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# Evaluation of the Scottish Strategy for Autism



**HEALTH AND SOCIAL CARE**



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# Executive Summary

The ten-year [Scottish Strategy for Autism](#) concludes in 2021 and the Scottish Government commissioned Blake Stevenson Ltd to undertake an independent evaluation to explore the delivery of the strategy's recommendations and priorities, its impact on the services offered to autistic people and the local services and charities that support them, and the lessons learnt that could inform future policy direction. This report presents the findings of the evaluation.

## Context

Autism (also referred to as autism spectrum disorder (ASD)) is the term applied to a range of neuro-developmental conditions which all affect how an individual communicates and relates to other people. [Research carried out in Scotland](#) estimated that there are approximately 44,000 autistic people in Scotland.

There is consensus that autism exists on a spectrum and that it affects individuals differently; there can be no 'one-size-fits-all' definition. The challenges faced by autistic people take many forms and can affect an individual's physical and mental health, engagement in education, access to employment and services and participation in social and cultural activities.

## Scottish Strategy for Autism

The [Scottish Strategy for Autism](#), launched in 2011, was the Scottish Government's response to the inequalities experienced by autistic people and an acknowledgment that action needed to be taken to address them. The vision was that by 2021:

'individuals on the autism spectrum 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'.

In 2015, the strategy was refreshed and reframed so that it was outcome focused, under four key areas - A Healthy Life, Choice and Control, Independence and Active Citizenship. It was further refined and re-launched in 2018 with the four key outcomes continuing as the guiding themes for the [final phase of the strategy](#) (2018-2021).

## Methodology

The evaluation approach included desk-based research and several activities to gather evidence and views from local and national stakeholders and autistic people and their families/carers. This involved:

- Interviewing 18 stakeholders from 14 organisations with discussions focused on the progress towards the strategy's recommendations and priorities, the impact of the activities delivered on autistic people and the services and charities that support them, and the lessons learned
- 11 local area virtual workshops involving 140 policy makers, service providers from the public and third sectors, autistic people, and family members of autistic people with discussions centred on the impact of the national strategy and local services and what needed to change to help local services improve.
- A short online survey with 154 responses with questions covering how the national strategy had helped to focus, resource, and influence the delivery of autism services and the impact of local services on the lives of autistic people and their families

This extensive qualitative data from the interviews, workshops and survey was analysed in line with the evaluation questions and a draft report outline was agreed which shaped the structure and content of the report.

## Findings – delivery of the strategy

### Phase 1 of the Scottish Strategy for Autism (2011-2014)

The first iteration of the [strategy](#) contained 26 recommendations organised across six themes. The early foundation years focused on consolidation and preparation, creating frameworks for assessment, diagnosis and training, commissioning research and producing resources.

Investment underpinning this early stage of the strategy gave £1.12 million to support the development of local authority action plans and the Autism Development Fund awarded almost £5 million to 53 projects to support autistic people and their families/carers and deliver elements of the strategy.

Key deliverables and activities in this first phase included:

- A mapping project that identified existing local autism services across Scotland.

- [Menu of Interventions](#) provided a guide to interventions and support for autistic people and set out the referral and assessment process for all other services and interventions.
- Increased engagement with autistic people was carried out in several different ways: through a scoping exercise to capture best practice, through facilitation by ANS and participation in policy consultation and key decisions.
- Improved cross-agency working including ANS partnering ARC Scotland's Scottish Transitions Forum (a national network committed to improving the experience of children and young adults with additional support needs) to develop the [Principles of Good Transitions Guide](#) and the Autism Strategy Review Group being instrumental in developing [SIGN guidelines](#) on assessing and diagnosing autism for children, young people, and adults.
- Expansion of autism training with the development of a four-tier model for classifying and standardising training, followed by an overview of good practice and an autism training plan looking at needs and gaps in provision.
- Funding for distance learning courses for professionals and parents of autistic people to increase their understanding of autism, and for NHS Education Scotland (NES) to develop an eLearning course and autism portal.
- Increased understanding of waiting times for autism assessments through research by Autism Achieve Alliance (AAA) with a national action plan to address the causes of delays.
- New measures to improve access to the workplace through targeted work, production of a summary Guide on Employment Policies and Initiatives by Autism Initiatives and funding several local projects to improve access to the workplace.

## Phase 2 of the strategy (2015-2021)

From 2015, activity was focused around four strategic outcomes. Once again, the delivery of the strategy's priorities was reinforced with funding through the Autism Innovation and Development Fund, which distributed £2,097,526 to 41 projects (2015-18), and the Understanding Autism Fund, which disbursed £435,801 to nine projects (2019-21). These funds were administered and managed by Inspiring Scotland, which also provided capacity-building support to projects throughout this period. Key progress against each strategic outcomes is summarised in the next section.

**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

This first outcome looks at diagnosis, post-diagnostic support, advocacy for autistic people and mental health policy and provision.

The Scottish Government created the National Autistic Improvement Team (NAIT), to provide support around education and inclusive practice, assessment and diagnosis and employment, in response to recommendations around diagnosis. For post-diagnostic support, sustaining the growth of one-stop-shops was established as a priority and saw a successful pilot of one-stop-shops replicated in five different locations with fixed term funding to support the roll out. More recently, the Scottish Government funded a pilot National Post Diagnostic Support Programme.

Exploring what needed to be done to support parents, and the role of advocacy services were seen as crucial to helping autistic people enjoy high standards of living and family life, as was reviewing provision in the [Mental Health \(Care and Treatment\) \(Scotland\) Act 2003](#).

ANS produced a report exploring what needs to be done to better support parents and Scottish Government funding was used by Scottish Autism to run an advice line throughout the COVID-19 pandemic to support families. A new website helping autistic people to set up advocacy services was created, alongside the production of a policy and practice paper about autism-informed advocacy and a successful pilot on parental advocacy training.

An [independent review](#) was commissioned to explore the impact of Scotland's current Mental Health Act on autistic people or people with learning disabilities. The report's recommendations identified legal and practical changes which could reduce or remove the discrimination that autistic people have experienced, and the Scottish Government is considering how these recommendations should be taken forward. The Scottish Government is also working with Social Work Scotland to assist health and social care partnerships (HSCPs) to improve how autistic people's needs are met and understood within all services to help address the lack of local services which can mean that autistic people with complex care needs experience delayed discharge or face out of area placements in order to support their needs.

**Choice and control:** Autistic people are treated with dignity and respect and services are able to identify their needs and are responsive to meet those needs

This outcome is focused on raising awareness among public and professionals about autism and what it means to be autistic. Recommendations centred on achieving this through awareness-raising campaigns, training, and education.

Awareness raising included:

- working with Scottish Offenders with Learning Disabilities (SOLD) to produce guides for support staff and defence solicitors on working with people with communication needs;
- establishing the Scottish Women's Autism Network (SWAN) and the Scottish Autism's Women and Girls Right Click Programme;
- campaigns like [Different Minds](#); and
- highlighting all autism alert card schemes in Scotland through the ANS website.

Training around autism within health has been spearheaded by funding NES to develop a training framework and plan and deliver resources via an autism team. Specific training in diagnostic assessments has upskilled clinicians to identify and screen, perform structured diagnostic services, and undertake complex assessments. Further investment for 2021/2022 will provide additional diagnostic training opportunities.

Work in education responded to the [Not included, not engaged, not involved](#) report on the experiences of autistic children missing school. A round table discussion chaired by the Deputy First Minister led to the creation of an Autism in Schools Short-Life Working Group, with an action plan that focused on driving improvement in education from the Initial Teacher Education (ITE) programmes, wider sharing of inclusive pedagogical work and quality practice to continued support for ongoing professional practice and development. Developments included the refreshed [Autism Toolbox](#), autism modules for teacher education and professional guides for teachers.

This part of the strategy also set out objectives around autism and ageing, which ANS responded to with the findings of their [2019 report](#) which formed the basis of an autism and ageing six-month pilot in three local authority areas.

**Independence:** 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

This strategic outcome included elements that supported autistic people to live independently, increased the number of autism friendly places in Scotland, enabled active travel and made sure autistic individuals have access to suitable housing.



ANS have supported several organisations in their drive to become more autism friendly through providing resources and training, and the blue badge scheme was extended to include carers of autistic people.

Ensuring the availability of appropriate accommodation for autistic people is an area that needs significant development. Two reports, one from the Scottish Government – [Housing to 2040](#) – and one from ANS – Housing and Homelessness – acknowledged the need for adapted housing and included recommendations on how this can be achieved.

**Active citizenship:** People with autism are able to participate in all aspects of community and society by successfully transitioning from school into meaningful educational or employment opportunities

The fourth outcome looked at obtaining and maintaining employment, transitions planning, social security arrangements, and reducing social isolation.

Strategic support, practical advice and resources and funding have contributed to addressing the barriers to employment and helping local areas deliver employment support to autistic people. This included funding six projects to increase awareness and understanding among employers of the benefits of employing autistic individuals and more than 60 employers across Scotland are participating in these projects. Two strategic overviews have contributed to the resources available to organisations looking into employment support. This was reinforced with practical discussion through the ANS-facilitated Autism and Employability Group, which also addressed issues and identified appropriate employment support.

Fair Start Scotland (FSS), the national employment support initiative, helps people facing multiple barriers into work by offering tailored one-to-one help and advice. Skills Development Scotland, another national organisation, also had initiatives targeting people under-represented or disabled and, although there is no autism-specific data, the measures in place can support autistic people into work and potential employers so that they provide a supportive work environment.

Work to support effective transitions between key stages in life has mainly been delivered in partnership with ARC Scotland or through the activities of local projects. This has included:

- continued funding of Scottish Transitions Forum;
- supporting the development and promotion of the [Principles of Good Transitions 3](#) and an Autism Transitions supplement, and

- trialling a training course that applies the principles into practice.

COVID-19 has exacerbated the social isolation and loneliness experienced by many autistic people because of the restrictions and reduced access to services. In recognition of the challenges resulting from the pandemic, £450,000 was provided to autism and learning disability support organisations to help support vulnerable people at risk of social isolation.

## Summary

The ten-year strategy was ambitious and multi-layered to address the broad and wide-reaching outcomes and priorities that it contained. Delivery of the strategy required commitment and implementation at a local and national level, and partnership working across several sectors and services to deliver the vision and bring about change. Most of the commitments in the strategy have been actioned to some extent, some have gained more traction than others and some still need much more focus and investment for real progress to be realised.

## Findings - Impact of the strategy

Across all types of respondents, participants and interviewees, there were repeated comments about the limited impact of the strategy. These comments related to its focus being too broad, a lack of authority to bring about change at a local level, and that the host of activities and projects had not led to real change for autistic people and their families/carers. However, despite the widely held belief that the strategy had under-delivered, contributors did attribute some positive changes as a result of the strategy.

### Impact of the strategy on local services and charities that support autistic people

Local stakeholders, autistic people, and their family members highlighted that the national strategy provided a welcome focus and recognition of the importance of addressing autism. The strategy set expectations for local authorities to respond and consider what services they should be supporting or delivering locally. Contributors noted that in the absence of the national strategy, their local strategies would not exist and there would be no progress in any aspect of service delivery, awareness raising or support for autistic people and their families/carers. Others described the national strategy as providing a platform for dialogue and action in local areas with the key priorities shaping and informing decisions amongst public sector and third sector organisations.

As well as providing a framework for local authority and service delivery, funding and support was made available to help develop and implement this work. This translated into local activity which ranged from commissioning research to support understanding and then informing the local strategy, to increased resources to meaningfully engage and work with autistic people and family members/carers to shape local decisions.

Skills and expertise in organisations such as ANS, NAIT and Inspiring Scotland helped to build capacity, share good practice, support the development of specific services and raise awareness amongst a wide range of stakeholders and those delivering services. This resulted in some local services having staff who were better equipped and more knowledgeable, thus providing support that was more appropriate and relevant to the needs of autistic people and families/carers.

