such as hand flapping, rocking or repeating sounds. They can experience intense anxiety and extreme unease around unexpected change. Many autistic people have sensory issues with noise, smells and bright lights, which can be very painful and distressing.

Without the right support or understanding, autistic people can miss out on an education, struggle to find work and become extremely isolated.

Introduction

In November 2011, the Scottish Government, together with COSLA (Convention of Scottish Local Authorities), published the *Scottish Strategy for Autism*, aiming to deliver strategic action both locally and nationally for the autistic people of Scotland. It included the welcome vision Scotland would strive to be a place where autistic people were 'respected, accepted and valued by their communities and have confidence in services to treat them fairly so that they are able to have meaningful and satisfying lives.' The *Scottish Strategy for Autism: outcomes and priorities 2018-2021* followed, setting out the priorities for action through to the end of the Strategy's lifespan.

With 2021 now in sight, the CPG took the decision to undertake a review of the Strategy, focused almost entirely on the experiences and views of autistic people, their families and carers, charities and professionals, to ensure that valuable feedback from lived experience is provided to the Scottish Government and COSLA as they consider what should follow. The review began in May 2019 and was originally due for publication in March 2020, but was delayed until the autumn due to the coronavirus pandemic.



Methodology

To gather the views of the CPG on Autism, four meetings were held to discuss the four strands/strategic outcomes of the *Scottish Strategy for Autism*, as identified in *Scottish Strategy for Autism: outcomes and priorities 2018-2021*:

- **A Healthy Life** – 28 May 2019
- **Choice and Control** – 27 August 2019
- **Independence** – 20 November 2019
- **Active Citizenship** – 15 January 2020

In addition, an online call for views was made, based around the four strands. The questions were:

- What are your views on how effective “Strand One: A Healthy Life” has been?
- Do you have any examples of good practice that you have experienced relevant to “Strand One: A Healthy Life”?
- Do you have any examples of areas “Strand One: A Healthy Life” has failed to improve?
- What are your views on how effective “Strand Two: Choice and Control” has been?
- Do you have any examples of good practice that you have experienced relevant to “Strand Two: Choice and Control”?
- Do you have any examples of areas “Strand Two: Choice and Control” has failed to improve?
- What are your views on how effective “Strand Three: Independence” has been?
- Do you have any examples of good practice that you have experienced relevant to “Strand Three: Independence”?
- Do you have any examples of areas “Strand Three: Independence” has failed to improve?
- What are your views on how effective “Strand Four: Active Citizenship” has been?
- Do you have any examples of good practice that you have experienced relevant to “Strand Four: Active Citizenship”?
- Do you have any examples of areas “Strand Four: Active Citizenship” has failed to improve?
- What other thoughts do you have on the effectiveness of the *Scottish Strategy for Autism*?

The survey received 140 responses including from autistic people, their families and carers, charities and professionals.

Contributions made at the four designated meetings were combined with submissions to the survey to develop this report.

We also supplemented our review with data collected by the National Autistic Society in 2019.¹ This was part of a UK-wide inquiry conducted by National Autistic Society under the auspices of the All-Party Parliamentary Group on Autism. The survey included questions for those living in Scotland on the *Scottish Strategy for Autism*.

Around 900 people in Scotland responded to these questions which provides an invaluable data set. This data is published for the first time in this report and used throughout. Further details can be found in Appendix B.

Executive summary

The Cross-Party Group (CPG) on Autism's review of the *Scottish Strategy for Autism* focused primarily on the lived experiences of autistic people, and their families and carers. This allowed those affected by the Scottish Government's strategy to directly shape our report, by having their voices heard and their views documented. This was supplemented by contributions by professionals, charities and other relevant parties.

Throughout our review, we received detailed, thoughtful, passionate and, at times, distressed contributions from people all over Scotland keen to have their voices heard.

Our review found great support for the aims and objectives set out in the *Scottish Strategy for Autism*. Indeed, the Scottish Government should be commended for the positive vision of the strategy and its ambitious reach.

However, we also found widespread frustration that the aims of the strategy have often not been put into practice or realised at a local level.

Furthermore, data from the 2019 UK-wide inquiry *10 Years On* carried out by the National Autistic Society found that from 900 people surveyed in Scotland, 72% reported that they still did not have enough support to meet their needs.²

We found that the diagnosis process is still too stressful and difficult a journey, often taking far longer than is acceptable, and that efficient, accessible post-diagnostic services are not available in all parts of Scotland. In terms of mental health services, the feedback we received was similarly critical, with the suggestion that the lack of appropriate support in this area was, in some

circumstances, worsening the mental health of autistic people.

We found that the level of training and autism awareness among education professionals varied considerably. Autistic families told us time and time again that more support was required in mainstream education to ensure that their children were not only able to cope, but to flourish.

We were pleased to receive evidence that autistic people believe there is an ongoing improvement in public awareness and understanding of autism in Scotland, including positivity around increased numbers of autism-friendly venues and facilities.

However, our review also found that there remain important concerns over access to appropriate levels of social care support for autistic adults, together with the availability of suitable housing. Both of which are needed for many in order to live independent and fulfilling lives.

Our review found that autistic people and their families are optimistic about the Scottish Government's plans for a new social security system in Scotland, and the improvements that this might bring, particularly in terms of how social security assessments are conducted and the support available.

However, participants in the review were critical of the lack of support needed to make the transition from education into employment, as well as the ongoing support to allow autistic people to build and progress within a career.

As well as findings pertinent to each of the Strategy's four strategic outcomes, some issues

were consistently highlighted throughout the review by a large number of participants. Firstly, we found that many autistic people continue to feel that they are ignored by those responsible for the design and implementation of the services and strategies that directly impact upon them. It was very clear from our review that the autistic people of Scotland do not believe their voices are consistently being heard and that, for Scotland to really progress in terms of support and service provision for autistic people, they must be at the forefront of developments.

Our review also found that it is the widespread belief of autistic people, families, carers and many professionals that there is a concerning lack of accountability when it comes to implementation at a local level. Many respondents told us that support they or family members desperately needed and were entitled to, was not forthcoming and that there was a feeling of powerlessness with little or no route to challenge.

Our review concludes therefore that a lack of accountability within structures is a major barrier to realising the aspirations of this strategy but will also impede future ones.

Following the review, we have identified 10 recommendations for Scottish Government and partners to consider. These are particularly pertinent at this point in time with the challenges of the pandemic. Building back services with autistic people's rights at their centre must be the focus.

From the recommendations, two are imperative if real progress is to be made.

The first is that there should be a new *Scottish Strategy for Autism* in 2021 building on the legacy of the current one. We strongly believe this strategy must be created with the full involvement of autistic people and families. Only by putting a wide cross-section of autistic voices at the centre of any future approaches will the desired progress be made.

The second is the importance of solving the issue of the accountability gap. To this end, the report recommends establishing in law an 'autism commissioner' tasked with ensuring that good policy and laws are implemented appropriately at a local level and have a very tangible and positive impact for autistic people and families throughout Scotland.

Throughout our review, we have heard first-hand the many challenges faced by autistic people and their families. It is our firm belief that if these key recommendations are acted upon, we would move significantly closer to realising our shared ambition – that autistic people and their families have the support and understanding needed to be fully included as equal citizens.



Recommendations

Key recommendations

1. Build on the legacy of the *Scottish Strategy for Autism* with a new fully funded strategy from 2021, co-created by the Scottish Government, COSLA and other partners, autistic people, families, professionals and autism charities.
2. Seek to solve the accountability gap by establishing a new autism commissioner role, who would uphold autistic people's rights and ensure that effective policy and laws are implemented appropriately at a local level.

Other recommendations

3. The Scottish Government, COSLA and local partners should undertake an audit of service provision throughout Scotland to identify unmet need in terms of both pre and post-diagnostic support, together with social care and housing, in order to inform the new strategy and ensure appropriate and sustainable funding is put in place.
4. Health and Social Care Partnerships should include specific KPIs to record, collate and publish autism diagnosis waiting times so we have an accurate countrywide picture of how long people are waiting and where improvements are needed.
5. NHS Education for Scotland should commit to providing autism awareness training for ALL healthcare, social care and mental health professionals.
6. Sustainable funding must be put in place either centrally or locally to ensure that post-diagnostic information, advice and guidance support services are available where needed.

7. The Scottish Government and Scottish Parliament should act on the findings from the Independent Review into Learning Disability and Autism within the Mental Health Act and legislate to end detention in hospital on the basis of disability.
8. The Scottish Government, Education Scotland and partners should progress the commitments from the 'Autism in Schools' working group and crucially introduce a baseline of autism knowledge into the Initial Teacher Education framework.
9. The Scottish Government, COSLA and partners should ensure there is a focus on improving the transition from child to adult services for autistic young people, be it through Ms Lamont's proposed Bill or other measures.
10. The Scottish Government and partners must ensure that specialist employment support is available to support autistic people into work as well as build and maintain their careers.

Strategic Outcome 1

A Healthy Life

Autistic people enjoy the highest attainable standard of living, health and family life and have timely access to diagnostic assessment and integrated support services.³

The first strategic outcome from the Strategy is focused on ensuring that autistic people have early access to clear diagnostic pathways and that accessible, efficient support services are put in place for autistic people and their families both during and after diagnosis. The Scottish Government has committed to facilitating improvement for autism assessment and diagnosis for all age groups and genders, as well as working with partners to provide appropriate post-diagnostic support to Scotland's autistic population. The strategic outcome also considers the mental health services provided to autistic people, how these can be improved, and what alternative solutions may be available for autistic people and people

with complex care needs. The overall aim of 'A Healthy Life' is to ensure that autistic people are supported during and after diagnosis to enjoy as high a standard of living as possible.

The CPG is already aware that autistic people die on average 16 years earlier than the general population.⁴ We also know that one in three autistic people has a learning disability⁵ and, for those with autism and learning disabilities, the life expectancy is more than 30 years before that of the general population.⁶ Such statistics starkly highlight the crucial need for effective, high-quality health services, from diagnosis to end-of-life, which can be easily accessed by autistic people in Scotland.



Data collected by the National Autistic Society during 2019

When presented with the statement, **“It has been easy to get the support I need in my local area”**, 896 people in Scotland responded. Of those:

- Almost half of respondents (47.2%) strongly disagreed with the statement and just under a third of respondents (30.4%) disagreed, meaning almost 80% said they did not find getting support in their local area easy.
- Just a small minority of respondents (9.5%) either agreed or strongly agreed with the statement.

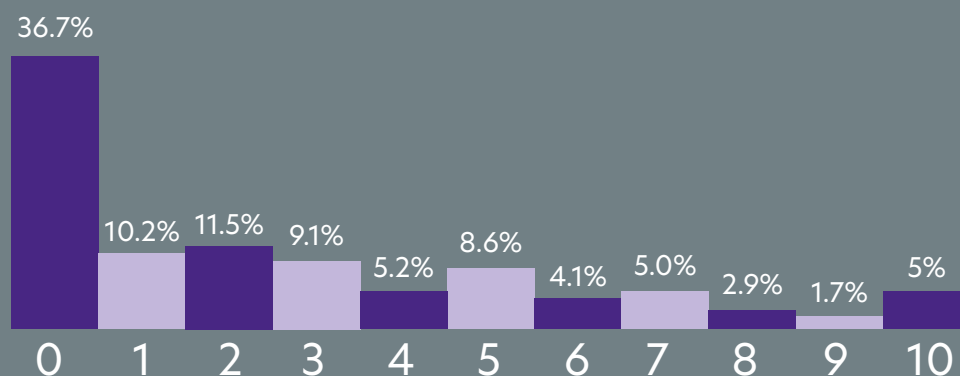


78%

of respondents said it was not easy accessing support locally.

And 824 people were asked, **“How much were you supported in the 12 months following the diagnosis?”**

0 = Not at all supported
10 = Fully supported



Getting a diagnosis

The CPG on Autism acknowledges that the Scottish Government has created the National Autistic Improvement Team (NAIT) at Queen Margaret University and welcomes its purpose to work in partnership with practitioners and clinicians across Scotland to improve the diagnosis process and care pathway for autism and other neurodevelopmental conditions. However, it remains difficult to assess impact in this area as diagnostic waiting times are not collated and published.