The work that took place at a national level resulted in the creation of new resources, like the [Menu of Interventions](#) and the [Autism Toolbox for Education](#), providing professionals and local services with the information and guidance to support and influence their policy and practice. The [Micro-segmentation report](#) was identified by some contributors as a valuable evidence base, not only in helping to define the services needed and the number of people requiring support, but also in influencing decision makers and informing action.

Contributors acknowledged that having a strategy enhanced the profile of autism and they also praised the awareness raising work through the [Different Minds](#) campaign and the work of the projects in receipt of Improving Understanding of Autism Funding. They felt that, because of this work, there were more positive representations and increased understanding of what autism means and how it affects people in everyday life.

### **Impact of the strategy on services offered to autistic people**

Some service providers and autistic people and their families/carers identified an expansion or improvement in specific services. These changes were often about an increase in the volume of services and the relevance of those services and support. There were accounts of a more person-centred, asset-based approach to supporting autistic people and genuine exchanges that resulted in a shared understanding of the issues facing service providers and service users.

The service that was repeatedly mentioned was the one-stop-shops, six of these were funded for a fixed period and many of the interviewees, workshop participants and survey respondents highlighted that the one-stop-shops were a well-used

resource that demonstrated good practice and a successful approach for providing a wide range of support to autistic people and families/carers. The more recent post-diagnostic support (PDS) pilots were also praised by some workshop participants and interviewees.

Although the training of professionals was a consistent concern for many contributors, for some, this was an area of improvement. Training within education and schools was the most common example and contributors felt that this work had resulted in greater levels of awareness and understanding in those educational settings. There were other examples of how the focus on training within the strategy became a driver for local action to improve the knowledge of health and social care professionals.

As well as better trained professionals, there were some accounts of improvements in the assessment and diagnostic pathway. However, these examples sat alongside the concerns of others who had experienced lengthy delays and difficulties in accessing a diagnosis, which continued to be a key issue for many.

## Discussion

Action over the ten years of the strategy has established insight into what is needed to improve and deliver appropriate services. The keystone for translating this into practice is action at a local level. For many reasons this has not occurred at the pace, breadth and spread that has been needed, resulting in inconsistency from one area to another. There are many factors that have influenced this, summarised in the next section.

### Emerging themes - the delivery and implementation of the strategy

#### **Factors that influenced implementation of the strategy at a local level**

Local mobilisation was crucial in the extent to which the national strategy had an impact.



There were several factors, summarised in the diagram, that influenced a local area's readiness to embrace the priorities and ability to undertake key activities.

These ranged from leadership and accountability arrangements, to use of autism resources and the history of partnership working.

### **The breadth and content of the strategy**

The ambitions of the strategy have often been commended, but this has meant that the focus and work at both a local and national level has been thinly spread and pulled in different directions. Changes to systems, processes, understanding, and knowledge take time and investment, so it is not surprising that there is a substantial gap between policy aspirations and the actual support available to autistic people, families/carers.

### **Short-term investment**

The implementation of the strategy was accompanied by a financial investment of £7.4 million disbursed to a wide range of projects. Whilst this funding was welcomed and supported a variety of well-used and valued services, many of these ceased, or elements of support were withdrawn, at the end of the funded period. Feedback suggested there should have been alternative central funding streams to fund projects or services that evidenced a successful and positive impact.

### **Nature of engagement and partnership working**

Responding to the needs of autistic people was best achieved through collaboration and partnership working at a local and national level and with autistic people. However, the longstanding frustrations among autistic people/families/carers and service providers about the difficulties accessing services and their experience of battling for appropriate support, has resulted in varying levels of mistrust and exasperation, an additional challenge when building partnerships and collaborating.

## **Influencers of policy at a local and national level**

Contributors highlighted the importance of widening the pool of people involved in decision making at a local and national level. There was repeated mention of the same individuals and representatives from the larger third sector organisations engaged in working groups and influencing policy decisions.

## **Emerging themes - the impact of the Scottish Strategy for Autism**

Despite the volume of activity, there is still some way to go to deliver on the vision, implement and then embed the service changes that will improve how autistic people are supported in Scotland. From this work, there were consistent issues, raised by contributors, about the impact of the strategy, in relation to the following:

### **The challenge of capturing progress or change**

Inconsistent adoption and application of the strategy's priorities across Scotland have made it difficult to capture an accurate picture of the service delivery changes that have happened in practice, compared to what is documented. This fragmented picture of support was captured by a workshop participant who described "islets of good practice dotted across the country".

### **Sharing local good practice**

Not only did the contributors agree that it was difficult to get a clear picture of what had happened at a local level across all areas, they also felt that there needed to be more opportunities to showcase work and share their practice. Whilst there was the local autism leads network there was not a similar forum for third sector organisations and they wanted to share their examples of successful collaborations and the alternative approaches happening at local level.

### **Persistent shortcomings in particular service delivery and support**

Despite the pockets of progress and "islets of good practice", gaps were consistently identified in particular services or support, most notably with: diagnosis and post-diagnostic support; transition points; support for autistic adults; and employment.

## The impact of COVID-19

The pandemic meant that most face-to-face services paused and, where possible, delivery moved online. Whilst the move to virtual services exposed the inadequacies of IT systems it also forced innovation and creativity to adapt services. For some, this meant services were more accessible and bespoke but for others, the changes were too great, and they disengaged with services. There was hope that the creativity and flexibility shown by some services would become a regular feature of future service provision.

## Disability vs neurodiversity

There is a lack of consensus with regards to how autism should be considered, and a key issue for the sector is the differing views on autism as a neurodiverse condition and not as a disability. There were also concerns expressed about the bringing together of the autism and learning disability agenda and a consistent view of the importance of maintaining a specific strategy/plan for autism services.

## Lessons gleaned for future policy direction

There are lessons from the implementation of the ten-year strategy that can inform decisions about the future policy. The Scottish Government could:

- narrow the focus of future work so there is more likelihood of effective delivery and sustainability;
- provide clarity about actions and implementation;
- explore what evidence or data could be routinely collected to inform the local and national picture;
- provide clarity on where autism sits within government policy;
- consider focusing on areas that need to see the greatest change – diagnosis, transitions, support for autistic adults, employment;
- place stronger requirements on local authorities to deliver;
- review who is contributing to the discussions and influencing policy; and
- build on the positive relationships that exist.

## Conclusions

The Scottish Strategy for Autism supported and funded a wide range of activities and developments at a local and national level designed to bring about improvements in services and support for autistic people and their families/carers. After ten years, valuable resources have been created and new and additional services delivered. However, real change for many autistic people, both in how they engage with services and in how they are supported to live productive lives, is not as evident. To have a greater impact, the services and support need to have greater reach, become embedded and be sustained.

Integration authorities play a crucial role in the degree of strategic impact because most services are designed and delivered at a local level. Until appropriate provision is commonplace, there will be a lack of accessible and relevant local autism services. After ten years, there is an increased understanding and knowledge about what needs to change and what works. It is evident that to enable more autistic people to live a full and meaningful life, future policy direction should focus on a targeted number of key areas to drive systemic change, rather than many piecemeal projects. Systemic change can only be realised in true partnership with autistic people and through collaboration across services and sectors. The current nature of engagement and tension between different interest groups spills into the way in which they can work together. This needs to be recognised and addressed for future collaboration to be effective.



# 1. Introduction

This report presents the findings from the evaluation of the ten-year Scottish Strategy for Autism.

## Aims of the evaluation

In August 2020, the Scottish Government commissioned Blake Stevenson Ltd to undertake an evaluation of the [Scottish Strategy for Autism](#). The strategy concludes in 2021 and Scottish Government wished to commission an independent evaluation to provide impartial evidence on the strategy's impact and inform future policy.

The Scottish Government's Autism and Learning Disability policy team specified that the evaluation should address three key questions:

- Have the strategy's recommendations and priorities been delivered and are additional deliverables evident?
- What impact has the strategy had on the services offered to autistic people in local authorities and the local services and charities that support them?
- What lessons might be gleaned from the delivery of the strategy's recommendations and what might these mean for the future policy direction?

## Structure of the report

The remainder of this report is structured as follows:

Chapter 2: Background and context

Chapter 3: Findings: Delivery of strategy recommendations and priorities

Chapter 4: Findings: Impact of the strategy

Chapter 5: Discussion

Chapter 6: Conclusions

## 2. Background and methodology:

In this chapter we set out the context and background to the ten-year Scottish Strategy for Autism and the approach for undertaking the evaluation.

### Context

Autism (also referred to as autism spectrum disorder (ASD)) is the term applied to a range of neuro-developmental conditions which all affect how an individual communicates and relates to other people. Scottish Autism describes autism as, 'a lifelong, developmental condition that affects the way a person communicates, interacts and processes information'. The National Autistic Society gives a similar definition, but adds, 'disability', 'a lifelong developmental disability which affects how people communicate and interact with the world'. Other sectors of the autism community prefer a definition of difference over disability, stressing that autism lends a different way of perceiving and engaging with the world, but to describe it as a 'condition' or 'disorder' is incorrect and even offensive. However, disorder, condition and impairment are clinical terms and frequently appear in material written from this perspective.

The autism community is represented by many national and local charities and organisations, often set up or led by autistic individuals or their family members and all offer wide perspectives and contrasting insights into autism and its impact on individuals and families.

[Research carried out in Scotland](#) estimated that the national autism prevalence rate is 103.5 per 10,000 meaning that there are approximately 44,000 autistic people in Scotland. A better understanding and recognition of what it means to be autistic, and easier access to diagnosis, is leading to increasing prevalence.

### Barriers and disadvantages faced by autistic people

There is consensus that autism exists on a spectrum and that it affects individuals differently; there can be no 'one-size-fits-all' definition. Autistic people face disadvantage in many areas of their life because of their neurological differences.

Although what it means to be autistic is becoming better understood, many professionals still have a lack of awareness and understanding of autism and the

different ways in which it might affect people. The 'invisibility' of autism can also make it difficult for people to access services; with no obvious physical signs of disability, their way of interacting with people may be seen as simply ill-mannered, or alarming.

Receiving support can rely heavily on good social and communication skills when completing forms or taking part in assessments. This can affect people's chances when taking exams or applying for a job, for example. At the same time, many talented, articulate individuals, adept at masking their differences, may not be given the support they need as professionals and employers may not recognise that they need help.

These challenges take many forms and can affect an individual's physical and mental health, engagement in education, access to employment and services and participation in social and cultural activities.

## **Evolution of the strategy**

The [Scottish Strategy for Autism](#) was the Scottish Government's response to the inequalities experienced by autistic people and an acknowledgment that action needed to be taken to address them.

The Scottish Government and COSLA launched the strategy in 2011. The original document set out 26 recommendations and the vision that by 2021 'individuals on the autism spectrum 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'.

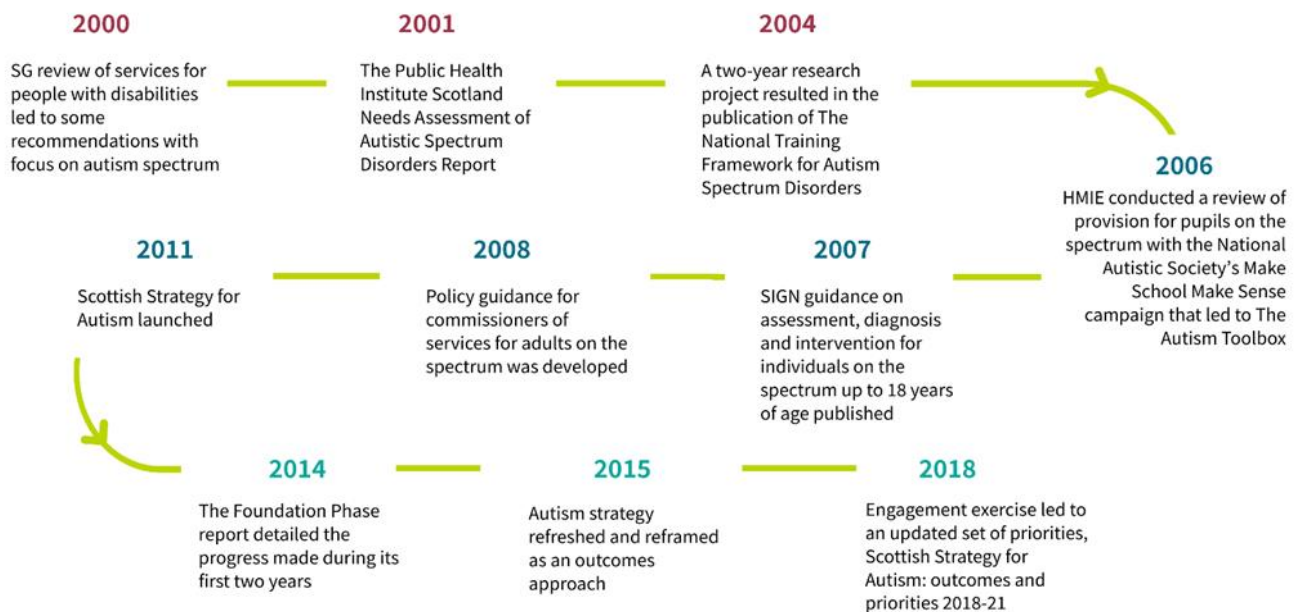
Following [a report](#) on the Foundation Phase of the strategy in 2014, the strategy was re-framed and refreshed in 2015 to an outcomes approach organised under four key areas:

- 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.
- Choice and Control: Autistic people are treated with dignity and respect and services are able to identify their needs and are responsive to meet those needs.

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

After further consultation with autistic people and their families, spokespeople from autism organisations and professionals working in autism services, and against a backdrop of evolving policy and increased devolution of powers, the [strategy was re-launched in 2018](#). The four key areas outlined in 2015 continued as guiding themes for the final phase of the strategy (2018-2021).

Image with a timeline of the strategies reviews, developments and outcomes



## National strategy, local delivery

In both its iterations, the national strategy presented a comprehensive overview of what actions were needed to address the inequalities experienced by autistic people. While it gave a broad vision and direction, actual implementation was expected to be undertaken at a local level.

To enable local areas to deliver on the national strategy, it was supported with funding and underpinned with advice and expertise. Initial investments took the

form of a succession of funding rounds - the Autism Development Fund (2011-2015), Autism Innovation and Development Fund (2015-2018) and the Understanding Autism Fund (2019-2021).

From 2015 onwards, Inspiring Scotland managed the funding programmes and co-ordinated the project monitoring. Their role also included on-going support for the fund recipients with issues like grant management, fundraising and sustainability. Inspiring Scotland encouraged collaborative working between the projects by hosting events to bring the projects together and they offered pro-bono support from a network of professional volunteers including accountants, lawyers and marketing specialists. Inspiring Scotland also delivered more intensive capacity building support for projects from 2017-20 through the Scottish Government-funded Resilience programme. This included a leadership and coaching programme, a series of learning seminars and an online charity knowledge hub.

In addition to the support provided by Inspiring Scotland, Autism Network Scotland (ANS) and the National Autism Implementation Team (NAIT) helped to build capacity and expertise and act as a bridge between the national strategy and its implementation at local level, providing a hub of professional autism support and information. ANS worked with local authorities with a range of issues from consultation, through to implementation of their autism strategies. NAIT provided practitioner-to-practitioner support around education and inclusive practice, assessment and diagnosis and employment.

## **Governance of the Strategy**

Within Scottish Government, the Autism and Learning Disability Team provided policy advice and were responsible for putting Scottish Government policy into practice. A governance group (the Autism Strategy Review Group) was set up to monitor progress against the strategy and this group provided strategic leadership and maintained an overview/governance of the strategy's priorities. Membership included autistic people, representatives from the third sector, government, and professional experts.

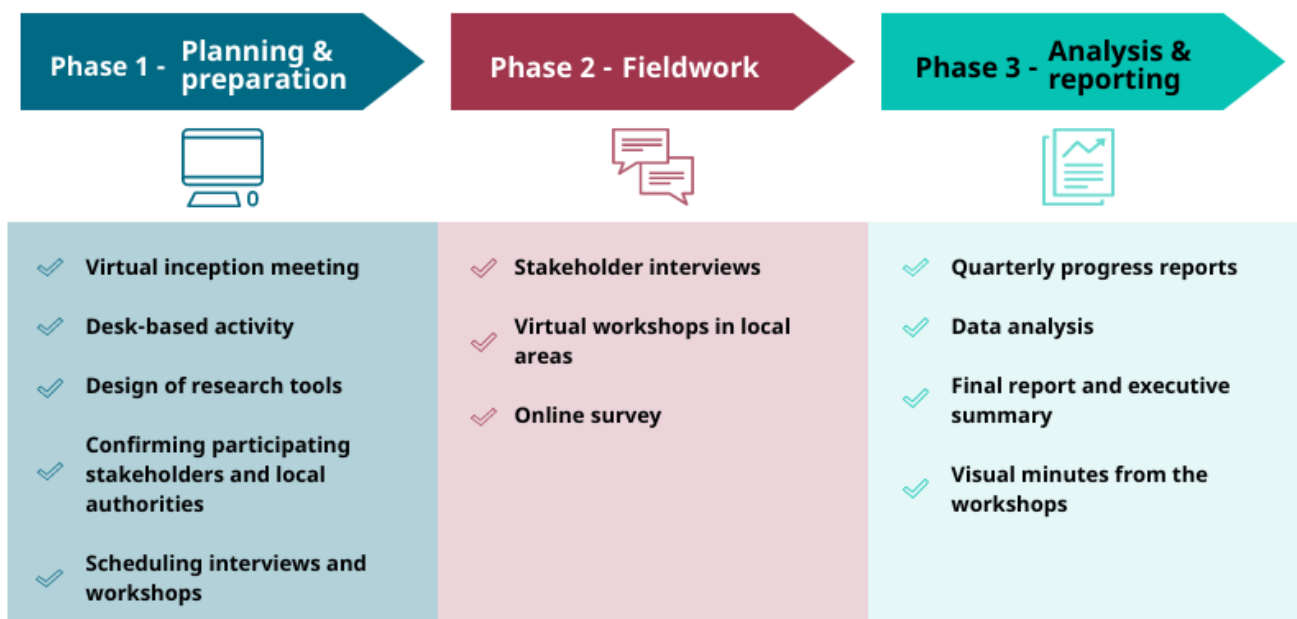
Sub-groups were established as off-shoots of this main governance group where specific areas merited further focus, such as employment, diagnosis and consultation. These smaller groups were responsible for delivering guidance, direction and relevant expertise in the development and delivery of the priority work plans.

Alongside this main governance group, and sub-groups focussing on specific parts of the strategy, in 2017 a further group was established. The Cross-Party Group (CPG) on Autism acts as a channel of communication between the Scottish Parliament and autistic people, their families and carers, professionals and organisations. It is a forum to raise awareness and promotes the interests of autistic people, their families and carers; and it influences Scottish Government policy. In 2020, the CPG published [The Accountability Gap Report](#), which was their review of the strategy.

## Methodology

In the remainder of this chapter, we describe the approach that we employed to complete this evaluation. The diagram below summarises the methodology, and each stage is described in more detail overleaf.

Image showing the three phases of the evaluation



We describe the key elements of our methodology in detail below.

### Desk-based activity

This stage involved reviewing key documents, including unpublished material, related to strategy implementation and delivery at a local and national level. We mapped the activity identified in the documents against the 26 recommendations from the original strategy, the strategy refresh and the [outcomes and priorities](#)

[identified for 2018-21](#). We shared our working document with key stakeholders in order for them to enhance the information and provide us with additional details and evidence.

This desk-based activity provided evidence of the activity delivered and progress achieved in implementation of the strategy, and helped us to identify topics for exploration in the interviews and workshops.

## Stakeholder interviews

We interviewed 18 stakeholders from 14 organisations. These interviews explored stakeholders' views of the progress made towards the recommendations and priorities laid out in the strategy, the impact of the activity delivered on autistic people and the services and charities that support them, and the lessons learned from the strategy. Appendix 1 contains a list of organisations represented by the interviewees.

As a result of COVID-19 restrictions, all interviews took place remotely via telephone, Microsoft Teams or Zoom.

## Virtual workshops

Initially, we were contracted to facilitate six virtual workshops. These were selected through the desk-based research and in discussion with Autism Network Scotland (ANS), taking account of a balance of urban/rural areas, each area's demographics, and ensuring a breadth of different health and social care partnerships and autism representatives across Scotland. Nine health and social care partnership areas were shortlisted for the workshops, and ANS approached the autism leads in these areas to establish if they would be able to host a workshop. To expand the opportunity for more areas to be involved in the virtual workshops, the decision was taken by Scottish Government to offer a workshop to any area that requested one.

As a result, we facilitated 11 virtual workshops in:

- Aberdeenshire
- Dumfries & Galloway
- East Dunbartonshire
- Edinburgh

- Fife
- Glasgow
- Highland
- Midlothian
- North Lanarkshire
- Renfrewshire
- South Lanarkshire.



Figure 2.2: Locations of virtual workshops

To recruit participants for the workshops, we liaised with the local autism leads and Inspiring Scotland and raised awareness amongst any individuals who contacted us about the evaluation. Participants included policy makers and service providers from the public and third sectors, autistic people and family members of autistic people. Table 2.1 shows the range of participants who attended the workshops.

Table 2.1: Types of participants

	Number of participants	Percentage of participants
<b>Public sector</b>	74	53%
<b>Autistic people/family members of autistic people</b>	42	30%
<b>Third sector</b>	24	17%



As a result of COVID-19 restrictions, all workshops were held online using either Microsoft Teams or Zoom. Both these packages allowed for the functionality of gallery views, screen sharing and breakout rooms which helped to maximise engagement in the virtual workshops and allowed smaller group discussions.

The workshops were led by a Director of Blake Stevenson and featured a pre-recorded message from the Scottish Government as well as a summary presentation from a local representative. Participants contributed to the discussion through breakout groups. The smaller breakout group discussions were facilitated by a member of our team from Blake Stevenson and a member of staff from ANS, who supported the workshops as independent facilitators. Participants were invited to discuss:

- how the national strategy had influenced local services for autistic people;
- the difference that local services had made for autistic people;
- how local services could improve; and
- what was needed at a local and national level for improvements to happen.

We also asked participants to take part in an online poll about the most pressing gaps in local autism services.

The sessions were visually-minuted by Jenny Capon, an artist and illustrator. These minutes (in Appendix 2) were sent to all workshop participants as a record of the discussions, and some of the images are also featured in this report.

### **Short online survey**

In addition to conducting stakeholder interviews, we administered a short online survey of additional stakeholders to increase our reach and gain an understanding of their views and experiences. This survey was conducted using Snap Surveys and included three key questions:

- How have the priorities defined in the national strategy 2011-2021 helped to focus and resource effective autism services?
- How did the national strategy support and influence the delivery of accessible and relevant local autism services?

- How have locally delivered autism services impacted on the life of autistic people and their families?

The survey link was distributed by email and social media and we received 154 responses. We offered respondents the choice of completing the survey questions via telephone for those that preferred to do this, but nobody took up this option.

The online survey was deliberately short to ensure it was not too onerous for respondents and in recognition of the extensive consultation that had taken place over recent years for the strategy refresh and, more recently, [the Accountability Gap report](#). However, the open-ended nature of the questions meant that respondents could give in-depth responses if they wished.

Table 2.2 indicates the different types of survey respondents, based on information provided by 151 respondents.

Table 2.2: Survey respondents<sup>1</sup>

	Number of participants	Percentage of participants
<b>Autistic person</b>	53	35%
<b>Family/friend/carers</b>	96	64%
<b>Work/volunteer for a service</b>	44	29%
<b>Policy maker</b>	13	9%

### Additional submissions

Unusually, throughout the evaluation we were contacted separately by people who were keen to give their views about the strategy. We invited these people to attend a workshop if they lived in an area where a workshop was taking place, or, if that was not possible, we invited them to take part in the online survey. In nine cases, these individuals sent us additional information by email. These included detailed personal accounts of autism services and views of the strategy. We have reviewed these submissions and most of them are included in the analysis for this report and the remainder are detailed in Appendix 3.