Throughout our review, the CPG consistently received concerns and frustrations regarding diagnosis waiting times and the battle to obtain access to a diagnosis in the first place.

Of the responses received, the overwhelming majority suggested waiting times are still unacceptable. Some respondents acknowledged slight improvements in this area, but a far greater number suggested there has been no noticeable improvements whatsoever:

"I don't think this aim is anywhere near being achieved. The diagnostic assessment process took 18 months from referral to getting a diagnosis in our case (much pushing needed to achieve this timeframe) and no support has been given or offered after diagnosis."

In some cases, we have even heard from people who felt waiting times for diagnostic assessments have increased over the lifespan of the Strategy:

"In 2009 I had to wait four-six months to see the Adult Autism Team. My friend is currently waiting for an assessment and so far her wait has been 18+ months."

Responses in this area also highlighted the many barriers to obtaining a diagnosis that are facing those in more rural or isolated

areas of the country, or are simply the result of local authorities not having implemented an effective diagnostic process – the result of which is an inevitable postcode lottery:

"I saw my doctor in April 2019. They referred me to the local mental health team in Shetland – there is no adult diagnostic pathway in NHS Shetland. They then referred me to Cornhill in Aberdeen for diagnostic assessment again, there is no adult diagnostic pathway in NHS Grampian."

The CPG is also aware that a number of local Health and Social Care Partnerships (HSCPs) do not have adult diagnosis pathways available to autistic people unless they have a co-occurring condition, something that we consider to be unacceptable. It seems clear that there is an accountability deficit resulting in local authorities, NHS Boards and HSCPs failing to provide the accessible pathways expected of them, despite the promises made in the Strategy.

The topic of pathological demand avoidance (PDA), and the difficulties associated with obtaining a PDA diagnosis, have also been discussed both in our review meetings and via the online survey:

"At diagnosis the psychiatrist told me 'your daughter has PDA but I can't say that is her diagnosis because I'm not allowed to but I will state that in the diagnosis report'. How unhelpful and unfit for purpose is that for a diagnosis process!"

The CPG acknowledges that the existence of PDA as a 'diagnostic term' and how it fits within the autism spectrum is widely debated, with limited evidence-based research and no conclusive, agreed-upon definition.⁷ The CPG recognises the number of voices on this issue and believes further research would be very valuable.

Overall, the review of the Strategy highlighted quite conclusively that autistic people and their families believe little, if anything, has improved in terms of diagnosis, particularly regarding the timeframes involved:

"Ineffective. Dreadfully difficult to obtain an autism diagnosis."

Post-diagnostic support services

The CPG recognises the ambitious and well-intentioned commitments to improving post-diagnostic support contained within the *Scottish Strategy for Autism* and believes that, if the Strategy was implemented in practice, Scotland would be a world-leader in services and support for autistic people. However, as has been suggested during the course of our review, we now have to acknowledge that the Strategy is retrospectively over-ambitious, resulting in a third of autistic people and families still receiving no support following diagnosis.⁸

The review has raised numerous concerns regarding the reality of integrated support services and the accessibility of post-diagnostic support. The majority of views raised support the suggestion that post-diagnostic support is still hugely lacking for autistic people of all ages:

"In my experience as a parent of a 14-year-old son, support could not be further away from being timely, accessible or integrated."

"As an autistic adult I get zero support. It could be assumed that I got by before diagnosis without support, but I did not."

As a result, the vital gaps in service provision on the ground are often being filled by charity and voluntary organisations:

"I don't know where my son and, in turn, my family would be today [without charities]. But it shouldn't be left purely to charities to help and support my son and his family."

One service that was consistently mentioned throughout the review was One Stop Shops. It seems clear that a large number of autistic people and their families in Scotland view the One Stop Shops as vitally important services that can provide adequate and efficient support where other providers fail, with a number of online survey submissions suggesting the sustainability of One Stop Shops should be a priority for the Scottish Government:

"One Stop Shops are a godsend to those autistic people who can make use of them. Not to fund them properly and create more throughout the country is (or should be) criminal. They provide so much support in so many ways."

"The One Stop Shops work. They help people. They provide support, advice, training and a hub for the community. So why were they not supported?"

A common theme identified throughout the review was a widespread view that, in general, NHS staff and other healthcare professionals still possess an inadequate level of knowledge and understanding of autism, despite the aims of the Strategy to address this:

"My daughter is still coming across professionals who do not understand autism. Mental health professionals not understanding autistic behaviour. Psychiatrists trying to change her diagnosis to borderline personality disorder instead. Psychologists not understanding autism."

Some respondents were particularly vociferous about this issue, highlighting the very real impact a lack of understanding is having on the daily lives of autistic people in Scotland:

"All medical and emergency services staff should be properly trained on recognising and accommodating autism. I can't even access basic healthcare at the moment and am missing out on desperately needed treatment because I wait six-12 months for a specialist appointment only to find they have no understanding of how to communicate with me."

Another common theme throughout the review was services that, once successful, have now seemingly deteriorated with no sign of improvements or replacement services:

"Unfortunately, autistic people are very far from attaining the highest standards of living, health etc and support services remain minimal in most of Scotland; in some places, like Glasgow, they are much worse than they were when the Strategy started."

Throughout the vast majority of the CPG's review, autistic people and their families told us that services to which they are entitled are usually only accessed after a long and arduous battle. It seems to be commonplace that those who eventually obtain support believe they have achieved this only after having to fight for it, rather than receiving it with minimal stress due to eligibility:

"Everything we have accessed we have had to fight for. It's like we have had to prove how his needs are worse than other children's in order to access any support."

Our review did highlight some positive experiences. In particular, a number of examples were provided of GPs communicating with autistic patients in writing, vastly improving the service provided to those

who experience issues around face-to-face communication. The positive impact this has had on the autistic people involved highlights what can be achieved when professionals understand autism:

"I have had one helpful NHS consultant – out of the many I have seen in recent years. He allowed me to communicate in writing, even going so far as writing down his response and allowing time for me to process this."

However, examples of good practice provided were largely specific, isolated cases, often involving just one particular staff member and usually only impacting on a fraction of local people, rather than experiences of widespread services accessible to the general population.

The review of the Strategy's impact on service provision in Scotland highlights clearly that efficient, accessible support services are still a long way from being a reality for autistic people. It appears that improvements have been made in some areas, where a degree of luck is required to guarantee access to a particular One Stop Shop or a specific GP, but, overall, the view expressed throughout the review is undeniably that services either seem to be inefficient, or are completely non-existent.

From the many contributions to our review, it seems to be the widespread opinion that the current situation is primarily a result of the lack of accountability regarding the implementation of services:

"It's been disappointing. It's largely built on making local authorities responsible for almost everything, but local authorities have grossly inadequate resources, and almost no accountability... The lack of accountability is glaring, and despite all their best efforts to pass the buck, this remains largely the Scottish Government's responsibility."

The CPG cannot overstate how important the reality of the lack of accessible services currently is, and the impact it is having:

"At 45 years old, I'm starting to see why the average life expectancy is 54 for people with autism. If total lack of healthcare doesn't kill me, inability to survive my lack of income, horrific job, and total isolation certainly will."

A mental health crisis

Autistic people are more likely to experience mental health problems than the general population, with over 70% of autistic people having had a mental health issue,⁹ and so it is vital that mental health services are capable of meeting the needs of autistic people. A concerning study from Sweden found that autistic adults who do not have a learning disability are seven times more likely to die from suicide. While there has not been a comparable study in Scotland, we might infer it is a very real concern here.¹⁰

The CPG recognises the Scottish Government's desire to make legislative changes in this area through the commissioning of an overarching review of the mental health legal framework led by John Scott QC. We believe it is critical that the challenges facing autistic people in terms of accessing mental health services appropriately play an important role in this review.

In our review, a lack of effective, satisfactory mental health service provision was something highlighted throughout both meetings and the online survey, with it being suggested that autistic people in Scotland are currently facing a crisis in mental health. The primary point raised by many was the inaccessibility of mental health support:

"Autistic people are routinely denied access to healthcare, most strikingly mental healthcare, by professionals and institutions who have done far too little to ensure services are accessible and autistic distress is recognised and taken seriously."

As with other support services, real concerns were also raised regarding a lack of knowledge and understanding of autism among mental health staff and service providers:

"There are some good, decent, skilled people within the CAMHS system, and also within Adult Mental Health Services, but autism staff training needs to be a priority."

The CPG received a number of contributions to the review that describe negative experiences, often leading to a breaking point. Given this, it is no surprise that many of those who participated in our review have felt forced into taking measures into their own hands, often travelling long distances to access services. In some of these cases, people feel they have had to travel south of the border to obtain the support they require:

"We have been knocked back from CAMHS now an uncountable number of times and have to travel from Glasgow to Manchester to a Priory hospital for support from a child psychologist as we can't access anything in Scotland. He is now seen every four weeks."

As detailed in the Scottish Government's own *Coming home*¹¹ report and last year's *Autism and complex care needs* report by the Mental Welfare Commission for Scotland,¹² there remains a situation in Scotland where autistic people are still being detained on the basis of their disability, facing delayed discharge and potential out-of-area placements due to a lack of local services. This critical situation was also understandably raised over the course of the review:

"My suicidal autistic teenager was an inpatient for 24 days following a suicide attempt. She received no medical care for 20 days, no mental health support at all or on discharge, did not eat for 24 days, and the hospital reported her to police for 'assault.'"

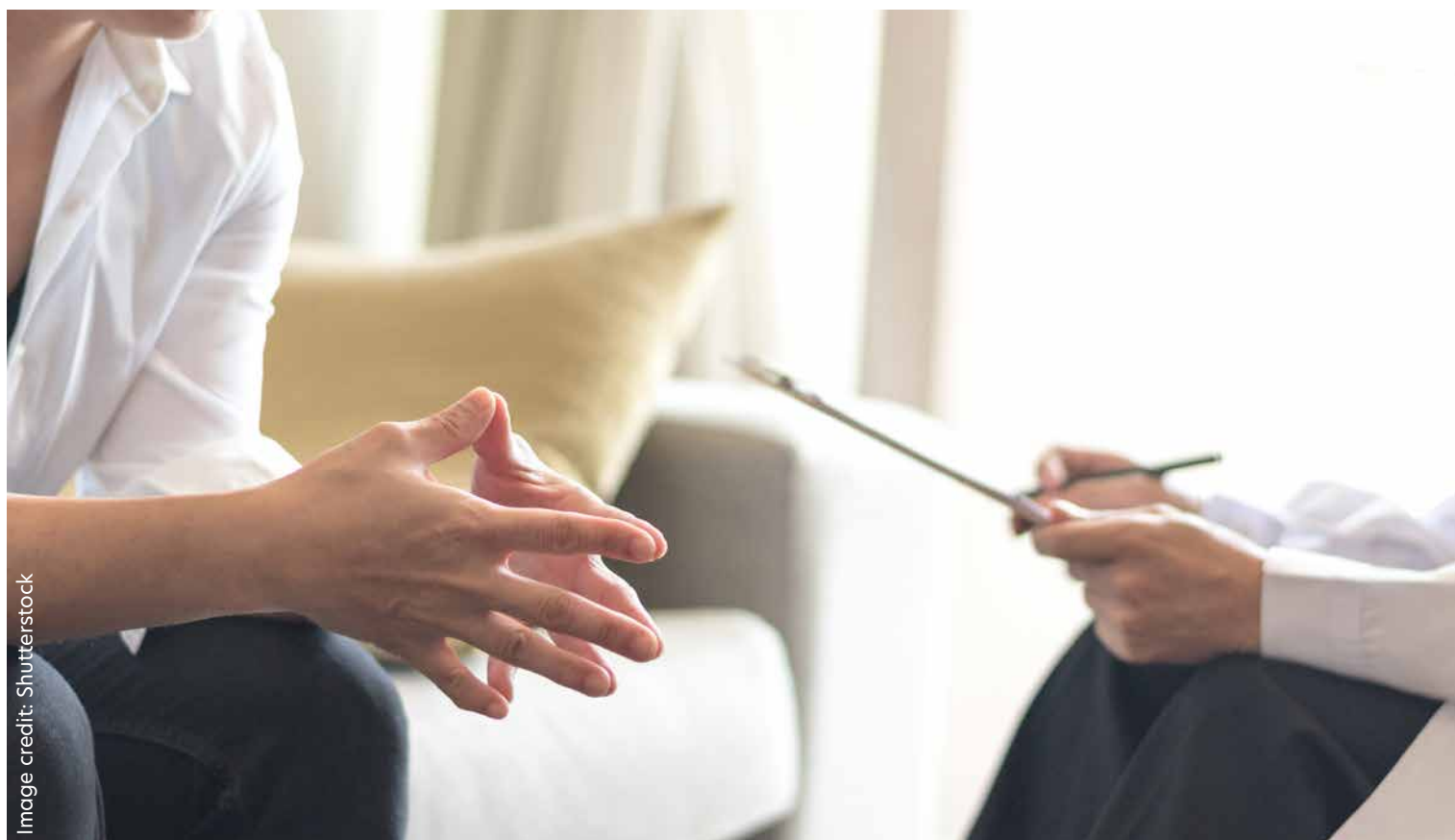
With over half of autistic people believing the process for receiving mental health support to be too long and too stressful,¹³ throughout this review, autistic people and their families have told us, in the time that has elapsed since the introduction of the *Scottish Strategy for Autism*, there has not been a meaningful reduction in the barriers they face to accessing efficient, often life-saving support:

"There is still a huge discrepancy between autistic people and non-autistic people being able to access mental health services."