<sup>1</sup> Respondents could select more than one option.

## **Analysis and report writing**

We analysed the extensive qualitative data we gathered from the interviews, workshops and survey in line with the evaluation questions. This involved a process of coding responses to allow us to identify key and recurring themes as well as any differences in viewpoints among different groups of participants.

The quantitative data collected through the online poll was collated and analysed using Microsoft Excel.

We held an internal team meeting to discuss the key emerging themes before holding a virtual discussion with the Scottish Government's Autism and Learning Disability policy team to discuss the main themes that had emerged and to agree the structure of this report.

The results of our analysis are presented in this report.

## **Challenges and limitations of the approach**

There were some challenges which we had to take account of in our methodology. The most significant of these was that the research took place during the height of the COVID-19 pandemic. This meant that all consultation had to take place remotely via web-based technology. Had the research taken place during "normal" times, face-to-face consultation would have been proposed for this type of research.

Online delivery of workshops may have deterred some autistic people who would have preferred a one-to-one approach from taking part. However, we took a variety of steps to make the workshops as welcoming and non-intimidating as possible by, for example, holding discussions in small breakout groups, providing clear guidance on how to engage during the sessions, e.g. use of the 'hands up' function in Zoom or Teams when anyone wanted to speak, and, where relevant, assigning support workers to groups with autistic people. We took advice from the local leads to ensure that participants were allocated to groups sensitively and appropriately. Those who did not feel comfortable taking part in a workshop were able to participate in the online survey.

Other issues arising included:

- High levels of interest from local authority areas to host a virtual workshop. All requests were accommodated, resulting in 11 workshops (five more than originally intended) being delivered.
- Ensuring that the recruitment process did not exclude anyone interested and able to take part. This was addressed by involving local leads in co-ordinating the workshop recruitment process.

As is frequently the case with qualitative research, the contributors to this report (who numbered 300+), are only a selection of people involved in shaping, delivering and accessing services designed for autistic people or their families and carers. Their views and experiences are therefore not necessarily representative of the wider autistic population, service providers or policy makers.

### 3. Findings: Delivery of the strategy's recommendations and priorities

In this chapter we describe in more detail the content and development of the strategy and the activities undertaken to deliver its recommendations and priorities. This includes discussion of activities delivered by projects funded by three Scottish Government funding programmes.

#### Phase 1 of the strategy (2011)

The first iteration of [The Scottish Strategy for Autism](#) (2011) marked the beginning of a ten-year strategy which sought to improve care and support for autistic people. It was an ambitious strategy that outlined seven underpinning values, a series of time-defined goals and ten indicators for best practice in providing autism services. There were 26 specific recommendations, organised across six themes, intended to deliver against these goals.

There was a funding investment of £1.12 million to support the development of Local Authority Action Plans and the Autism Development Fund awarded £4,891,579.82 to 53 projects. This funded activity between 2011 and 2015 and enabled projects to support autistic people and their families/carers, and deliver elements of the strategy at a local and national level.

Table 3.1: Funding programmes 2011-21

	Total funding awarded	Number of projects	Lowest grant amount	Highest grant amount
Autism Development Fund 2011-15	£4,891,579.82	53	£5,000	£362,170
Autism Innovation and Development Fund 2015-18	£2,097,526.00	41	£4,300	£281,948
Understanding Autism Fund 2019-21	£435,801.00	9	£9,991	£72,601
<b>TOTAL</b>	<b>£7,424,906.82</b>	<b>103</b>		

This section outlines the work delivered to fulfil the goals set out in the 2011 strategy using the 26 recommendations it outlined, listed under the six original themes.

## Theme 1: Strategic leadership from the Scottish Government

Four recommendations around governance and support proposed that the governance group be reconvened to work collaboratively with COSLA, the NHS, and other public bodies to support local area implementation of the strategy. As part of this, the governance group was tasked with investigating the benefits of autism lead officers.

A governance group (the Autism Strategy Review Group) was set up to monitor progress of the strategy. Membership included autistic people, representatives from the third sector, government and professional experts.

Each local authority was given £35,000 to develop a local autism strategy, supported by a central autism hub – the organisation now known as Autism Network Scotland (ANS). Where autism lead officers were in place, they were invited to be part of a network facilitated by ANS.

## Theme 2: Achieving best value services

Recommendations in this area related to research and evaluation. They included: evaluating the economic costs of autism; identifying gaps in research relating to autism services; assessing current outcomes for people with autism and their quality of life and; developing a 'menu of interventions' to identify the support available to autistic people, their families and carers.

Two pieces of work were commissioned to look at the services and support available to autistic people, their families and carers. The first was the Autism Mapping Project, completed in 2013. A partnership comprising the National Autistic Society Scotland, Autism Initiatives Scotland, Scottish Autism, the Convention of Scottish Local Authorities (COSLA), the Association of Directors of Social Work (ADSW) and the Scottish Government conducted research to explore what autism services were available across the country.

The Autism Mapping Project identified and located existing autism services across Scotland and provided each local area with an initial mapping of the services available in their authority. The project looked at what autistic people wanted in terms of services, what they felt worked well and identified priority areas for action that reflected local need. The report given to each local area was intended as a starting point for planning and improving future service delivery.

The second piece of work, which looked at interventions and support mechanisms, was also undertaken in 2013. The [Menu of Interventions](#) ('the Menu') – 'a guide to interventions and supports for people on the autism spectrum' aimed to help identify available advice and support and set out the referral and assessment process for all other services and interventions.

It provided information, drawn from a wide range of professionals, individuals and families of autistic people, regarding, 'the challenges faced by autistic people across the lifespan and ability range' and how these might be best addressed. This was intended to be a flexible approach allowing for the guidelines to be used both generally, across services and locations, but also as required by individuals.

The Autism Mapping Project, [Menu of Interventions](#), support from ANS and government funding were intended to provide a starting point for the development of local strategic plans.

The other main thread for this theme was research into the economic cost of autism. Although not delivered within the original timeframe, [The Microsegmentation of the autism spectrum: research project](#), published in March 2018, provided a foundation for identifying 'preventable' costs of autism – those that would not be incurred if appropriate interventions and adaptations were provided to autistic individuals when required. It also:

- provided an accurate pooled prevalence estimate of 1.035% (103.5 per 10,000) for autistic people and applied the figures to Scotland to provide an accurate representation of the number of autistic people in each age group, by location and whether they also had intellectual disability;
- concluded that most figures around the proportion of people with autism and intellectual disability were too high and suggested a more accurate figure of 32.7%;
- looked at the economic cost of autism and concluded that the incremental annual cost to the national economy was £2.2 billion;
- proposed a model of segmentation of autism based on a matrix of eight segments looking at intellectual ability, symptom severity and additive risks; and
- linked segmentation and interventions to cost and proposed incremental saving amounts for each effective intervention.

### Theme 3: Involving autistic people, their families and carers with decision making

These recommendations centred around increasing consultation and involvement with autistic people. They proposed that the governance group explore options to improve user and carer involvement in service planning, and that the Self-Directed Support Strategy Implementation Group ensured representation from the autism community.

Increasing engagement with autistic people was carried out in several different ways: through a scoping exercise to capture best practice, through facilitation by ANS and by enabling autistic people to participate in policy consultation.

In looking at how to increase engagement from autistic people, the governance group carried out a sample scope on what the NHS, local authorities and voluntary organisations were doing as a baseline for consultation good practice at the launch of the strategy. The governance group itself included representation from autistic people's organisations.

A key part of the ANS role in helping local areas to develop their own strategies was to facilitate input from local steering groups including autistic people, their families and carers. Some local authorities chose to use part of their initial funding pot for establishing their strategy on consultation exercises with autistic communities.

Autistic people and their families commented on the proposed guidance and regulations for the [Self-directed Support Act](#) and policy development.

Furthermore, one-stop-shops were expected to report back about how they supported involvement from autistic people and the evaluation of the one-stop-shops identified effective involvement and engagement of autistic people in how their services were provided.

### Theme 4: Improved cross-agency working

Recommendations included: developing good practice guidelines to support autistic people as they transition between services at different points in their lives; the governance group should contribute to a review of existing SIGN guidelines; a training sub-group to look at gaps in training provision; assessment of the impact of ANS.



ANS worked with the Scottish Government-funded Scottish Transitions Forum (part of ARC) to develop the [Principles of Good Transitions Guide](#) which details what support young people need for positive transitions. They introduced this to funded projects and worked with ANS to produce research and run transition events.

When the Scottish Strategy for Autism was launched in 2011, there were only SIGN guidelines for autistic children and young adults. The Autism Strategy Review Group was instrumental in developing SIGN guidelines around autism for adults, with Dr Ian McClure, a member of the group, going on to chair and co-author [SIGN 145](#), which included guidelines on assessing and diagnosing autism for children and young people and for adults.

The early years of the strategy saw some work taking place to expand autism training. This started with the development of a four-tier model for classifying and standardising autism training in Scotland, continued with an overview of good practice in autism training and culminated in the publishing of a [training plan](#). This looked at the training needs of practitioners, matched them to existing resources and identified any gaps in training provision.

Training for a wider audience was also considered, with Scottish Government-funded Open University and University of Strathclyde distance learning courses being offered to professionals and parents of autistic people to increase their understanding of autism.

The [2016 review of ASN](#) identified the need for clarity in its remit and governance structure but highlighted the positive impact of its role in networking, sharing good practice, providing information and resources, and awareness-raising.

## **Theme 5: Improving diagnosis**

These recommendations focused on steps that could be taken to improve guidance and training on diagnosis of autism, looking at how and by whom it is diagnosed, under what guidelines, how this information is shared and waiting times for diagnosis.

In the early years of the strategy, diagnosis and assessment of autism was guided by the [NICE standard for autism](#), which had a limited evidence base for the interventions suggested and only looked at children and young people. In recognition of the life-long nature of autism and its different manifestations in later life, this was superseded by [SIGN 145](#) in 2016 (as referenced in the previous

theme) which provides guidance on diagnosis, assessment and interventions around autism for both children and adults.

Information about autism and how to diagnose it was shared with the Royal College of Physicians and Surgeons, included in the [NES training framework](#) and autism portal available to all healthcare professionals and became part of an eLearning course developed by ANS.

The Autism Achieve Alliance (AAA) was commissioned by the Scottish Government, to undertake research into waiting times for autism assessment. The results of this research were published in August 2014 and included a national action plan to address the causes of the delays and how to reduce them.

## Theme 6: Improving access to the workplace

Recommended evaluating the impact of the supported employment framework for Scotland.

There were several areas of activity around improving access to the workplace in the formative years of the strategy. In a direct response to the objective outlined under theme six, a specially convened sub-group of the governance group submitted a response to the supported employment framework, outlining how it could best support autistic people to access employment opportunities.

More recommendations around employment were included in the 'Summary Guide on Employment Policies and Initiatives' in Scotland which was produced by Autism Initiatives. The guide provided a background to employment policies and initiatives in Scotland and was intended as a resource for local areas setting up supported employment initiatives.

Some of the local initiatives received funding to improve access to the workplace and these included Project SEARCH, Diversity works 4 me, Iwork4me, the Shirly Project, Autism Rights Group Highland and the Richmond Fellowship.

## Summary

The foundation phase of the strategy rationalised various strands of work into a coherent action plan to tackle the inequalities and disadvantages experienced by

autistic people and those close to them. The early years, guided by the initial 26 recommendations, were ones of consolidation and preparation, creating frameworks for assessment, diagnosis and training, commissioning research and producing resources to help local authority partnerships translate a national strategy into local action.

The intentions of this phase provided a basis for the evolution and expansion of the strategy as it entered its next phase.

## Phase 2: An outcomes approach from 2015-2021

In 2015, the Scottish Government and COSLA refreshed the strategy and reframed it into an outcomes-based approach with the intention that these new outcomes – healthier life, choice and control, independence and active citizenship - would help realise the strategy’s vision for autistic people and their families.

Once again, the strategy’s priorities were reinforced with funding through the Autism Innovation and Development Fund (2015-18), which distributed £2,097,526 to 41 projects, and the Understanding Autism Fund (2019-21), which disbursed £435,801 to nine projects. These funds were administered and managed by Inspiring Scotland, which also provided capacity-building support to projects throughout this period. Table 3.2 includes details of the amount of funding awarded and the number of projects that align with each of the four strategic outcomes.

Table 3.2: Autism Innovation Fund (2015-18) and Understanding Autism Fund (2019-21)<sup>2</sup>

Strategic outcome	Total funding awarded	Number of projects
Active citizenship	£1,740,433	31
Choice and control	£152,546	4
Healthy life	£502,310	9
Independence	£138,038	6
<b>TOTAL</b>	<b>£2,533,327</b>	<b>50</b>

### Strategic outcome 1: A healthy life

<sup>2</sup> Many projects contributed to more than one outcome, but we have categorised each funded project by the one outcome they most closely align with.

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

This first outcome looks at diagnosis, post-diagnostic support, advocacy for autistic people and mental health policy and provision.

The focus of recommendations around diagnosis was to improve assessment and diagnostic services and increase capacity. For post-diagnostic support, sustaining the growth of one-stop-shops was established as a priority, alongside the development of a post-diagnostic support 'toolbox'. Exploring what needed to be done to support parents, and the role of advocacy services were seen as crucial to helping autistic people enjoy high standards of living and family life, as was reviewing provision in the [Mental Health \(Care and Treatment\) \(Scotland\) Act 2003](#).

Our analysis of the funding awarded to projects in 2015-21 shows that nine projects were most closely aligned with this strategic outcome. These projects accounted for a total of £502,310 across the two funding programmes. Some examples of funded projects are identified in the sections below.

## **Diagnosis**

The Scottish Government created the National Autistic Improvement Team (NAIT), involving professionals from education, speech and language therapy, occupational therapy and psychiatry who provided practitioner-to-practitioner support around education and inclusive practice, assessment and diagnosis and employment. Their website shares information about who can diagnose autism and the process for doing so, clinical guidelines and neuro-developmental pathways.

## **Post-diagnostic support**

The recommendations captured in 'A Healthy Life' recognised that diagnosis must be followed by appropriate support. A successful pilot of one-stop-shops was replicated in five different locations with funding from the strategy of approximately £2 million to support the roll out. One-stop-shops offer autistic individuals, their families and professionals information and advice about autism and local support services.

More recently, the Scottish Government funded a pilot National Post Diagnostic Support Programme. This service aims to support newly diagnosed people across

Scotland to understand and embrace their identity as an autistic person. The service is delivered in partnership with national and local charities<sup>3</sup> and focuses on ensuring that autistic children and adults, as well as their families, are empowered with the information and support that they need after a diagnosis, whilst also providing autism-led peer support. The pilot started in December 2020 and will run for six months. It will then be independently evaluated and the results of the review used to determine the direction of a national service.

## **Parents and autism**

The pilot National Post Diagnostic Support Programme will consider how best to support parents as part of its service, ensuring they get the information and support they need to help their child or children with an autism diagnosis and life as an autistic person.

ANS produced a summary report with recommendations on what needs to be done to better support parents and Scottish Government funding was used by Scottish Autism to run an advice line throughout the COVID-19 pandemic to support families.

Several local projects funded by the Autism Innovation and Development Fund supported parents and families. These included the following:

- Barnardo's Intensive Behaviour Support Service aimed to improve parents' ability to positively manage their child's autism in Southeast Scotland.
- The Richmond Fellowship's Scotland-wide Positive Pathways project offered training, support, and advice for family carers of autistic individuals aged 5-18 who have emotional and behavioural challenges.
- Perth Autism Support's Partnership Family Support Project supported families with autistic children.
- The Tailor Ed Foundation offered home-based support in developing practical skills and strategies for autistic children and their families in Edinburgh.

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<sup>3</sup> Scottish Autism, National Autistic Society Scotland, Autism Initiatives Scotland and Autistic People's Organisations, Autistic Mutual Aid Society Edinburgh (AMASE), Autism Rights Group Highland (ARGH), Triple A's and the Scottish Women's Autism Network (SWAN)

## Advocacy and autism

One of the outcomes of the strategy has been a new website which was set up to support organisations supporting autistic people to create websites and set up new advocacy services.

Another outcome has been the work by ANS, whose report into Autism and Advocacy led to the production of a policy and practice paper about autism-informed advocacy and a successful pilot on parental advocacy training, which will be rolled out nationally when funding is secured.

There are a few examples of projects funded by the Autism Innovation and Development Fund that focused on advocacy. Kindred, for instance, provided advocacy support to ten families with autistic young people in Fife, Edinburgh and the Lothians, and the Speak Out Advocacy project in South Lanarkshire offered a dedicated advocacy service for autistic people.

## Mental health provision and law

An [independent review](#) team gathered evidence on how people with learning disability or autistic people experience the [Mental Health \(Care and Treatment\) \(Scotland\) Act 2003](#) and their report, published in 2019, identified a set of legal and practical changes which could reduce or remove the discrimination that autistic people and people with intellectual disability have experienced under Scotland's current Mental Health Act. The Scottish Government is considering how these recommendations should be taken forward.

The Scottish Government also committed to exploring alternative solutions to out of area placements for people with complex care needs and autism. [The Coming Home Report](#) and the [Mental Welfare Commission's themed report](#) identified the challenges faced by autistic people and the Scottish Government's team is working with Social Work Scotland autism and learning disability sub-group to assist HSCPs to improve how autistic people's needs are met and understood within all services and funding a post at Glasgow University to support work on complex needs.

## Strategic outcome 2: Choice and control

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

The focus of this outcome was to raise the awareness of both the public and professionals about autism and what it means to be autistic, whether it be in school, the criminal justice system or in day-to-day life. Recommendations centred on achieving this through awareness-raising campaigns, training and education. This part of the strategy also set out objectives around autism and aging, recognising that autism affects a person throughout their lives.

A total of £152,546 of funding was awarded to four projects that aligned with this outcome between 2015 and 2021 through the Autism Innovation and Development Fund and Understanding Autism Fund. Some examples are provided below.

### Raising awareness of autism

There was significant activity focused on raising awareness of autism among different groups in the community.

Whilst there is an acknowledged lack of understanding of autism across many areas of public and professional life, the criminal justice system was identified in the strategy as an area needing particular focus. Work with the Scottish Offenders with Learning Disabilities (SOLD) produced guides for support staff and defence solicitors on working with people with communication needs and developed training and awareness raising for advocacy workers and support staff to help them support autistic people who find themselves in the criminal justice system.

Women and girls, who are thought to be under-diagnosed<sup>4</sup> were another area of focus and Scottish Women's Autism Network (SWAN) was established to support autistic women by sharing advice and knowledge on autism and how it affects women. The Scottish Autism's Women and Girls Right Click Programme, funded by the Autism Development and Innovation Fund was set up 2016. The online service

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<sup>4</sup> [A Qualitative Exploration of the Female Experience of Autism Spectrum Disorder \(ASD\), V Milne et al](#)

provides information about addressing health and wellbeing challenges for women who live with the condition as well as their parents, carers and other professionals working in the field of autism.

Another funded awareness-raising project, delivered by Autism Initiatives, involved autistic people producing a visual image of what life is like for them. The images created were then displayed through various medium to enhance understanding of autism among the wider community.

In the latter part of the 10-year strategy, a 2020 campaign was launched to raise public awareness of autism. The [Different Minds](#) campaign aimed to dispel some of the myths around autism and build empathy and support for autistic individuals through a more nuanced understanding. Development of Phase 2 of the campaign is due to begin in 2021.

In a more practical drive to raise awareness of autism and to help enable people to identify as autistic, ANS developed a webpage to highlight all autism alert card schemes in Scotland and provided a template to develop your own.

Finally, the Scottish Government team discussed the National Autism Awards proposed in the strategy with autistic people's organisations and, on their advice, took the decision not to pursue this recommendation.

## **Training**

There has been a host of activity to help increase knowledge about autism and train professionals. Since 2013/14 the Scottish Government has provided £671,000 to NHS Education Scotland (NES) to support autism training resources. Further investment for 2021/2022 will include an Allied Health Professional joining the NES team and provision of additional diagnostic training opportunities.

Work has continued to build on the training framework that was developed early in the strategy. There are three elements to the NES approach - the training framework, which shows practitioners the knowledge and skills they need to have; the NES training plan which details what training is available to acquire the skills and knowledge outlined in the framework; and an autism team who provide training, consultation, support, and resources.

Progress has also been made in training people outwith the NHS. The Care Inspectorate delivered training on autism to care inspectors (with ANS), developed an autism action plan and appointed an autism champion



More recently, specific training in diagnostic assessments has been progressed. A national scoping exercise in 2019 identified significant gaps in diagnostic assessment training across Scotland. In response, Developmental Diagnostic Dimensional Interview (3Di); Autism Diagnostic Observation Schedule (ADOS); and Diagnostic Interview for Social and Communication Disorders (DISCO) came together to train clinicians to identify and screen, perform structured diagnostic services and undertake complex assessments.

## Education

Work is ongoing to raise awareness of autism and the needs of autistic learners both in teacher training and in schools.

The publication of the [Not included, not engaged, not involved](#) report on the experiences of autistic children missing school, was followed by a roundtable discussion, chaired by the Deputy First Minister, with key autism stakeholders to discuss and agree next steps. This led to the establishment of an Autism in Schools Short-Life Working Group in 2019 with an action plan that focused on driving improvement in education from the initial Teacher Education (ITE) programmes, wider sharing of inclusive pedagogical work and quality practice to continued support for ongoing professional practice and development.

NAIT have produced Initial Teacher Education Autism Course Materials: 'We were expecting you!' developed in recognition of the needs of autistic learners and those with related support needs.

For those already teaching, Education Scotland launched a refreshed [Autism Toolbox](#) in partnership with the Scottish Government and the Autism in Schools Working Group. The Toolbox is a free online resource developed to support the inclusion of autistic learners in Scottish nurseries and schools.

Other developments to raise awareness of autism in education include:

- An autism module for Post Graduate Diploma in Education designed by ANS;
- A commitment from the General Teaching Council Scotland (GTCS) to revise the framework for ITE and professional standards documents to ensure specific reference is made to autism;
- A sub-group of the autism governance group and GTCS co-created [Meeting the Needs of Autistic Learners: a professional guide for teachers](#), published in November 2020;

- The Open University continued to offer free autism modules to professionals and parents of autistic people.

## **Autism and ageing**

Support and services for autistic adults and older people is another area that has been repeatedly highlighted as one that needs to be addressed. The [2019 report](#) by ANS, Autism and Ageing highlighted several areas of concern for the autistic community including social isolation, lack of service provision for older people and poor access to accurate and accessible information. The findings from this report formed the basis of an autism and ageing pilot in three local authority areas which ran from October 2020 to March 2021. One of the key aims was to increase knowledge and understanding among HSCP staff working with older people.

## **Strategic outcome 3: Independence**

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.

This outcome included elements that support autistic people to live independently focused on increasing the number of autism friendly places in Scotland, enabling active travel and making sure autistic individuals have access to suitable housing.

Six projects aimed at supporting independence were awarded £138,038 in funding between 2015 and 2021 from the Autism Innovation and Development Fund and the Understanding Autism Fund. Some examples are provided below.

### **Autism friendly places and communities**

ANS have supported a number of organisations in their drive to become more autism friendly through provision of resources and training.

Three of the nine projects currently funded are focused on improving access to the community for autistic individuals through increasing understanding of autism among the non-autistic community.

- Perth Autism Support, for example, is working with Asda and other retailers to deliver training to staff on autism awareness in Perth, Aberdeen, Angus and Highland. It is also providing resources for managers on how to best support autistic employees.
- Project Ability is working with Glasgow Life to produce videos, created by autistic people, to describe their experiences of autism during lockdown and of visiting Glasgow Life venues. The aim of the project is to enhance understanding of autism among Glasgow Life staff and improve their facilities for autistic people.
- Autism Atlas is delivering autism awareness training, drama presentations and question and answer sessions in communities and organisations including Police Scotland, supermarkets and the Crown Prosecution Service across the central belt and Dundee. The sessions are led by autistic individuals and aim to enhance understanding of autism among members of the community.