The CPG recognises the Scottish Government's desire to make legislative changes in the area of mental health law which have the ability to make a profound positive impact for autistic people.

Firstly, the Independent Review of Learning Disability and Autism in the Mental Health Act led by Andrew Rome which was published earlier this year included an important set of recommendations. Crucially, it recommended 'that Scotland works towards law that removes discrimination in detention and compulsory treatment on the basis of disability'. This has been widely welcomed as it is hoped it would lead to fewer autistic people being inappropriately detained in inpatient settings. The CPG urges the Scottish Government to act on these recommendations.

Secondly, the Scottish Government has commissioned an overarching review of the mental health legal framework led by John Scott QC. We believe it is critical that the challenges facing autistic people in terms of accessing mental health services appropriately must play an important role in this review.



Case study:

Leanne

Leanne had struggled with mental health issues since childhood and, following a traumatic incident, she suffered a mental breakdown, becoming mute and communicating with her husband by gestures and basic sounds only. She was referred for psychotherapy that she attended for around two years, despite feeling that the experience was making things worse. Eventually, Leanne was diagnosed with borderline personality disorder.

Despite this, Leanne remained unconvinced that this was accurate and, while watching a documentary about autism soon after, she was intrigued to learn more. Leanne began her own research into autism and autistic women, and completed a number of online quizzes and tests. The more research Leanne did, the more she began to believe that her original diagnosis was incorrect and she was, in fact, autistic.

Leanne decided to seek an autism assessment, in the hope that a diagnosis would allow her to access life-changing and life-saving support. However, when Leanne approached her GP about a possible assessment, the suggestion made her GP laughingly claim “she could not possibly be autistic”. Following this negative experience, Leanne was instead referred for an assessment at a psychiatric unit.

During this assessment, Leanne felt listened to and understood by the mental health professional responsible for her, resulting in the assessor agreeing with her that an autism assessment was necessary. The referral for this was subsequently granted.

When eventually undergoing the autism assessment, Leanne had another negative experience – feeling she was being misunderstood and not listened to properly. During the assessment, Leanne stressed the struggles to cope she had experienced since childhood, listing the negative coping mechanisms she had developed as a result, such as self-harming and bulimia. These concerns were largely dismissed as irrelevant by the assessor. Leanne was informed during the assessment that, even with a diagnosis of autism, the post-diagnostic support she sought was simply not available for her as an adult. Following the assessment, she asked for a copy of the finished report which she found had numerous factual errors and assumptions. Despite this, Leanne was diagnosed as autistic.

Despite the assessor’s suggestion that no post-diagnostic support would be available, Leanne received a letter a few months later inviting her to a local support service. Leanne attended and found the advice and support provided invaluable, allowing her to understand her struggles with change, noise and social interactions. Unfortunately, funding for the service was cut soon after. Leanne has been unable to access any further post-diagnostic support, other than undertaking her own research and contacting charities for learning materials and practical advice.

Strategic Outcome

Choice and Control

2

Autistic people are treated with dignity and respect and services are able to identify their needs and are responsive to meet those needs.¹⁴

This strategic outcome is focused on raising the awareness of autism needs among professionals and services that encounter or work with autistic people, and ensuring professionals across various areas, such as health and social care, education, and the criminal justice system, receive the appropriate level of training required to support autistic people. The Scottish Government has committed to achieving this by building on the autism training framework, working with a variety of partners and organisations, from local authorities and health boards to autism charities and autistic people's organisations, and providing adequate information and resources. Also included was a commitment to improving teacher training and building on education resources such as the Autism

Toolbox. The strategic outcome also aims to ensure satisfactory support for the ageing autistic population. The overall objective of 'Choice and Control' is to ensure that the support autistic people access is provided to the highest possible standard, ensuring that services are efficient and well-informed.

The CPG recognises the Scottish Government's commitments, and welcomes the acknowledgement in this particular strategic outcome that older autistic people face a number of challenges and barriers that increase as they age. Our review has looked at these particular aspects in more depth, in the context of the overall aim to provide services that identify and meet the needs of autistic people.



Data collected by the National Autistic Society during 2019

The statement **"I have enough support to meet my needs"** was posed to 899 people in Scotland. Of those:

- Almost three-quarters of respondents (72.5%) either disagreed or strongly disagreed with the statement.
- A small number of respondents (11.5%) agreed.
- Just 19 of the 899 respondents (2.1%) strongly agreed.



72%

of respondents said they did not have enough support to meet their needs.

The statement, **"The Scottish Autism Strategy has helped me to get the support I need"** was posed to 895 people in Scotland. Of those:

- More than a third of respondents (34.4%) strongly disagreed with the statement and over a quarter of respondents (27.2%) disagreed, meaning over 60% said they did not feel the *Scottish Strategy for Autism* has helped them to get the support they need.
- A small minority of respondents (7.8%) either agreed or strongly agreed.



Over 60%

said the *Scottish Strategy for Autism* hasn't helped them get the support they need.

Training for professionals

The CPG on Autism recognises the important commitment in this strategic outcome of the *Scottish Strategy for Autism* to improve the understanding of autism across Scotland's health and social care workforce by working with NHS Education Scotland, the Scottish Social Services Council, health boards, local authorities and integration authorities. Ensuring that autistic people are receiving support from knowledgeable, well-trained professionals should be a basic and fundamental expectation in Scotland and a priority for the above agencies.

Our review has, unfortunately, highlighted that the majority of autistic people, their families and carers, and even some professionals, feel this objective has not been realised.

At both our designated CPG meetings and via our online survey, we received a number of contributions which sought to make this clear:

"Very little has changed. Still coming across doctors who refuse to use my daughter's preferred method of communication. Still being turned down for services due to autism. Very little signs of staff understanding autism and making adjustments and allowances."

Our review even included accounts where individuals would ensure that the professional involved was aware of their autism at the beginning of an interaction, only for this to make little difference to the subsequent experience:

"Even when I tell people at the beginning of a phone conversation that I am autistic I invariably get told that I'm angry when I'm not, that I'm shouting when I am not. Professionals' knowledge of autism must come from the back of a cereal packet."

Even in some cases, where respondents to our review did mention some degree of knowledge and understanding on the part of professionals, it was clear from their experiences that they felt the limited information being provided was often out-of-date and no longer relevant:

"I think there is more general awareness but the quality of the information that some professionals have is doubtful. It tends to be outdated, negative and excludes girls and women."

Overall, autistic people and their families told our review that their experiences show that there is a considerable way to go in terms of professionals having the required level of autism awareness and understanding. Tackling this must be a priority for organisations across health and social care.

"I have Asperger's and suffer from depression and anxiety. Since I was diagnosed with Asperger's six years ago, I have been horrified by the complete lack of autism awareness among many mental health staff in the NHS. They do not give me the support I need, and on several occasions they have severely worsened my depression."

Responsive support services

Following on from commitments regarding service provision in the previous strategic outcome, the Scottish Government has made commitments to deliver services that are able to identify the needs of autistic people and are subsequently responsive in meeting those needs.

Despite these commitments, many respondents were keen to point out that services were still unable to meet the needs of autistic people or, in some cases, were simply non-existent:

"Services simply do not exist in many cases and, when they do, they are inflexible and require the autistic person to comply with service needs and priorities without question. If they fail to do so, they are refused support for being uncooperative."

"No choice or control over services as no services available, except the One Stop Shop."

As in other areas of the Strategy, our review found clear evidence that service provision is still considered a lottery by autistic people and their families. There was the point raised that more rural and isolated parts of Scotland experience a lack of accessible services, but it was also highlighted that some areas simply did not implement a local strategy as instructed by the *Scottish Strategy for Autism*:

"The strategy in our area has not been implemented. It won't be implemented until money is provided specifically for autism services. Until then, no services have had training and there is no understanding."

Responses in this particular area also emphasised both the positive and negative experiences associated with engaging with an understanding and well-informed professional – the positivity of the support received, paralleled with the fear of it ending abruptly. This would suggest a belief among autistic people in Scotland that such positive experiences are rare rather than the norm:

"The only person who treats me with dignity and respect is my GP. She not only allows me to communicate the way I am most comfortable with – via email – but she allows extra time for me to process information, advocates for me and is just a generally lovely person. I fear her upcoming retirement."

"The initial doctor who I saw at my local practice was wonderful and was actually diagnosed as autistic herself. She was so kind and really took the time to listen. Unfortunately she is no longer at the practice and I really don't feel like anyone else I have spoken to understands in the same way that she did."

A common theme in this area of discussion was the lack of direct involvement from autistic people and local communities in the development of services. A number of respondents were keen to state that autistic people cannot obtain choice and control, or dignity and respect, without having the ability and opportunity to shape what that looks like in the first place. A regular criticism from autistic people at recent CPG meetings in particular has been the perceived lack of involvement of autistic voices when developing initiatives, projects and strategies, and this remains an issue:

"I would feel better about choice and control if autistic people's words were good enough."

Despite the negative responses, there were still positives to be found. A noticeable trend in the responses of those keen to express a level of satisfaction with this particular strategic outcome was that of obtaining efficient services, but only after having to fight to do so. This continues the narrative we have uncovered throughout our review that autistic people either do not seem to be able to access adequate services, or have to win a battle in order to do so:

“When we have been able to access services, they have been able to identify my son’s needs and be responsive to meet those needs to some extent... Families need someone to co-ordinate and link in with the different professionals involved in their lives.”

In terms of service provision, it is clear that this is still something of a lottery. The majority of survey respondents and participants at CPG meetings have made it quite clear that, while there are examples of good practice and efficient support, the general picture is that of a Strategy that has not delivered the needs-based objectives of dignity and respect it set out to achieve. And in some extreme cases, people not only feel dissatisfied but victimised as a result:

“Autistic people are humiliated, abused, bullied by services daily... Treated with respect? No, treated with contempt.”

Support in education

The CPG on Autism welcomes the progress that has been made in recent years in terms of teacher training and access to resources to ensure that autistic children are better supported in Scottish education. Our review included a contribution from Education Scotland regarding the Autism Toolbox and we are both encouraged and impressed by the hard work and commitment that went into developing, and subsequently re-developing, an arsenal of resources for teachers across Scotland.

The CPG also acknowledges the announcement by the Scottish Government in September 2019 that £15m has been allocated to local authorities to enable them to appoint around 1,000 extra pupil support staff to work with children with additional support needs.¹⁵



The CPG also acknowledges the formation by Scottish Government, Education Scotland and partners of the 'Autism in schools' working group in response to the *Not included, not engaged, not involved* report¹⁶ from Children in Scotland, National Autistic Society Scotland and Scottish Autism which focused on the disproportionately high rate of exclusions among autistic learners.

The CPG now urges Scottish Government, Education Scotland and partners to progress the commitments from the working group and crucially introduce a baseline of autism knowledge into the Initial Teacher Education framework.

Despite this progress, which will naturally take a longer timescale to make any noticeable impact, the CPG also acknowledges the widespread feelings of negativity and criticism that were expressed over the course of this review. This mirrors the data collected as part of the National Autistic Society's *10 Years On* inquiry which found that about a quarter of those surveyed in Scotland feel that teachers and other education professionals have no understanding of autism or autistic people's needs.¹⁷

Concerns over autism awareness among teaching staff were expressed by a number of respondents.

"School staff are not getting good quality training at all. Training is not mandatory. The quality is depressing."

"Teachers do not get compulsory training in autism as part of teacher training... Teaching assistants, pupil support assistants etc have been cut to the bone and they don't have any specific training in autism anyway."

In some of these cases, the parents of autistic children expressed dismay at the circumstances their sons and daughters had

found themselves in, a lack of understanding from teachers worsening the situation and potentially resulting in restraint and seclusion:

"My child was not given choice or control over his education. Certainly not treated with dignity or respect when needs were unmet and resulted in avoidable challenging behaviours with unnecessary restraint and seclusion."

The CPG is already aware, from the aforementioned *Not included, not engaged, not involved* report, that 34% of parents who responded said that their autistic child had been unlawfully excluded from school.¹⁸ However, our review has also been informed of certain situations where the lack of understanding in schools and local authority areas is so great, parents of autistic children have been threatened with action for not being able to ensure their child attends school on a regular basis:

"Treated like a criminal when I was unable to 'get my kids into school'. Threatened by local authority services with having my children taken from me instead of them offering advice and support. Having to seek legal advice and attend court to get vindicated."

It is worrying that such accounts seem to suggest the existence of a culture in some areas in Scotland where schools are free to exclude autistic children without recourse, contrasted with parents who, if unable to ensure their autistic children attend school, are left vulnerable to threats and the potential implementation of serious action.

Issues with the mainstream schooling of autistic children were also raised during this section of the CPG's review, with many parents of autistic children describing negative experiences of mainstreaming and the lack of specialised support available as a result:



"Education has not been a great experience with respect to identifying and meeting needs. A mainstream education setting with a 'fit in or fail' attitude is what we have experienced."

"Our experience of presumption of mainstreaming and inclusion has left a lot to be desired. Personalisation of the school experience has not been achieved and true inclusion, not just physical presence, has not been evident."

Once again, a common thread throughout this topic of discussion was one of autistic people and their families having to fight for the services and support required, with some respondents describing long, stressful battles to achieve their requirements:

"After a 12 month battle involving lawyers, hearings and tribunals our child was finally granted a place at a special school that suits him well. He is thriving there and all professionals who are in contact with him cannot believe that anyone thought mainstream inclusion was a realistic option for him."

Ultimately, the review has highlighted the clear feeling among autistic people and the parents of autistic children that, despite recent progress and commitments, there is much more to do in terms of serious improvements to the support of autistic children in schools. More tellingly, this is a view supported by some education professionals who also participated in the review:

"Budgets mean that choice and control are necessarily limited. I am a teacher of ASN and we are unable to provide the support autistic young people in the mainstream require and some of them struggle in classes of 30+."

Adults and the ageing population

As well as various commitments to improvements in training for professionals and educators, this strategic outcome also ties the Scottish Government to a promise of establishing what needs to be done to support the ageing autistic population. The CPG recognises this commitment as one of ever-increasing importance, as far more autistic people receive their diagnosis in adulthood and the first generations of diagnosed autistic people reach their later years. However, our review has not found any tangible evidence that this promise has been implemented and any subsequent action taken.

The CPG was also made aware of the very real worries and fears facing autistic people and their families regarding the future. In particular, our review highlighted a number of concerns that some autistic people would simply struggle to survive in Scotland without their family members present to provide support and fight for service provision, a very real prospect as the individual ages:

"The parents won't live forever, so provision has to be made to accommodate autistic people so that they can live their lives in as constructive a manner as possible. Since the carers save the Government so much money, there can be no excuse for not catering for this."

Furthermore, there continues to be a widespread view among autistic people and their families and carers that services for adults of all ages are worryingly thin on the ground:

"There seems little in the way of services for autistic adults. So much emphasis is aimed on childhood autism but seems to disappear once they are adults or out of education."

"Many parts of Scotland have no support at all for autistic adults with anything less than the greatest level of support needs. Autistic people in most of the country are isolated, unable to access employment and healthcare, unable to access a community of like-minded people."

This parallel between a supposed emphasis on services for children and a lack of provision for adults was most evident in the experiences of review participants who were both autistic and the parents of autistic children. Such a unique viewpoint was effective in highlighting the majority view that autistic people can feel abandoned in adulthood:

"For my son, this seems to be working in an educational setting. For myself as an autistic adult, no one is able to support me."

The overwhelming response at CPG meetings and from our online survey suggests that autistic adults are continuing to be let down in Scotland, even long before their older years, often left without support and feeling isolated and forgotten, in stark contrast to this strategic outcome's objectives of dignity and respect:

"No effort has been made to meet my needs, or even hear me when I express what they are, and I would say I have been treated with significantly less dignity and respect since my diagnosis."

Case study:

John

John started primary school with an eagerness and enthusiasm to learn, already knowledgeable about shapes, colours and numbers, and considered something of a 'sponge for knowledge' by his parents. His first three years in a composite class in a small rural primary school went well and he was reasonably supported, particularly in primaries two and three with a teacher who understood autism.

Things changed in primary four for John. He began to be told off for completing reading work ahead of the rest of the class, while simultaneously being told off for working too slowly in subjects such as writing and maths, causing confusion and having a detrimental impact on his self-esteem and confidence. By primary five, his parents were fighting with the school for an assessment of his needs, being told that he was "just lazy".

Eventually, his parents managed to obtain a diagnosis for John of autism. Believing that John could still excel in mainstream education with the right support, his parents continued to seek support from the school but were met by a dismissive response from the headteacher, suggesting that the school already had enough children with special plans and "didn't need more".

In primary six, while continuing to receive negative feedback because of his writing ability, an OT referral, initiated by the local hospital through his diagnosis, found he had hypermobile joints, resulting in pain when gripping a pencil. A referral for further support was recommended, however, the headteacher refused to consider this.

Despite this, John's confidence took a positive upturn after taking on a speaking role as the main character in a school performance. This renewed self-belief resulted in an award for achievement at the end of school year, standing him in good stead for the final year of primary school and the subsequent step up to high school.

Unfortunately, a new headteacher, with even less awareness of John's needs and autism in general, had moved into post at the school prior to John's start in primary seven. John was punished for behaviour associated with his autism, leading to his parents writing a number of letters to the local authority to complain about his treatment and to ask for support for John, requests which were either ignored or rejected.

This lack of understanding and support, coupled with active punishment and criticism for his behaviour and schoolwork, had a hugely negative impact on John. Just a few months into primary seven, he had again lost his confidence and self-esteem, was suffering from anxiety, and had developed a stammer, a matter of months after starring in the lead role in the school play, all while preparing to make the transition from primary to high school.

Strategic Outcome

Independence

3

Autistic people are able to live independently in the community with equal access to all aspects of society. Services have the capacity and awareness to ensure that people are met with recognition and understanding.¹⁹

This strategic outcome is focused on raising awareness and acceptance of autism among the general public, growing the number of autism-friendly places in Scotland in the process, and ensuring autistic people have access to suitable housing. The Scottish Government has committed to a national autism awareness campaign, building on the assisted travel offer for Scotland's autistic people in order that they can independently access their community, and working with local housing partners to ensure that autistic people have the means to live in homes that meet their needs. The overall objective of Independence is to ensure that an autistic person is able to live as independent a life as possible, with equal access to all aspects of society.

The CPG welcomes the Scottish Government's commitments to improving the opportunities and support available to allow autistic people to enjoy independence in adulthood. In particular, we recognise that this strategic outcome's very existence highlights the understanding by the Scottish Government that more has to be done to support autistic people throughout their lives, not just in childhood.

The findings as part of the All-Party Parliamentary Group on Autism's *10 Years On* inquiry provide yet more figures of relevance to our review.



Data collected by the National Autistic Society during 2019

When provided with the statement, **“Public understanding of autism has improved since the *Scottish Autism Strategy* came in”**, 898 people in Scotland responded. Of those:

- Over a third of respondents (35.6%) either disagreed or strongly disagreed with the statement.
- Over a quarter of respondents (29.6%) either agreed or strongly agreed.
- Just under a quarter of respondents (23.3%) told us that they neither agreed nor disagreed.

And 901 people were presented with the statement, **“Since the *Scottish Autism Strategy* came into force, health and social care services for autistic adults in my area have improved”**.
Of those:



53%

of respondents said that the *Scottish Autism Strategy* had made no difference to them.

Support to be independent

The strategic outcome's aims of ensuring autistic people can live independently, enjoy equal access to all aspects of society, and benefit from services with recognition and understanding are clearly described in the *Scottish Strategy for Autism: outcomes and priorities 2018-2021*²⁰, and so our review was interested to ascertain if progress had been made in relation to these objectives.

For some, there has been progress made in this area, with invaluable support and opportunities provided as the result of a committed, collaborative process:

"Everyone involved with my son is trying to help find a way for him to be as independent as he can. They are trying to broaden his skills and interests so there are more opportunities for him."

For others, there was a more balanced stance – recognising some success, while simultaneously acknowledging the need for improvements. There was also a recognition from a number of those that participated in our review that there is still a degree of luck involved when it comes to the standard of relevant support available:

"There has been some positive success on this, I think. Many more people are being supported to live more independently, however there is still a lot more that services need to do, to tailor their services to meet the needs of the users. Also more stringent assessment of the services needs to be in place to ensure that guidelines are being followed and that it is not down to luck whether you get a good or bad experience."

The fear revolving around the potentially short lifespan of support, due to funding or other reasons, was also clearly demonstrated during our review. Some survey respondents gave examples of instances where their

independence could be curtailed by the loss of a service, such as public transport:

"My bus pass gives me independence but it might be taken away soon."

It has proved to be difficult to evaluate the strategy's objective around promoting best practice around assisted travel training as we received little input during the review. Given the importance of this in contributing to people's independence, the CPG believes further evaluation is needed here.

The general level of efficient and accessible services that support an autistic person's independence in Scotland raised numerous concerns throughout our review. Many survey respondents and contributors at CPG meetings highlighted the perceived failure on the part of many local authorities, demanding that more is done at a local level to ensure services are provided:

"Local authorities need to support more, understand more and stop making it about money, but more about the individual."

Many respondents were critical of a variety of areas of service provision and support of importance to a person's ability to be independent:

"Still inadequate housing, poorly trained support staff, lack of access to social work assessments, lack of support for parents/carers, lack of access to employment and mental health support and social support and independent living support, which all impacts on autistic people being able to successfully live independently."

"Still problems with housing, employment, education, mental health – very little has changed and in some instances it has become worse."

Our review involved a number of autistic people who wanted to share their views on what they perceive as failures in this particular strategic outcome. These responses were particularly stark, detailing experiences that describe both abandonment, isolation and, at times, hostility:

"The withdrawal of funding from social work has meant I no longer am able to socialise, participate in activities in the community, manage my home or my finances. It has led to me becoming very socially isolated and depending on my parents but there are difficulties with my relationship with them which is being put under more strain due to lack of support."

"I am completely isolated now. I have encountered responses from ignorant indifference to open hostility, but never anything positive."

"In my experience I have been fending for myself most of my life and masking my autism in fear of judgement and ridicule. I have had some awful life experiences."

The CPG believes that, from the findings of this review, there is no question that autistic people are still being failed in adulthood and a great deal more has to be done to improve this situation:

"I feel completely cut off from society since my diagnosis and services I have approached have shown absolutely no recognition or understanding for my needs."