### **Autism-friendly travel**

Assistance with travel supports autistic people to be independent and most of these services are shaped and delivered at a local level. Contributors to this report agreed that there had been positive changes. At a national level, the blue badge scheme was extended to include carers of autistic people.

### **Autism-friendly housing**

Appropriate accommodation for autistic people to live independently is an area that needs significant development. Progress has been made both strategically and practically in moving towards supporting the availability of autism-friendly housing through research and pilot projects.

Two reports, one from the Scottish Government – [‘Housing to 2040’](#) – and one from ANS – ‘Housing and Homelessness’ – acknowledge the need for adapted housing and include recommendations on how this can be achieved. Pilot projects, like the one in East Ayrshire, was funded to deliver autism training to all housing managers and officers.

## **Strategic outcome 4: Active citizenship**

People with autism are able to participate in all aspects of community and society by successfully transitioning from school into meaningful educational or employment opportunities. This looks at obtaining and maintaining employment, social security arrangements, transitions planning and reduction of social isolation.

In this final section we outline some of the work designed to promote active citizenship among autistic people, including support to transition from school into educational or employment opportunities, other types of employment support and activities designed to address social isolation and enhance community involvement among autistic people.

Activities like this, particularly those supporting autistic people to move towards employment and to combat social isolation through participation in community activities, were a key focus of the Autism Innovation and Development Fund, and the Understanding Autism Fund. Thirty-one of the funded projects were most closely aligned with this outcome and they shared £1,740,433 in funding.

### **Employment**

Strategic support, practical advice and resources and funding have contributed to addressing the barriers to employment and helping local areas deliver employment support to autistic people who want to enter or stay in the job market.

### **Supporting autistic people to enter or sustain employment**

National agencies like Fair Start Scotland (FSS), the national employment support initiative, help people facing multiple barriers into work by offering tailored one-to-one help and advice. People looking for work are matched with an adviser who will advise on the best places to look for work, how to apply and how to work with an employer should adaptations be necessary to continue employment. Although there is no data specific to autism, latest statistics from FSS note they have supported 904 people with a 'developmental disorder' in which they include autism and ADHD.

There are several local projects funded by the Autism Innovation and Development Fund which aimed to improve the ability of autistic people to move into employment. For example:

- SWAN received funding to deliver employment-related mentoring support for autistic people in several local authority areas including Fife, Highland and Borders,
- Clydesdale Community Initiatives supported autistic people to develop new skills to enhance their employability; and
- TCV Scotland's Discovering Nature Programme, delivered in partnership with Scottish Autism, provided outdoor-based science training workshops for autistic adults.

### **Work with employers to develop inclusive work environments and support autistic employees**

Two strategic overviews<sup>5</sup> have contributed to the resources available to organisations and local authority partnerships looking into employment support. This is reinforced with practical discussion through the ANS-facilitated Autism and Employability Group, which also addresses issues and identifies appropriate employment support.

Skills Development Scotland is another national organisation broadening opportunities for autistic people. Although many of its initiatives have a wider definition of 'disabled' or under-represented, the measures in place can support autistic people into work. Their Apprenticeship Equality Action Plan (EAP) sets out the approach to working with partners to ensure individuals from a diverse range of backgrounds, including autistic people and those with learning difficulties, can access work-based learning opportunities and achieve equal outcomes. This has been followed up with autism training for potential employers.

Six of the nine projects funded by the Understanding Autism Fund focus on increasing awareness and understanding among employers of the benefits of employing autistic individuals. Over 60 employers across Scotland are participating in these projects, which include the following:

- IntoWork's initiative to work with employers in Edinburgh and the Lothians to improve their understanding of autism.

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<sup>5</sup> *A Fairer Scotland for Disabled People: Employment Action Plan (2018)* and the *Recruitment and Retention Plan for Disabled People (2019)*

- The Usual Place, which is engaged with businesses in Dumfries & Galloway through seminars to challenge misconceptions and negative attitudes towards autism.
- Values Into Action, Scotland's Modern Apprenticeship pilot, which worked with local partners to secure Modern Apprenticeships for more than 20 autistic young people.
- Enable Scotland is working with employers across the country to improve recruitment and retention of autistic people, supported by an autistic people's forum.

## Transitions

The strategy acknowledged the importance of effective transitions between key stages in life, to support positive outcomes for autistic people. Much of the work completed under this priority has been in partnership with the Association for Real Change Scotland (ARC Scotland) or delivered through local projects. This has included:

- Funding ARC Scotland's Scottish Transitions Forum (STF), a national network committed to improving the experience of children and young adults (14 to 25 years) with additional support needs as they make the transition to young adult life.
- Supporting the development and promotion of the [Principles of Good Transitions 3](#) and an [Autism Transitions](#) supplement. The supplement was produced in partnership with ANS after consultation with autism communities. The supplement identifies key practice considerations, tools, and resources to help ensure autistic people and their families have access to appropriate transition planning.
- Trialling Principles into Practice, a training-based course based on [Principles of Good Transitions 3](#), in ten local authority areas in Scotland.

At a local level, Autism Innovation and Development funding focused on supporting autistic people making the transition from school to education or employment. Some examples included:

- Central Advocacy Partners provided independent advocacy for autistic young people aged 14-25 in Forth Valley to support them through their transition from school.

- The Shirly Project's Bigger Picture programme supported autistic young people and their families in Highland to make the transition from education to life after school.
- The Thistle Foundation's InterAct project in Edinburgh and Midlothian worked with young people with additional support needs including autism, their schools, families, and communities to support the transition from school to adulthood. This included developing traineeships and other opportunities for young people, as well as establishing opportunities for peer support.

## **Social security**

Social Security Scotland, the new social security system is committed to treating people who access the services with dignity and respect and treat everyone equally. Its charter outlines an approach to inclusive communication, with an Inclusive Communication Stakeholders Group of which Scottish Autism is a member, and it is hoped that this new service will result in an improved experience for autistic people and their family members/carers when accessing the benefit system.

## **Social isolation**

When autistic people are active citizens, they can be socially engaged, participate within their local community, and feel a sense of belonging.

Before the COVID-19 pandemic, isolation and loneliness was experienced by many autistic people and it is likely that this has been exacerbated with the restrictions and reduced access to services.

In recognition of the challenges resulting from the pandemic, £450,000 was provided to autism and learning disability support organisations to help support vulnerable people at risk of social isolation.

A few examples of projects delivered under the Autism Innovation and Development Fund 2015-18 that aimed to address social isolation are listed below:

- Project Ability provided weekly classes in Glasgow which included opportunities for social activities.

- The Royal Conservatoire of Scotland (in collaboration with the National Theatre of Scotland, National Autistic Society and NHS Greater Glasgow and Clyde) delivered a project to address and challenge barriers that autistic children, young people, and adults face accessing drama and theatre.
- The Watermill Foundation supported the first all-abilities cycle track in Scotland (the Highland Cycle Ability Centre) to enable autistic people to take part in social activities, as well as enhancing their self-esteem, confidence and overall health and wellbeing.

The National Post-Diagnostic Support pilot will also address social connection and isolation and put in place support for autistic people to engage across their communities.

## **Summary of delivery of the strategy's recommendations and priorities**

The ten-year strategy was ambitious and multi-layered to address the broad and wide-reaching outcomes and priorities that it contained. Delivery of the strategy required commitment and implementation at a local and national level, and partnership working across several sectors and services to deliver the vision and bring about change.

Most of the commitments in the strategy have been actioned to some extent, some have gained more traction than others and some still need much more focus and investment for real progress to be realised.

In the next chapter we explore the impact of these activities and deliverables within the strategy.



## **4. Findings: Impact of the strategy**

In chapter 3 we described the wide range of activities, and the resources that supported them, which were designed to deliver elements of the strategy's priorities and recommendations. In this chapter, we discuss the impact of that work as reported by those who responded to the survey, took part in the virtual workshops or participated in the stakeholder interviews.

### **Introduction**

Across all types of respondents, participants and interviewees, there were repeated comments about the limited impact of the strategy. Some of these comments related to its focus being too broad, a lack of authority to bring about change at a local level and that the host of activities and projects had not led to real change for autistic people and their families/carers.

We discuss these views in more detail in chapter 5 but, despite the widely held belief that the strategy has under-delivered, contributors did attribute some positive changes as a result of the strategy. This chapter focuses on those changes.

Our first consideration looks at the impact of the strategy on local services and charities that supported autistic people and their families and carers.

### **Impact of the strategy on local services and charities that support autistic people**

#### **An impetus for local areas and a high profile for autism**

Local stakeholders and autistic people and their family members highlighted that the national strategy provided a welcome focus and recognition of the importance of addressing autism.

The strategy set expectations for local authorities to respond and consider what services they should be supporting or delivering locally.



“The national strategy put autism front and centre and pulled everything together in one place.” *Workshop participant*

For many areas, this provided the needed impetus and focus that resulted in a local autism strategy and associated activities like local strategy groups and multi-disciplinary working to progress actions around autism. Contributors to this work believed that, in the absence of the national strategy, their local strategies would not exist and there would be no progress in any aspect of service delivery, awareness raising or support for autistic people and their families and carers.

“The National Strategy has highlighted the need to develop awareness and understanding of Autism, as well as the need to develop services. It has identified gaps, some of which still need attention.” *Survey respondent*

Others described the national strategy as providing a platform for dialogue and action in local areas with the key priorities shaping and informing decisions amongst public sector and third sector organisations.

“The national strategy led to the creation of a local strategy group and has left a legacy of a group of multidisciplinary professionals willing to work together to progress around autism.” *Workshop participant*

## Resources and funding to develop and deliver services

As well as providing a framework for local authority and service delivery, funding and support was made available to help develop and implement this work. From the workshops and survey responses we were given plenty of examples of how this translated into local activity - ranging from commissioning research to support understanding and to inform the local strategy, to increased resources to meaningfully engage and work with autistic people and family members/carers to shape local decisions.



“I can see that more and more charities and community projects gain funding to support autism-specific causes or come up with autism-inclusive ideas.” Survey respondent

In Chapter 3 we provided examples of how the funding attached to the strategy, financed additional or new local services delivered by a wide range of projects, and contributors to this evaluation named local services that had been able to support them or their family members because of this funding.

“The national strategy helped to create the only autism support we have by allowing a Third Sector organisation to deliver accessible and quality support.” Survey respondent

## Resources that provide support

In the earlier chapter, we also described the resources that sat alongside the funding, in the form of ANS, NAIT and Inspiring Scotland. The skills and expertise within these organisations have helped build capacity, share good practice, support

the development of specific services such as a diagnostic pathway, and facilitate networking and awareness raising amongst a wide range of third sector organisations, local government and health and social care partnerships.

“Support of ANS was important, especially in sharing what worked in other areas.” Workshop participant

“The leadership training from Inspiring Scotland was incredibly useful and supportive.” Stakeholder interviewee

“The work of NAIT is key to what has been recently achieved in improving diagnosis.” Stakeholder interviewee

This translated into some local services with staff who were better equipped and more knowledgeable providing support that was more appropriate and relevant to the needs of the local autistic population and families or carers.

Examples of these local developments and improvements include:

- creating structures like parent and carers forums to guide local work;
- establishing dedicated roles like Autism Co-ordinators to support individuals; and
- increasing capacity within existing professional teams so that specialist support could be provided without having to go out of the area.

## Resources to use

The work that took place at a national level resulted in the creation of new resources, like the [Menu of Interventions](#) and the [Autism Toolbox for Education](#).



Workshop participants and interviewees explained that these resources provided professionals and local services with the information and guidance to support and influence their policy and practice.

They explained that with these tools, organisations and services have been able to explore what aspects of service design and delivery, provision and support needed to be developed or enhanced and improved the knowledge of professionals.

The [Micro-segmentation report](#), again a product of the strategy, was identified by some contributors as a valuable evidence base, not only in helping to define the services needed and the number of people requiring support, but also in influencing decision makers and informing action.