These views and experiences were also reiterated by the parents of autistic children who are currently dealing with the anxiety caused by their lack of confidence that their children will have the support to live independently in adulthood, and the parents of autistic adults who have witnessed the lack of support available:

"Services are null and void, we have no access to any services that can help my son to be able to prepare to live independently in the future."

"My son has not been able to access any aspects of society for four years. Isolated and forgotten."

The CPG acknowledges the well-intentioned objective around independence but our review finds that much more needs to be done to realise this in practice.

"This strand is a failure. Services do not have the capacity and service providers are not trained or aware of what autism really means."

Housing for autistic people

The CPG recognises that housing provision is primarily a matter for local authorities. However, as part of the Strategy, the Scottish Government has made clear commitments to ensure that all autistic people have the opportunity to access adequate and suitable housing. These commitments are a vital aspect of this particular strategic outcome as autistic people should have the right to a home which meets their needs. Our review was keen to collect the experiences of those who had attempted to access adequate housing in recent years.

The majority view on this, from those autistic people or families of autistic people who had engaged with housing associations and local authorities regarding suitable housing, was clear that there simply is not the housing provision available for autistic people in Scotland:

"Clearly there is not a great deal of suitable accommodation."

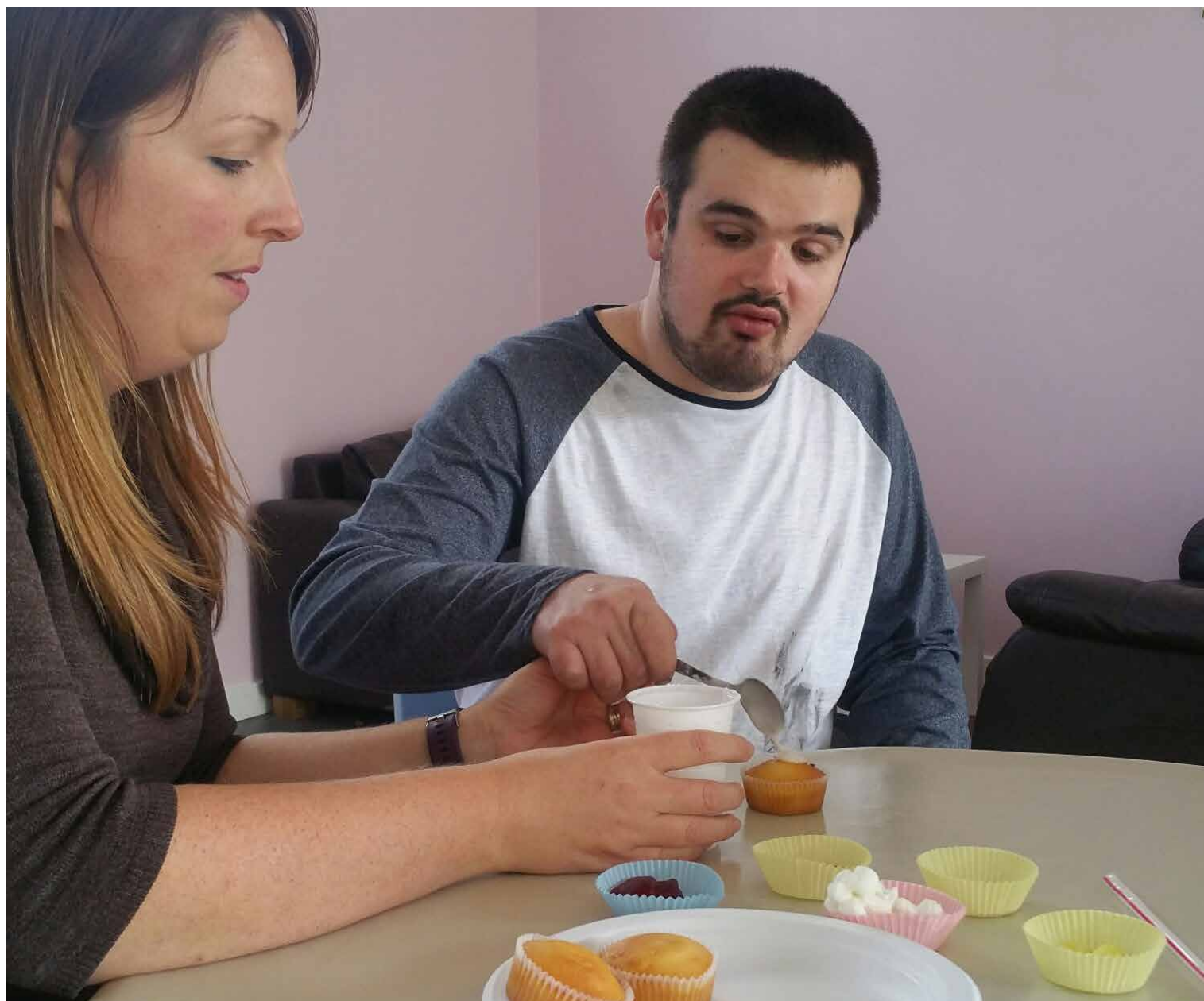
For many, this is particularly problematic. It can perhaps be assumed that an autistic adult unable to source suitable accommodation will have the opportunity to live with parents or family members when, in reality, this is simply not often the case, with many autistic people having to live in unsuitable housing through no fault of their own.

This not only leads to circumstances where an autistic person is placed in a home that does not meet their needs, but can result in the individual being housed in a residential environment that is entirely inappropriate:

"My son was given his own flat in a block with drug addicts and recently released repeat offenders. We had asked for support but they refused as he 'seems' fine. They wouldn't listen to me or him."

As stated above, we acknowledge that local authorities in Scotland are required to ensure that appropriate housing is available. Our review has reflected the reality of the situation, that local authorities are simply not undertaking the work required to achieve this.

The evidence of lived experience through the review has highlighted to the CPG that local authorities are generally not providing the housing or the support required and promised



by the Strategy. In some cases, this has led to a lack of confidence in the ability of local authorities to provide support to autistic people and their families:

"The local authority has assessed our housing needs but sees no priority in three sets of medical needs that are identified and supported by medical professionals. As two autistic people and a carer, we feel entirely unsupported when it comes to our housing needs."

The CPG acknowledges that providing housing provision that is suitable and adequate for Scotland's autistic people is a huge undertaking, requiring both time and resources. However, our review found little evidence that huge strides had been made:

"Still no adequate, suitable housing to enable autistic people to live independently in the community."

This, again, also led to the highlighting of accountability during the course of our review, with the CPG noting a clear disconnect between the commitments of the Strategy and the implementation at local level, and some suggestions being made as to how this issue could be addressed:

"Independence comes in lots of ways. There needs to be an Autism Tsar, who can make sure that necessary changes are made."

Raising awareness

The CPG welcomes last year's announcement that an autism awareness campaign in partnership with the charity Inspiring Scotland is set to be implemented. We support its objectives, in particular its aims to highlight the many strengths autistic people can bring to society. We acknowledge that this is a recent development and look forward to monitoring the positive impact such a campaign may have

on Scottish society and the experiences of autistic people.

And for some who took part in our review, this work is already proving beneficial:

"Inspiring Scotland is running a series of forum meetings which are genuinely about getting our feedback and allowing us to access on our own terms without it being seen as a special favour."

The topic of public awareness of autism over the Strategy's lifespan to date was discussed during the course of our review, providing a mixed response. This was perhaps unsurprising given the relatively balanced data sourced via the 10 Years On inquiry, laid out at the beginning of this chapter.

For some who participated in the review, there was a recognition that public awareness has improved, and is continuing to improve, believing that a level of success is potentially being realised by the Scottish Government's initiatives:

"Attitudes to autism are improving in Scotland."

For others, the general public's awareness of autism is still at an unacceptably low level, particularly in specific areas of the country:

"The general public do not have a good understanding of autism and how it can affect people's daily lives."

"I would say that awareness is extremely poor among the public here in Dumfries."

Overall, it seems fair to conclude that the most popular view on autism awareness from our review is that there has indeed been an improvement in recent years, although a great deal of work is still required.

This suggests that, should the Scottish Government's autism awareness campaign achieve the success hoped for, real progress could be made in this area from a fertile starting point:

"Autism awareness is improving but still has a way to go."

Autism-friendly venues

The CPG acknowledges the commitment made by the Scottish Government through the Strategy to both acknowledge the growing number of autism-friendly places in Scotland and encourage organisations to consider following suit. A number of venues and facilities have been certified as autism-friendly in recent years and the CPG is hopeful that this upwards trend will continue in the future.

It is, however, difficult to ascertain how much of an impact the Strategy itself has had on this trend, given the existence of other factors such as the Autism Friendly Award,²¹ administered by the National Autistic Society, and the connected 'Autism Hour' campaign. However, the CPG notes that a number of MSPs, including the First Minister, lent their support to the Autism Hour 2019 version of the campaign which had a wide-reaching impact and we hope parliamentary support for such initiatives will continue.

This positive progress over recent years was highlighted during our review:

"The local swimming pool are good about turning off the music without having to go through an interrogation as to why you want the music turned off."

"There has been some evidence of greater awareness – autism hours in shops for example."

As more and more organisations and businesses decide to join the likes of Edinburgh Airport and the Scottish Parliament in developing autism-friendly premises, the CPG is pleased that contributions to our review suggest that this is an area of ongoing progress that will hopefully continue to bear fruit:

"It's good to see that many venues and events are now trying to make their environment more inclusive for everyone."

Independence or autonomy

An issue discussed at our CPG meeting on this particular strategic outcome was the difference between independence and autonomy:

"The idea of independence as a marker in an assessment of quality of life makes little sense – where an individual without independence may be extremely happy in their residential care facility where their needs and preferences are met, while a so-called 'high functioning' person may be living in chaos and desperation in their bedsit, struggling to keep down a job that doesn't suit them and drains the joy out of their days."

A similar viewpoint was evident in our survey responses, with some respondents keen to stress that the focus should be on autonomy and not independence:

"There needs to be more emphasis on autonomy, so that people who need more support and cannot be said to be independent still have their views respected and are still the boss of their own lives with professionals working for them, not on them."

The CPG recognises this as a valuable piece of feedback to come from our review and we would be keen for the Scottish Government to keep this in mind when discussing further commitments and policy decisions related to this topic.

It is important that, if real progress is to be made moving forward, autistic people should be consulted on the language used to ensure that there are no feelings of confusion or exclusion:

“Need to be careful about the use of the term ‘independence’. This should really be replaced with ‘autonomy’. Our daughter is likely never to live independently but we aspire to have her able to live as positive and involved a life as possible.”



Case study:

Sandra

Both Sandra and her husband are autistic, with Sandra receiving her diagnosis in adulthood after a long journey through the process involving a number of misdiagnoses.

While a student, Sandra got into debt on the assumption she would obtain a graduate level job following university. However, she experienced difficulties in gaining employment after dropping out of education. As a result, Sandra struggled to establish a strong financial position to subsequently move into appropriate, independent accommodation. Furthermore, Sandra was unable to access any financial or housing support, either during the diagnosis process or post-diagnosis.

Money that could have been saved for a deposit had, instead, been spent on qualifications, driving lessons, and “generally keeping afloat”. With debts, no substantial savings and no eligibility for additional financial support, Sandra and her husband approached the local authority regarding housing but they were not deemed a priority. Sandra and her husband were forced to find private rented accommodation via Gumtree that they could both afford, despite being inappropriate for their needs and located in an area that caused fear of antisocial behaviour.

Eventually, having secured stable employment, Sandra’s physical and mental health concerns meant that she and her husband took the decision to move closer to her workplace. They managed to find a residence that they felt they could live in. This was at the cost of double their previous rent and meant being placed in one of the highest council tax bands, and yet also meant that their home was still inefficient, with only electricity provided.

Sandra has found the task of seeking housing as an autistic person to be a challenging one. Sandra has periodically looked at local authority and housing association properties but has always been put off pursuing this route by the competition, uncertainty, and lack of choice and accessibility. She has found financial management and communicating with mortgage lenders, landlords and other related personnel to be difficult, and has been unable to access support or guidance, other than via the local One Stop Shop.

Strategic Outcome

Active Citizenship

4

Autistic people are able to participate in all aspects of community and society by successfully transitioning from school into meaningful educational or employment opportunities.²²

This strategic outcome is focused on ensuring that autistic people who want to obtain and maintain employment have the opportunities and support to do so, designing a new social security system for Scotland that is fair and accessible, and ensuring that young people with additional needs are provided with efficient and appropriate transition planning.

The strategic outcome is also focused on challenging the issue of social isolation by ensuring that autistic people have the opportunity to develop meaningful relationships and working with partners to reduce social isolation in the autistic population. The Scottish Government has committed to ensuring effective person-centred employment services and in-work support through the new Fair Start Scotland employment programme, consulting with public sector bodies and disabled people's organisations on how to increase the disability employment rate in the public sector, and working with partners to ensure an effective transition process for autistic young people. The overall objective of 'Active Citizenship' is to ensure that autistic people have the ability to participate in all aspects of society through meaningful educational and employment opportunities.

The CPG applauds the Strategy's onus on supporting autistic people to become active citizens and the importance this subsequently places on the life journey, not just the childhood, of an autistic person.

Being an active citizen does not just result in an individual contributing positively to their community, but can also help to vastly improve other aspects of their life such as mental health and social isolation. With this in mind, the CPG began this review keen to hear particularly lived experience from those who have gone through the recruitment process, maintained employment, and experienced transition.



Data collected by the National Autistic Society during 2019

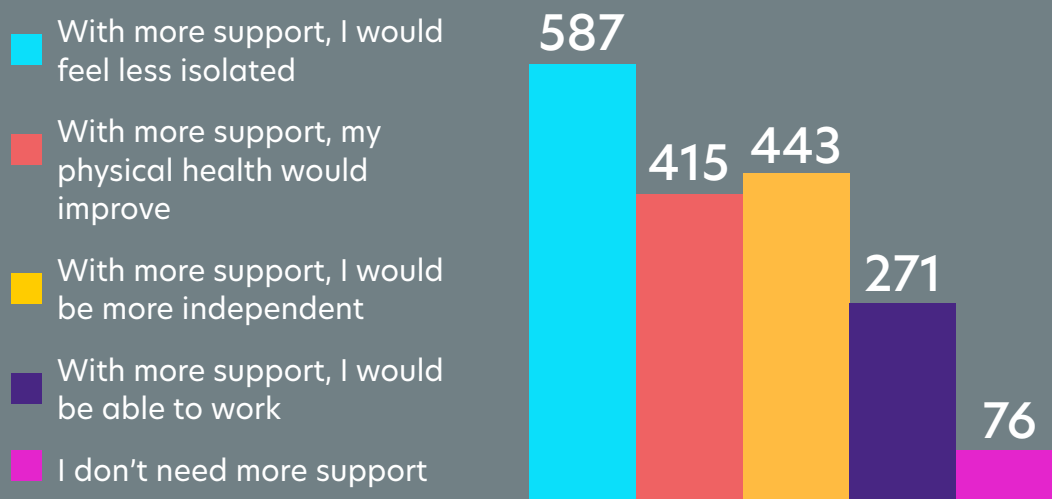
Shown the statement, **"I was supported properly throughout the transition process"**, 249 people in Scotland responded. Of those:

- Almost two-thirds of respondents (64.2%) either disagreed or strongly disagreed with the statement.
- Under a fifth of respondents (16.9%) agreed with the statement.
- Just 16 respondents (6.4%) strongly agreed.



Over **64%**
said they weren't supported properly from childhood to adulthood.

And 915 people were asked, **"Which of the following statements reflect your situation?"**. Of those:



A route into employment

The CPG understands that less than a third of autistic people are in full or part time paid work,²³ in comparison to 45% of disabled people and 81% of non-disabled people in Scotland.²⁴ We also recognise that recent statistics show that a majority of autistic people believe the support they receive does not help them to get or keep a job.²⁵

The CPG welcomes initiatives by the Scottish Government to ensure specialist support is in place in the workplace for autistic employees, such as Fair Start Scotland, from whom the CPG received an update through the course of the review. Similarly, funding from sources such as 'Cashback for communities' has seen funding provided for specialist employment services for autistic people with emerging positive outcomes. We are encouraged by the progress being made and are optimistic that such projects can have a powerful and long-lasting impact. Despite these positive projects, our review found persistent barriers to employment which must be addressed.

During the course of the review, the CPG heard from a number of autistic people and families who were keen to work but faced obstacles both in the recruitment process and in obtaining in-work support.

In terms of opportunities to work, our review was conclusive in identifying the majority view that such opportunities were not universally available:

"There are very few meaningful employment opportunities for autistic people. More needs to be done to right this wrong."

In addition to this, a large number of contributors were keen to highlight a perceived void in support for those who were not leaving education and were over 25 years old, reinforcing the views put forward elsewhere in this report that autistic adults continue to struggle:

"Where is the support for those who left school years ago and are only just at the stage of trying to find employment? There seems to be plenty of support until you are 25 years old and then it just vanishes."

"There is no help for older autistic people who want to find employment or return to university. My partner is 36 years old and has never had a job, he has no support, no help, nothing. Nobody seems to care about those over 25. He wasn't even diagnosed until he was 27, he had no chance."

A number of participants in the review were keen to highlight that engaging with the recruitment process remained a difficult task, partly due to a belief that employers were still actively put off from giving them the opportunity to work or were placing far too much focus on the interview stage of the process:

"I find employer recruitment procedures seem to be designed to filter out autistic people from the recruitment process. I simply can't get past the interview stage no matter how much advice or practice I get."

This could be compounded by the experience of accessing employment services, such as Jobcentres. We now know that, from data collected during the 10 Years On inquiry, just a tiny fraction of autistic people feel that Jobcentre Plus staff have a good understanding of autism.²⁶

Our review has also found that, for those able to progress through the recruitment process and acquire employment, in-work support remains a constant battle for too many of Scotland's autistic workforce:

"Still hearing about autistic people not being treated with understanding in the workplace, if they are lucky enough to be employed."

Responses to this topic of discussion also shed some light on the stereotypes and misunderstandings that still appear to contribute to the issues surrounding an autistic person's ability to gain employment:

"In employment there is no 'in-work' support that is desperately required. Employers are reluctant to provide adjustment, one employer said 'all autistic people are good at maths and very intelligent' - our daughter is neither and did not know what to say. Where should they go to ask for help?"

In contrast, the CPG also welcomed the views from some autistic people who have had positive experiences when seeking employment support, when those involved had some level of understanding of autism:

"I think there is good employment support available from people who understand autism."

"I know of several organisations that have sought out and paid for training delivered by autistic people. This both provides meaningful employment opportunities for autistic people, and provides necessary insight to help them to work with other autistic people."

This section of the review highlighted to the CPG the difficulties faced by autistic employees in Scotland when accessing support, to enable them not just to maintain employment but to succeed and progress in their career. Unfortunately, respondents to our review were clear that this remains a vastly under-explored and under-appreciated area:

"There is no account taken of autistic people who are already in the workforce - the emphasis is solely on supporting young people."

The review was not only interested in the degrees of success or failure of recruitment and in-work support, but also the reasons behind this. Many of those we heard from were steadfast in the belief that the lack of support provided by employers was a knock-on effect caused by the lack of support provided to employers in the first place:

"Employers have no support given to them, it's a shambles and waste of funded resources. People are so blinded by their lack of knowledge and speciality in this area they'd rather hide the issue to the detriment of young people."

However, the CPG must also highlight that other respondents felt some progress had been made thanks to several employment initiatives having a positive impact on employers' perceptions of autistic employees:

"I think there have been some employment initiatives to tell employers they don't need to be scared of autistic people (they don't seem to ever recognise the fact that they must already be employing some without knowing it!)."

The CPG received a variety of submissions from autistic people regarding this particular area, and a number highlighted the very real impact that the struggle for employment is having on their lives. Often, this can be the crushing realisation that, despite the ambitions to follow a particular career path, the support simply does not exist to allow this to be achieved:

"I have failed to pursue my ambitions as a secondary teacher in Scotland because of the tight prejudice mould. I am expected to be just like everyone else except I am different. My overthinking and over-caring approach has been a setback for me and I am unemployed right now."

For some, it is the temporary nature of employment, and lack of support to deal with this, that causes distress and low mood:

"I have been employed many times, I have also had many volunteer roles. When these activities come to an end, I am left devastated and suicidal. There is absolutely no support here."

And for many others, the entire experience of employment as an autistic person in a neurotypical working environment can be incredibly negative:

"I have had a horrendous time in the workplace."

These findings should not only be considered in terms of the large number of autistic people who could play a more positive role in Scottish society if given proper opportunities and correct support, but also on the distressing impact an inability to gain and maintain employment can have on an individual's confidence, self-worth and mental health:

"An autistic friend who is in his mid-30s has a Masters degree but has never been able to gain employment. He did have a voluntary job for a while but he couldn't even cope with this as he had no support. However, if there had been the correct services and support available, he might have been able to secure a job. He has no self-worth, he feels he doesn't have a purpose in life."

Effective transitions

The CPG understands that there has long been issues with supporting autistic people to successfully make the transition from child to adult services and into positive destinations such as independent living, further learning and employment. The CPG welcomes the proposed *Disabled Children and Young People (Transitions) (Scotland) Bill* proposed by CPG member Johann Lamont MSP.²⁷ We note that

the proposed Bill has received consent to proceed and look forward to supporting its progress.

Despite the *Scottish Strategy for Autism's* aim to improve transitions, our review has found limited progress. Over half of autistic people and their families have said that they did not receive enough information and did not feel properly supported during the transition process.²⁸ For instance, we received contributions from some who felt that a process did exist in their area but felt the quality of this process, and its related support, was poor:

"Transitions are useless, children who can't travel independently are put to college with no support – schools put autistic people out at 16 then wash their hands of all responsibility."

"Transition is appalling. One young man I know has only just got a placement in December though he finished school in June. There are very few opportunities for autistic students as colleges do not understand an autistic profile, resulting in young people being placed in groups for people with learning disabilities when they are not learning disabled. There is no support for young people with good intelligence in mainstream college courses who need help with executive funding."

For some of those respondents, this was particularly down to a lack of knowledge and understanding on the part of those tasked with guiding autistic young people, and their families, through the transition process:

"We don't have enough trained specialists involved in transitions and this transition planning by untrained staff is not working."

However, the CPG must acknowledge that the majority of contributions specifically regarding the topic of transitions suggested that no process was even in existence in their particular local authority area:

"What transitions? We had none! There is no accountability throughout the system and the local authority are a disgrace."

Some of these responses were keen to highlight the effects of this void in support and the impact it would subsequently have on an autistic person's attempts to obtain employment and become an active citizen in Scotland:

"No transitional support offered at all - the anxiety of finishing school, going to college and expecting them to perform in an interview situation without any preparation or support; experiencing rejection because they haven't been able to complete the application form correctly or not understanding the questions asked or written."

Additionally, a large number of contributions were provided by the parents of autistic young people at the age of transition who, at the time of participating in the review, were dealing with a complete lack of support:

"No transition planning has even begun for my son who will be 16 this year."

"My 16-year-old has not had any transition planning, not a mention, not a meeting, not an informal discussion - nothing."

From what autistic people and their families told our review, the CPG has to acknowledge the majority feeling in Scotland that transition processes seem to be either well below the expected standard or, completely non-existent:

"Transitions is non-existent and a human rights failure."



Fairer social security

The CPG acknowledges the work the Scottish Government is currently putting into building the new Scottish social security service and welcomes the commitments by the Government to achieve a fairer, more dignified system in Scotland.

Our review did hear from a number of autistic people, family members and carers about the awful experiences of those attempting to obtain social security in the current UK-wide system, supported by the recent analysis into disability benefit claims undertaken by the Scottish Government.²⁹ These accounts often detailed the very stark reality of the current situation for Scotland's autistic people:

"My son received nothing while claiming Universal Credit. Then the basic tiny amount. He had to wait three months before being assessed for his ability to work, this despite his GP signing him off and him receiving PIP and having gone through that assessment... My son was incredibly suicidal as a result of losing money through the transition from child services to adult."