## Awareness raising

Contributors acknowledged that having a strategy enhanced the profile of autism and they also praised the awareness raising work through the Different Minds campaign and the work of the nine projects in receipt of Improving Understanding of Autism Funding. They felt that because of this work there were more positive representations and increased understanding of what autism means and how it

affects people in everyday life. A few described how the campaign portrayed and celebrated autism as a difference, not a disability, which they welcomed.

“I’ve appreciated raising awareness campaigns that help people rethink their perspective of autism.” Survey respondent

Our second consideration is the impact of the strategy on the services offered to autistic people.

### **Impact of the strategy on services offered to autistic people**

The contributors to this evaluation were able to describe changes to services and whilst there were many examples, it is important to note that some of those changes were often time-limited because of the short-term funding that enabled a service or project to operate.

#### **Increase in volume and relevance of services**

Nevertheless, some service providers and autistic people and their families or carers identified an expansion or improvement in specific services that had been of value to them or their families.

“The national strategy helped to create the only autism support we have by allowing a Third Sector organisation to deliver accessible and quality support.” Survey respondent



These changes not only related to an increase in the volume of services but also the relevance of those services and support. The workshops offered an insight into the developments and experiences of accessing services at a local level and there were accounts of a more person-centred, asset-based approach to supporting autistic people and genuine exchanges that resulted in a shared understanding of the issues facing service providers and service users. Some people also provided details about the development of stronger local networks and examples of autistic people co-producing and delivering training to professionals.

“While much remains to be done, there have been more individualised improvements in approaches used by services. Also been a stronger focus on promoting inclusive practice, understanding and empathy.” Survey respondent

### **New service provision**

The new or expanded service that was repeatedly mentioned was the one-stop-shops. Six one-stop-shops were funded for a fixed period, early in the strategy, enabling the expansion of the successful Edinburgh model to other areas. Many of the interviewees, workshop participants and survey respondents highlighted that the one-stop-shops were a well-used resource that demonstrated good practice and a successful approach for providing a wide range of support to autistic people and families/carers.

The short-term funding from the strategy has meant that alternative funding was required to sustain the services and five of the six one-stop-shops secured the finance to continue to provide a vital service in those locations.

“There are small pockets of really good practice that we could be learning from and building on nationally, e.g., autism-led one-stop-shops.” Survey respondent

As well as the one-stop-shops, contributors to this evaluation named specific services that had been established, new posts within services that had been created and new partnerships with third sector organisations that had helped them and their families.

The more recent development of the post-diagnostic support (PDS) pilots was also praised by some workshop participants and interviewees. Whilst several people considered the one-stop-shop model as more relevant post-diagnostic support, others felt that, with the new pilots, there was more PDS support available now to help navigate through the various systems and access help.

### **More knowledgeable and skilled professionals**

Although the training of professionals was a consistent concern for many contributors, in this evaluation there were clear signs that, for some, this was an area of improvement.

Training within education and schools was the most common example and these new developments included the use of the refreshed [Autism Toolbox](#) in schools, whole school training using SCERTS®<sup>6</sup> and roll out of training to Speech and Language Therapists, educational psychologists and some nurseries and parents. Contributors felt that this work had resulted in greater levels of awareness and understanding in those educational and home settings.

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<sup>6</sup> The SCERTS® Model is a research-based educational approach and multidisciplinary framework that directly addresses the core challenges faced by autistic children and adults and related disabilities, and their families.





There were other examples of how the focus on training within the strategy became a driver for local action to improve the knowledge of health and social care professionals, using the resources produced by NES.

For one area for example, the training was mandatory for staff in certain roles. In these cases and with these training opportunities, the contributors identified that this led to the upskilling of professionals so that they could improve the support and services for autistic people and their families and carers.

### Development of diagnostic pathways

As well as better trained professionals, there were some accounts of improvements in the assessment and diagnostic pathway. These examples sat alongside the concerns of others who had experienced lengthy delays and difficulties in accessing a diagnosis, which continued to be a key issue for many.

However, where the changes had been made, the contributors recognised:

- the development and introduction of adult diagnostic pathways that has not previously existed;
- the involvement of a wider pool of professionals who were now able to diagnose; and
- an improved understanding of the under-representation of girls and women in diagnosis and support.

All changes these had increased capacity for diagnostic assessments in some areas or improved access to a diagnosis for sections of the autistic population.

## Summary

The strategy has led to change and the development of services and support that have made a difference to the lives of autistic people and their families/carers. However, the priorities, outcomes and recommendations in the strategy were extensive and the volume of activity and investment has been substantial - for the contributors to this evaluation, the pockets of change highlighted in this chapter have not matched this ten year endeavour.

Many of the changes relied on local implementation and, even when there were positive developments identified by the contributors to this evaluation, these were often short-lived and were not consistent across the country or even within a local area.

In the next chapter, we discuss the reasons for this under-achievement and patchy implementation of the strategy's outcomes and priorities.

## 5. Discussion and conclusions

In Chapter 3, we described some of the extensive work that has been carried out and the resources committed to delivering the priorities and recommendations within the Scottish Strategy for Autism. In Chapter 4, we identified how that activity has led to change and the impact on services designed to support autistic people, their family and carers.

### Emerging themes in relation to the delivery and implementation of the Scottish Strategy for Autism

Whilst the strategy was ambitious, much of the work has been done to understand what is needed to improve and deliver appropriate services. The keystone for translating the changes into practice is the required action at a local level. For many reasons this has not occurred at the pace, breadth and spread that has been needed, resulting in inconsistency from one area to another. There are many factors that have influenced this, and these are discussed here in more detail.

#### Factors that influenced implementation of the strategy at a local level

The local response and mobilisation was crucial in the extent to which the national strategy had an impact. A number of factors heavily effected the local area and readiness to embrace the priorities and ability to undertake key activities and collaborate to achieve short term changes. These factors are discussed in turn.

**Leadership and commitment** – the progress in local areas was dependent on the individuals driving forward the work and securing commitment from their local leadership to be able to push through the strategy, create partnerships and engage the wide range of local services that needed to be involved in the programme of change. For those involved in implementing changes, without the visible top level support taking forward service developments could be delayed or stall.

**History of partnership working** – in areas with a tradition of working well with third sector partners and/or engaging with autistic people and their families/carers, developing local strategies and shaping services was an easier task because the relationships were already established. In areas that had not engaged previously with the local autistic population or relationships with the third sector were more

fragile, it took more time and effort to agree on the necessary changes and progress developments locally.

**Effective use of autism resources** – all local authorities received £35,000 to help develop their local strategies and they received mapping reports to inform their decision making. Some used this funding for various activities - to work with local people, create forums and working groups, develop approaches and pathways into services, and allow dedicated time to draft and then secure approval of their local strategy. For others, their work did not lead to a finalised and tangible output and so, in some areas, the local strategies have remained in draft form since 2014.

There were also resources that local areas could access, from ANS facilitated local leads network to the guidance within the [Menu of Interventions](#). The engagement with and use of these valuable resources also varied from area to area.

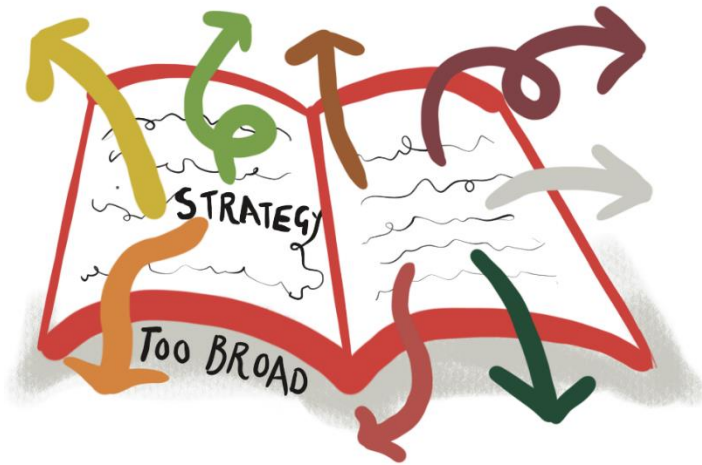
**Sustaining change** – over the ten years of the national strategy there have been changes on a national scale, from austerity to a global pandemic and locally from the creation of integration authorities to changes in key personnel, all of which resulted in shifts in responsibilities, priorities and commitments levels. Even in areas that created their first local autism strategy, the impetus and focus had often waned by the time a second strategy was due to be developed.

Local commitments to fund autism services were also less common, the one-stop-shops were a good example of a successful and valued model for supporting the local autistic population but, once Scottish Government ended, most local funders were not able, or willing, to offer funding to continue the service.

**Governance and accountability** – the national strategy did not place mandatory requirements on local authorities to develop and deliver their local strategies but used encouragement, support and resources to bring about action at a local level. The local strategies did not need to be submitted or reviewed and for areas that did not prioritise or pursue real change, there were no consequences for this inaction.

## **The breadth and content of the strategy**

The original strategy was produced by several authors and tried to address the needs and interests of many, and needed to be far reaching to address the multitude of issues that autistic people and families/carers faced over their lifetime.



Contributors to this evaluation often commended the ambition within the strategy, but it has meant that the focus and work at both a local and national level has been thinly spread and pulled in different directions.

So many of the changes required were to systems, processes, understanding and knowledge which takes time and investment, so it is not surprising that there is a substantial gap between the policy aspirations and the actual support available to autistic people and families and carers.

### Short-term investment

The implementation of the Scottish Strategy for Autism was accompanied by a financial investment of £7.4 million and, in the earlier chapters, we described the rounds of funding that were disbursed to a wide range of projects.

Whilst this funding was welcomed and supported a variety of well-used and valued services, many of these ceased or elements of support were withdrawn at the end of the funded period.



Some participants and survey respondents explained that for them, services had diminished over the ten-year period and there should have been alternative central funding streams to fund projects or services that evidenced a successful approach that was having a positive impact on autistic people or families and carers.

### **Nature of engagement and partnership working**

From the discussions, the successful delivery of projects and services that meet the needs of autistic people was best achieved through collaboration and partnership working at a local and national level and with statutory and third sector organisations working with autistic people.

Working nationally and locally, across sectors and disciplines requires healthy collaborative working and what was evident undertaking this work was that the longstanding frustrations among autistic people/families/carers and service providers about the difficulties accessing services and their experience of battling for appropriate support has resulted in varying levels of mistrust and exasperation.

This is an additional challenge when building partnerships and sometimes led to unproductive discussions. Our evaluation team experienced the extent of adversarial dialogue in the way in which people engaged with us, how they communicated with, and about, others and it did not appear to be unusual in the sector. Effective partnership working is crucial to bring about the changes needed

but it will be difficult to work collaboratively if acrimonious exchanges remain commonplace.

### Influencers of policy at a local and national level

Interviewees and workshop participants highlighted the importance of widening the pool of people involved in decision making at a local and national level.

There was repeated mention of the same individuals and representatives from the larger third sector organisations, the 'usual suspects', engaged in working groups, championing their particular interests and influencing policy decisions.

They acknowledged that it was challenge, that it is a crowded, yet fragmented, autism landscape of third sector organisations with differing views of how autistic people should/could be supported. However, it was felt that a minority monopolised the conversations at all levels and the balance of influence needed to shift.

These interviewees and workshop participants asked for a wider selection of contributors who had a lived experience at all levels and stages of life in order to expand the voices and views that were being heard around the decision making tables at local and national level.



## **Emerging themes in relation to the impact of the Scottish Strategy for Autism**

As already described, despite the volume of activity, there is still some way to go to deliver on the vision, implement and then embed the service changes that will improve how autistic people are supported in Scotland.

From this work, there were consistent issues, raised by contributors, about the impact of the strategy.

### **A challenge to capture progress or change**

Inconsistent adoption and application of the strategy's priorities across Scotland have made it difficult to capture an accurate picture of the service delivery changes that have happened in practice, compared to what is documented.