However, we did receive a number of responses suggesting that there is a trust being placed in the Scottish Government to get its new social security system right:

"I think the benefits system should improve when it comes under the control of the Scottish Government."

Preventing social isolation

Research by the National Autistic Society has shown that autistic people are among the most isolated and lonely in the UK, with autistic people four times as likely to be lonely as the general public.³⁰ We also know that 66% of autistic people in Scotland say that they feel socially isolated.³¹ The CPG acknowledges that social isolation can be a difficult issue to solve with specific, targeted measures, but also recognises that the chances of an autistic person becoming socially isolated can be drastically reduced by improving many of the areas already identified in this report.

"My own experience of school, community etc, was being isolated and alienated, bullied and alone."

In addition it is very possible that the pandemic and lockdown has contributed to the issue of social isolation. It was welcome to see therefore Scottish Government to award funding to tackle this in part through a grant to National Autistic Society Scotland to fund online social groups.

Our review overall has suggested that developments in areas such as education, transitions, employment and post-diagnostic support as well as greater public awareness of autism are required and would achieve positive improvements in the lives of autistic people in Scotland. We believe that such improvements could then be expected to subsequently help tackle the very real and important issue of social isolation.

Case study:

Brian

Brian was diagnosed as autistic when he was four years old, following a routine doctor's appointment. Now in his 20s, Brian lives with his parents and faces numerous challenges as a result of being autistic.

Brian was keen to enter employment following education and attended several interviews within the public sector. However, he found the interview process difficult. In particular, he found that both he and prospective employers were unaware of the reasonable adjustments that could be made for autistic employees and was told that, by making small adjustments, Brian would be receiving preferential treatment.

Despite these difficulties, Brian managed to enter employment as a Modern Apprentice with a public-sector organisation. This proved to be a positive experience for Brian and he was ultimately kept on as an Administrative Assistant, a role he continues to be employed in.

Brian has been lucky enough to work for an employer who has a degree of understanding about autism, describing his employment experiences as "relatively positive with a few bumps along the way". His employer has made changes to help in the workplace, including providing mentoring and guidance documents.

In addition, Brian is permitted to undertake small measures that allow him to manage his role. He wears clip-on ties and Velcro shoes due to the difficulties he has with motor skills, headphones to reduce background noise, and is given notice before changes occur in the workplace. He also finds it difficult to receive a lot of verbal information at once and is able to manage this by writing notes so he knows and understands exactly what he has been asked to do.

It has been difficult for Brian to progress in his career, however, because of the interview process and the barriers it continues to present. Despite the adjustments made by his employer, a lack of more supportive and inclusive recruitment practices has resulted in Brian being unable to move forwards in employment, despite having the desire to do so.

Conclusion

"There is a total disconnect between intention, as laid out in the Strategy, and reality."

"I think the theory behind it is excellent. In practice it fails hugely."

The original vision set out in the *Scottish Strategy for Autism*, that autistic people are: 'respected, accepted and valued by their communities and have confidence in services to treat them fairly so that they are able to have meaningful and satisfying lives' is a commendable one and one which attracted praise and agreement from respondents to our review.

Similarly, our review received a number of excellent examples of good practice and progress where the strategy has been realised or is progressing well. For example; effective employment support projects, quality post-diagnostic support through 'One Stop Shops', strong commitments to move forward with improved teacher training and a soon to be launched campaign of autism awareness targeted at the general public.

However, a huge number of autistic people and families responding to the review told us that the vision and aims of the strategy have yet to be realised at a local level.

The responses paint a picture of autistic people and families across Scotland who continue to be frustrated by the availability and quality of services and support across the lifespan. This included diagnosis, education, transition into adulthood, housing, employment as well as access to mental health support and social care.

We conclude therefore that for the Scottish Government's vision to be realised, much work is still needed and the case for a new strategy to build on the foundations of the current one is crucial.

We believe that our ten recommendations will aid the development of a new strategy, one which should be developed in partnership with autistic people, families, professionals and charities. Crucially it should also be accompanied with an appropriate and sustainable level of funding.

However, the vision and objectives of the current and any future strategy will not be realised without solving the issue of the accountability gap which came up time and time again through our review.

Many respondents told us that support they or family members desperately needed, and were entitled to, was not forthcoming and that there was a feeling of powerlessness with little or no route to challenge.

To this end, we strongly recommend establishing in law an 'autism commissioner' or similar mechanism which would ensure that good policy and laws are implemented appropriately at a local level, leading to a very tangible and positive impact for autistic people and families throughout Scotland.

"It is a wonderful document full of promises and aspirations. But the technical and practical measures required to make the changes don't seem to be undertaken."

Recommendations

Key recommendations

1. Build on the legacy of the *Scottish Strategy for Autism* with a new fully funded strategy from 2021, co-created by the Scottish Government, COSLA and other partners, autistic people, families, professionals and autism charities.
2. Seek to solve the accountability gap by establishing a new autism commissioner role, who would uphold autistic people's rights and ensure that effective policy and laws are implemented appropriately at a local level.

Other recommendations

3. The Scottish Government, COSLA and local partners should undertake an audit of service provision throughout Scotland to identify unmet need in terms of both pre and post-diagnostic support together with social care and housing in order to inform the new strategy and ensure appropriate and sustainable funding is put in place.
4. Health and Social Care Partnerships should include specific KPIs to record, collate and publish autism diagnosis waiting times so we have an accurate countrywide picture of how long people are waiting and where improvements are needed.
5. NHS Education for Scotland should commit to providing autism awareness training for ALL healthcare, social care and mental health professionals.
6. Sustainable funding must be put in place either centrally or locally to ensure that post-diagnostic information, advice and guidance support services such as One Stop Shops are available where needed.

- 7.** The Scottish Government and Scottish Parliament should act on the findings from the Independent Review into Learning Disability and Autism within the Mental Health Act and legislate to end detention in hospital on the basis of disability.
- 8.** The Scottish Government, Education Scotland and partners should progress the commitments from the 'Autism in Schools' working group and crucially introduce a baseline of autism knowledge into the Initial Teacher Education framework.
- 9.** The Scottish Government, COSLA and partners should ensure there is a focus on improving the transition from child to adult services for autistic young people, be it through Ms Lamont's proposed Bill or other measures.
- 10.** The Scottish Government and partners must ensure that specialist employment support is available to support autistic people into work as well as build and maintain their careers.

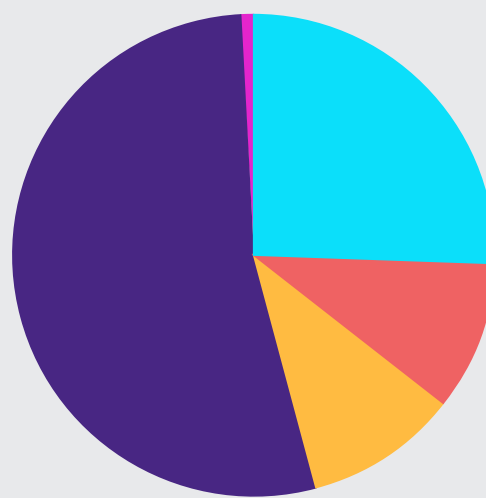
Appendix A: CPG online survey data

CPG on Autism – online survey

Are you personally autistic?

Our survey received 140 responses to the questions detailed in the 'Methodology' section of this report. Of those responses:

- 25.71%** were from autistic people.
- 10.71%** said they “might be” autistic.
- 10.71%** said they were not autistic.
- 52.14%** said they were not autistic, but a relative of theirs is.
- 0.71%** preferred not to say.



Appendix B:

2019 survey from the National Autistic Society








In 2019, the National Autistic Society collected UK-wide data as part of a review led by the All-Party Parliamentary Group on Autism (the equivalent of the CPG in Westminster).

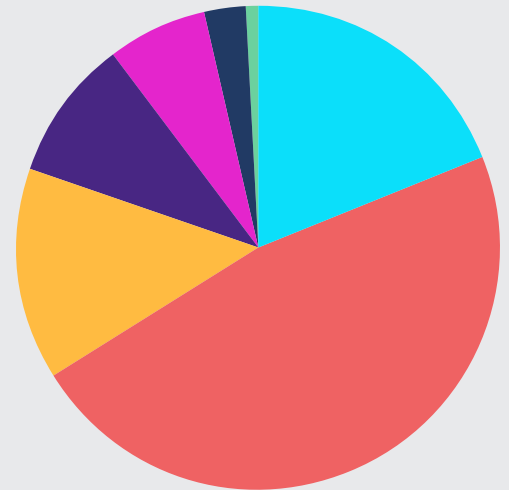
The data pertaining to England was published in the autumn as part of the *Autism Act: 10 years on* report.

The survey included questions for those living in Scotland on the *Scottish Strategy for Autism*, the data from which is published for the first time in this report.

Around 900 people in Scotland responded to these questions. The data is recreated in full in the following tables.

Table B1: What is your connection to autism?

	Response per cent	Response total	
	28.52%	261	I am autistic
	70.16%	642	I am the parent/carer of someone who is autistic
	21.64%	198	A member of my family is autistic
	14.64%	134	I know someone who is autistic
	10.49%	96	I am a professional working in the field of autism
	4.70%	43	I have another connection with autism
	0.33%	3	I have no connection with autism
answered		915	
skipped		0	








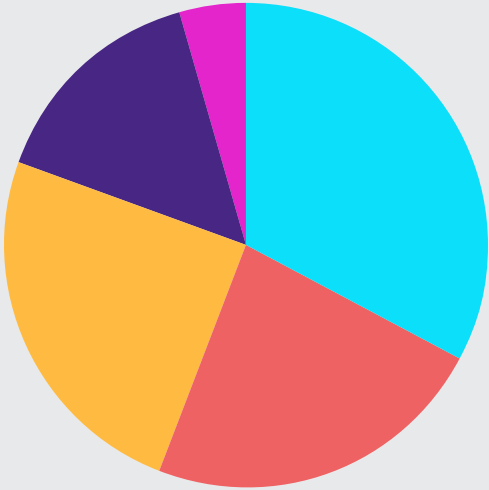
Appendix B1

How much do you agree or disagree with these statements? The support I receive helps me to:

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't know	Response total
Get or keep a job	2.2% (19)	3.7% (32)	13.6% (119)	12.0% (105)	15.6% (136)	52.9% (461)	872
Have good mental health	3.9% (34)	16.4% (144)	17.8% (156)	18.5% (162)	22.5% (197)	20.9% (183)	876
Stay out of trouble with the police	5.6% (49)	5.9% (52)	18.5% (162)	5.1% (45)	6.4% (56)	58.4% (511)	875
Keep out of financial difficulties	2.6% (23)	7.2% (63)	18.3% (161)	13.3% (117)	14.3% (126)	44.3% (389)	879
Meet people and socialise	4.8% (42)	16.2% (142)	14.6% (128)	20.1% (176)	20.5% (179)	23.7% (207)	874
Feel less isolated	4.6% (40)	18.6% (163)	13.8% (121)	18.8% (165)	21.3% (187)	22.9% (201)	877
Have good physical health	3.1% (27)	15.9% (140)	22.9% (201)	17.0% (149)	15.6% (137)	25.6% (225)	879
						answered	886
						skipped	29

Table B2: Which of the following statements reflect your situation?

	Response per cent	Response total	
	68.82%	587	With more support, I would feel less isolated
	48.65%	415	With more support, my physical health would improve
	51.93%	443	With more support, I would be more independent
	31.77%	271	With more support, I would be able to work
	8.91%	76	I don't need more support
	answered	915	
	skipped	0	



Appendix B2

Thinking about the *Scottish Strategy for Autism*, how much do you agree or disagree with these statements?

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't know	Response total
The Autism Strategy has made a positive difference to autistic people generally.	3.5% (31)	19.5% (175)	30.6% (274)	16.0% (143)	12.5% (112)	18.0% (161)	896
The Autism Strategy has made no difference to me personally.	24.4% (219)	28.5% (256)	18.8% (169)	12.0% (108)	5.7% (51)	10.7% (96)	899
Public understanding of autism has improved since the Strategy came in.	3.1% (28)	26.5% (238)	23.3% (209)	22.9% (206)	12.7% (114)	11.5% (103)	898
I know where to go to ask for the support I need.	5.1% (46)	24.1% (216)	13.4% (120)	30.4% (273)	24.3% (218)	2.7% (24)	897
I have enough support to meet my needs.	2.1% (19)	11.5% (103)	12.1% (109)	35.3% (317)	37.2% (334)	1.9% (17)	899
Since the Autism Strategy, things have improved for me/my family member.	1.4% (13)	7.4% (67)	26.6% (240)	26.5% (239)	27.0% (243)	11.0% (99)	901
It has been easy to get the support I need in my local area.	1.8% (16)	7.7% (69)	10.9% (98)	30.4% (272)	47.2% (423)	2.0% (18)	896
The Autism Strategy has helped me to get the support I need.	1.5% (13)	6.3% (56)	19.9% (178)	27.2% (243)	34.4% (308)	10.8% (97)	895
Since the Autism Strategy came into force, health and social care services for autistic adults in my area have improved.	1.0% (9)	6.7% (60)	18.2% (164)	21.0% (189)	32.1% (289)	21.1% (190)	901
						answered	901
						skipped	14

Appendix B3

How much do you agree or disagree with these statements?

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A	Response total
The process of getting support from mental health services took too long.	64.4% (378)	19.8% (116)	5.6% (33)	4.9% (29)	2.7% (16)	2.6% (15)	587
The process of accessing mental health was stressful for me.	53.0% (311)	30.5% (179)	7.0% (41)	4.3% (25)	2.7% (16)	2.6% (15)	587
The process of accessing mental health services was stressful for my family.	50.7% (298)	25.0% (147)	8.7% (51)	6.3% (37)	2.0% (12)	7.3% (43)	588
There were enough mental health services locally to meet my need.	4.8% (28)	7.8% (46)	8.5% (50)	25.5% (150)	51.4% (302)	2.0% (12)	588
						answered	589
						skipped	326

Appendix B4

Thinking about transition, how much do you agree or disagree with these statements?

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Response total
Enough time was given to enable me to prepare for the transition.	4.8% (12)	18.8% (47)	14.8% (37)	29.6% (74)	32.0% (80)	250
My family and I received enough information about the transition and understood options.	5.6% (14)	18.3% (46)	14.7% (37)	28.7% (72)	32.7% (82)	251
I was fully involved in the transition process.	8.9% (22)	23.0% (57)	17.7% (44)	24.6% (61)	25.8% (64)	248
I was supported properly throughout the transition process.	6.4% (16)	16.9% (42)	12.4% (31)	29.7% (74)	34.5% (86)	249
					answered	251
					skipped	664

Appendix B5

How would you rate the autism understanding of the following professionals?

5 = very good understanding of autism. 1 = no understanding of autism

	5	4	3	2	1	N/A	Response total
GPs	6.4% (57)	15.8% (141)	31.3% (279)	22.3% (199)	18.5% (165)	5.7% (51)	892
Hospital doctors	4.2% (37)	13.0% (116)	23.2% (206)	22.0% (196)	15.7% (140)	21.8% (194)	889
Social workers	4.1% (36)	8.0% (71)	16.0% (142)	14.0% (124)	17.1% (151)	40.8% (361)	885
Support workers	9.1% (80)	16.1% (141)	17.2% (151)	11.4% (100)	11.1% (97)	35.0% (307)	876
Nurses	3.9% (34)	12.7% (112)	20.3% (178)	19.7% (173)	14.4% (127)	29.0% (255)	879
Mental health professionals eg psychiatrists, psychologists	16.3% (144)	24.0% (212)	21.5% (190)	11.3% (100)	11.8% (104)	15.3% (135)	885
Health visitors	3.3% (29)	6.8% (60)	13.4% (118)	10.7% (94)	16.2% (143)	49.6% (437)	881
Other health professionals	2.4% (21)	7.2% (63)	19.9% (173)	15.0% (131)	16.3% (142)	39.2% (341)	871
Reception staff (at GP surgeries and other health and social care settings)	2.1% (19)	6.1% (54)	18.4% (163)	19.4% (172)	36.2% (321)	17.7% (157)	886
Speech and language therapists	17.1% (152)	18.9% (168)	14.7% (130)	7.8% (69)	6.2% (55)	35.3% (313)	887
Occupational therapists	13.2% (116)	15.8% (139)	14.4% (126)	6.6% (58)	7.6% (67)	42.3% (371)	877
Jobcentre Plus staff	0.9% (8)	1.1% (10)	4.5% (40)	6.3% (56)	25.8% (228)	61.3% (542)	884
Police officers	2.3% (20)	3.9% (34)	10.1% (89)	11.0% (97)	19.3% (170)	53.5% (472)	882
Teachers	5.0% (44)	10.3% (91)	22.0% (195)	19.8% (175)	26.9% (238)	16.0% (142)	885
SEN Co-ordinators	5.9% (51)	9.3% (81)	12.4% (108)	6.8% (59)	9.4% (82)	56.1% (487)	868
Other education professionals	3.5% (31)	9.2% (81)	16.8% (148)	14.1% (124)	24.3% (214)	32.0% (282)	880
Other criminal justice professionals	0.6% (4)	1.4% (9)	5.7% (37)	6.4% (42)	13.3% (87)	72.6% (475)	654
						Answered	897
						Skipped	18

Appendix B6

How much were you supported in the 12 months following the diagnosis?

0 = Not at all supported

10 = Fully supported

	0	1	2	3	4	5	6	7	8	9	10		Response Total
Not at all supported	36.7% (302)	10.2% (84)	11.5% (95)	9.1% (75)	5.2% (43)	8.6% (71)	4.1% (34)	5.0% (41)	2.9% (24)	1.7% (14)	5% (41)	Fully supported	824

Answered 824
Skipped 91

Appendix C:

Non-MSP members of the CPG

Individuals

- Steve Billingham
- Rachel Birch
- Dr Catherine Compton
- Dr Aurora Constantin
- Fiona Clarke
- Rachael Davis
- Jasmine Ghibli
- Pauline Grigor
- Marion McLaughlin

Organisations

- The National Autistic Society Scotland (**Joint Secretariat**)
- Scottish Autism (**Joint Secretariat**)
- AMASE (Autistic Mutual Aid Society Edinburgh)
- Artlink Edinburgh and Lothians
- Association for Real Change
- Autism Initiatives
- Autism Network Scotland
- Autism Rights Group Highland
- Borders Additional Needs
- Caern Project Learning Disabilities & Autism Services (Barnardo's)
- Central Advocacy Partners
- Disability Shetland
- Edinburgh Lothian Asperger Society
- Glasgow Children's Hospital Charity
- Grampian Opportunities
- Highland Cycle Ability Centre
- Indepen-dance
- Into Work
- Lothian Autistic Society
- Mental Welfare Commission
- Nordoff Robbins in Scotland
- PASDA
- Perth Autism Support
- The Richmond Fellowship Scotland
- The Salvesen Mindroom Centre
- Scottish Courts and Tribunals Service
- Scouts
- The Shirlie Project
- Speak Out Advocacy Project
- SWAN (Scottish Women's Autism Network)
- Tailor Ed Foundation
- TCV Scotland

References

¹All Party Parliamentary Group on Autism (2019), *The Autism Act, 10 Years On*. Available at: <https://www.autism.org.uk/what-we-do/campaign/not-enough>

²Appendix B: 2019 survey from the National Autistic Society

³Scottish Government (2018), *Scottish Strategy for Autism: outcomes and priorities 2018-2021*. Available at: <https://www.gov.scot/publications/scottish-strategy-autism-outcomes-priorities-2018-2021/>

⁴Autistica (2017), *Personal tragedies, public crisis*. Available at: <https://www.autistica.org.uk/downloads/files/Personal-tragedies-public-crisis-ONLINE.pdf>

⁵Scottish Government (2018), *The microsegmentation of the autism spectrum: research project*. Available at: <https://www.gov.scot/publications/microsegmentation-autism-spectrum/>

⁶The Telegraph (2016), *Doctor's diary: Why do people with autism die so young?* Available: <https://www.telegraph.co.uk/health-fitness/body/doctors-diary-why-do-people-with-autism-die-so-young/>

⁷National Autistic Society, *What is pathological demand avoidance (PDA)*. Available: <https://www.autism.org.uk/advice-and-guidance/topics/diagnosis/pda>

⁸Appendix B3

⁹Autistica (2017), *Personal tragedies, public crisis*. Available at: <https://www.autistica.org.uk/downloads/files/Personal-tragedies-public-crisis-ONLINE.pdf>

¹⁰NHS (2016), *People with autism are 'dying younger', warns study*. Available at: <https://www.nhs.uk/news/neurology/people-with-autism-are-dying-younger-warns-study/>

¹¹Scottish Government (2018), *Coming home: complex care needs and out of area placements 2018*. Available: <https://www.gov.scot/publications/coming-home-complex-care-needs-out-area-placements-report-2018/>

¹²Mental Welfare Commission for Scotland (2019), *Autism and complex care needs*. Available at: <https://www.mwscot.org.uk/publications>

¹³Appendix B3

¹⁴Scottish Government (2018), *Scottish Strategy for Autism: outcomes and priorities 2018-2021*. Available at: <https://www.gov.scot/publications/scottish-strategy-autism-outcomes-priorities-2018-2021/>

¹⁵Holyrood (2019), *Scottish Government announces plans to recruit 1,000 extra pupil support staff*. Available at: <https://www.holyrood.com/news/view,scottish-government-announces-plans-to->

recruit-1000-extra-pupil-support-sta_10777.htm

¹⁶Children in Scotland, National Autistic Society Scotland, and Scottish Autism (2018), *Not Included, Not Engaged, Not Involved*. Available at: <https://www.notengaged.com/>

¹⁷Appendix B5

¹⁸Children in Scotland, National Autistic Society Scotland, and Scottish Autism (2018), *Not Included, Not Engaged, Not Involved*. Available at: <https://www.notengaged.com/>

¹⁹Scottish Government (2018), *Scottish Strategy for Autism: outcomes and priorities 2018-2021*. Available at: <https://www.gov.scot/publications/scottish-strategy-autism-outcomes-priorities-2018-2021/>

²⁰Scottish Government (2018), *Scottish Strategy for Autism: outcomes and priorities 2018-2021*. Available at: <https://www.gov.scot/publications/scottish-strategy-autism-outcomes-priorities-2018-2021/>

²¹National Autistic Society, *The Autism Friendly Award*. Available at: <https://www.autism.org.uk/get-involved/autism-friendly-award>

²²Scottish Government (2018), *Scottish Strategy for Autism: outcomes and priorities 2018-2021*. Available at: <https://www.gov.scot/publications/scottish-strategy-autism-outcomes-priorities-2018-2021/>

²³Scottish Government (2018), *The microsegmentation of the autism spectrum: research project*. Available at: <https://www.gov.scot/publications/microsegmentation-autism-spectrum/>

²⁴Scottish Government (2018), *A Fairer Scotland for Disabled People: employment action plan*. Available at: <https://www.gov.scot/publications/fairer-scotland-disabled-people-employment-action-plan/>

²⁵Appendix B1

²⁶Appendix B5

²⁷Johann Lamont MSP (2019), *Proposed Disabled Children and Young People (Transitions) (Scotland) Bill*. Available: <https://www.parliament.scot/parliamentarybusiness/Bills/113161.aspx>

²⁸Appendix B4

²⁹Scottish Government (2020), *Majority of disability benefit claims refused by UK Government*. Available: <https://www.gov.scot/news/majority-of-disability-benefit-claims-refused-by-uk-government/>

³⁰National Autistic Society (2018), *Hidden crisis: Autistic people four times more likely to be lonely than general public*. Available at: <https://www.autism.org.uk/what-we-do/campaign/public-understanding/too-much-information>

³¹National Autistic Society, *Too Much Information*. Available at: <https://www.autism.org.uk/what-we-do/campaign/public-understanding/too-much-information>

Cross-Party Group on Autism

The accountability gap

A review of the Scottish Strategy for Autism

October 2020