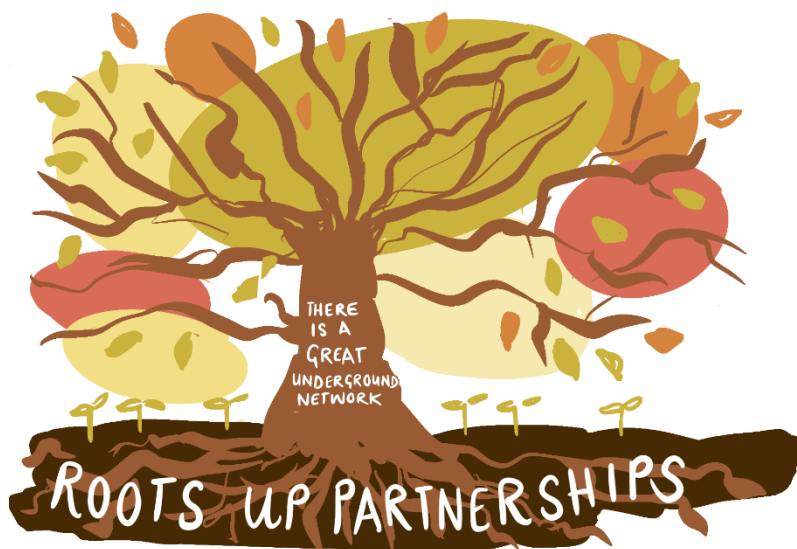
From the discussions with interviewees and workshop participants and comments from survey respondents, improvements in accessing services or absence of any service varied from one area to the next. This fragmented picture of support was captured by a workshop participant who described "islets of good practice dotted across the country".

### **Sharing local good practice**

Not only did the contributors agree that it was difficult to get a clear picture of what had happened at a local level across all areas, they also felt that there needed to be more opportunities to showcase work and share their practice.

They acknowledged that the local autism leads network, facilitated by ANS, supported local government and health and social care partnership representatives to do this, but interviewees and workshop participants from local third sector organisations said they had no platform to do so.





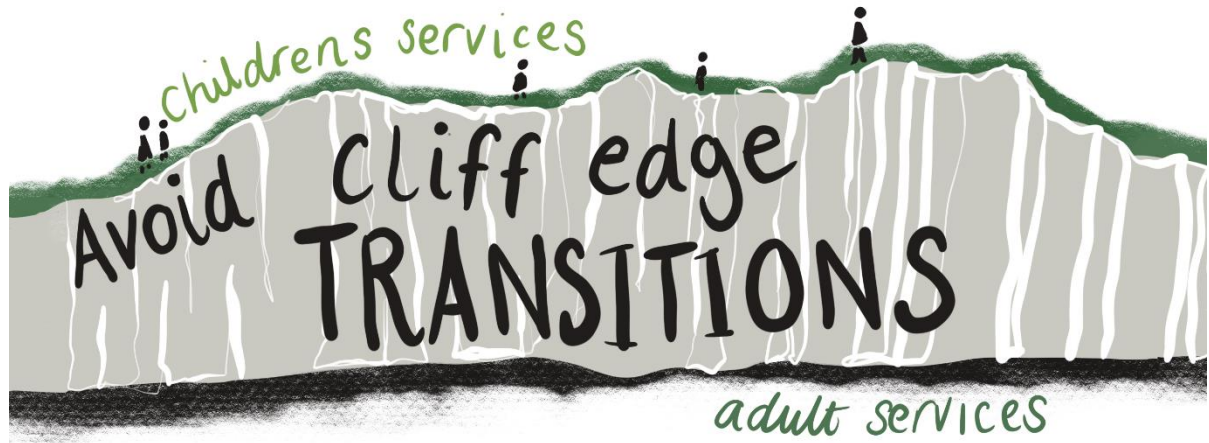
They wanted to share the examples of successful collaborations with local agencies and autistic people to design and deliver local services, and the alternative approaches happening at local level but felt ‘over-shadowed’ by the larger charities and their limited mechanisms to gather information and showcase widely.

### Persistent shortcomings in particular service delivery and support

In Chapter 3, we described the progress and improvement in some areas, for some people but we acknowledged that, for many, their experience was not a positive one. Despite the pockets of progress and “islets of good practice”, gaps were consistently identified, in particular with:

- **Diagnosis and post-diagnostic support** – there were accounts of difficulties accessing a diagnosis, long waiting lists, no diagnostic pathway in places (especially for adults) and debates about where diagnosis should sit and who should take ownership. When a diagnosis was given, for some it was a gateway to understanding and support, but others there was an absence of accessible post-diagnostic support which was needed through their lifetime, not just as a child or young person.
- **Transition points** – although there was recognition of improved resources and knowledge about the transition process, there were several accounts of

the negative experiences of the transition from child to adult services, with one workshop participant describing their son's experience like 'falling off a cliff'. To improve the transition process, it was suggested that there needed to be more extensive and earlier planning for the change, greater overlap between the services and where they intersect, and a continuity of support to minimise the disruption and distress.



- **Support for autistic adults** – Contributors to this report were frustrated that many autistic adults must fend for themselves and, as autism is a life-long condition, the need for a whole-life approach to supporting someone should be recognised so that appropriate services are available as a person gets older. Consideration also needs to be made for autistic people with ageing parents who might be their mainstay – what happens when they are no longer around?
- **Employment** – support and access to meaningful employment opportunities, for those who wanted to pursue work, was described as very challenging and, even when a role was secured, sustaining employment required support and greater awareness and understanding from employers. Participants were aware of some of the funded projects that had improved the prospects for some local employees, but it was piecemeal and small scale. It was felt that a more significant focus and concerted effort at a local and national level was needed to address and improve the routes into and support during employment and this should be for all ages, not just the under 25s.

## The impact of COVID-19

The pandemic meant that most face-to-face services paused and, where possible, delivery moved online. Workshop participants explained that the move to virtual services exposed the inadequacies of some IT systems and their ability to handle

large volumes of information or bring together significant numbers of people in data complaint ways.

The impact of COVID-19 forced innovation and creativity to adapt services and move them online. For some this meant they were more accessible, with autistic people accessing them from their own home, a place they were very happy to be, for others, the changes were too great, and they disengaged with services.

It was acknowledged during several of the workshop discussions that although COVID-19 brought about significant change in the way in which services operated, people and processes adapted in a short space of time, and with the additional flexibility, some autistic people experienced a more bespoke support package. Some contributors identified that, where their programmes were successfully delivered online, these will continue with a blended approach of virtual and face-to-face support once restrictions and physical distancing is lifted.

There was hope that the creativity and flexibility shown by some services would become a regular feature of future service provision.

## **Disability vs neurodiversity**

There is a lack of consensus with regards to how autism should be considered, and a key issue for the sector is the differing views on autism as a neurodiverse condition and not as a disability.

There was strong resistance to learning disability and autism strategies being merged. Autism within the Scottish Government currently sits alongside learning disability and some would prefer a broader neuro-diversity approach to reflect autism as a neuro-developmental difference.



Throughout the discussions, the concern about bringing together autism and learning disability was repeatedly raised. A minority of autistic people have a learning disability and whilst there is some overlap in the disadvantages both populations face, the types of support and services to address their needs differ. Whilst some felt that being an autistic person and having a learning disability meant easier access to services, the majority of autistic people do not have a learning disability and were frustrated with this focus.

There were concerns expressed about the bringing together of the autism and learning disability agenda and a consistent view of the importance of maintaining a specific strategy/plan for autism services and not combining the two.

## Lessons gleaned for future policy direction

There are lessons from the implementation of the ten-year strategy that can inform decisions about the future policy. The Scottish Government could:

- narrow the focus of future work which will mean less might be achieved but there is more likelihood of effective delivery and sustainability;
- provide clarity about actions and implementation so that there are identified achievements within a clear plan;
- explore what evidence or data could be routinely collected to inform a picture of what is happening locally and nationally;
- provide clarity on where autism sits within government policy – lack of consensus of how autism should be considered, the disability vs neurodiversity debate;
- consider focusing on areas that need to see the greatest change – diagnosis, transitions, support for autistic adults, employment;
- place stronger requirements on local authorities to deliver, especially if funding is provided to support them;

- review who is contributing to the discussions and influencing policy so that the usual suspects are not always around the table and the contributors are from a wider pool to reflect the small and large charities supporting autistic people, and individuals with a lived experience from across the ages; and
- build on the positive relationships that exist – the nature of the dialogue has on many occasions been acrimonious and hostile, require a standard of acceptable engagement if people want to genuinely be involved in progressing this agenda in a more positive way.



## Conclusions

The Scottish Autism Strategy supported and funded a wide of activities and developments at a local and national level, which were designed to bring about improvements in services and support for autistic people and their families/carers.

After ten years, valuable resources have been created, new and additional services have been delivered but real change, for many autistic people in how they engage with services and are supported to live productive lives, is not as evident. To have a greater impact, the services and support now need to have a wider reach, become embedded and be sustained.

Integration authorities play a crucial role in the degree of impact because most services are designed and delivered at a local level and until appropriate provision is commonplace, there will be a lack of accessible and relevant local autism services.

At this ten year pause point, there is an increased understanding and knowledge about what needs to be change and what works. To enable more autistic people to live a meaningful and fuller life, the future policy direction should focus on key areas and drive systemic change rather than piecemeal projects.

This can only be achieved in true partnership with autistic people and collaboration across services and sectors. The current nature of engagement and tension between different interest groups spills into the way in which they are able to work together and this will need to be recognised and addressed if future collaboration is to be effective.

# Appendix 1: List of organisations represented by interviewees

Autism Initiatives Scotland

Autism Network Scotland, University of Strathclyde

Autism Rights Group Highland (ARGH)

Autistic Mutual Aid Society Edinburgh (AMASE)

Inspiring Scotland

National Autism Implementation Team (NAIT)

National Autistic Society

One-Stop-Shop Aberdeen/Triple As

Pasda

Perth Autism Support

Scottish Autism

Scottish Parliament Cross Party Group on Autism

Scottish Women's Autism Network (SWAN)

Tailor Ed

## **Appendix 2: Visual minutes from the virtual workshops**

Appendix 2 is provided as a separate document and contains the visual minutes from the virtual workshops.



## Appendix 3: Additional comments/requests for action received by email not incorporated into the report

### Email received on 29 December

This my submission in relation to the review of the Scottish Autism Strategy.

I am contacting you as an individual. I am disappointed at the scope of the review. To have only 9 local authorities involved in the review evidences a subjective bias which limits the scope of an effective review of a national strategy, especially considering some of the local authorities not consulted actually have developed statutory services to provide support – why these services (like the one I work I work in) were not included is concerning. A national review that is not engaging with 23 local authorities is a concern? I have sent a FOIR to the Scottish Government to try and get more context ( [https://www.whatdotheyknow.com/request/autism\\_strategy\\_review\\_blake\\_ste#incoming-1687973](https://www.whatdotheyknow.com/request/autism_strategy_review_blake_ste#incoming-1687973) ). To date, I am still waiting on a reply.

Also, the questions put forward in the open survey do not offer the opportunity needed to capture the complexity of the reasons as to why the Scottish Autism Strategy has failed autistic people ... hence my approach via this email.

Also, for your review team/the SG, not to consult with the Cross Party Working Group for Autism within the Scottish Parliament again is concerning, hence the FOIR.

I have been very concerned from the narrative from the SG. They have launched the intended policy 'Learning/Intellectual Disability and Autism – Recovery and Transformation Plan', where they have openly said that the plan is to bridge the gap of the closing of the autism strategy and learning disability 'keys to life' policy together in 2023. This will then mean a joint policy of learning disability and autism, this is no legacy from an autism 10 year strategy.

I have tried to influence post autism strategy thinking. I have a petition live at the Scottish Parliament. You can view the petition at: <https://www.parliament.scot/GettingInvolved/Petitions/supportingautism> .The petition is 'PE01837: Provide clear direction and investment for autism support'. My critique of the Scottish Autism strategy is within the petition. I would ask you to read the comments. I would also ask you to reflect on the fact that there is over 1,000 signatures supporting the lack of influence the autism strategy has had.

Here is a link of the petition being discussed at Holyrood:

[https://www.scottishparliament.tv/meeting/public-petitions-committee-december-16-2020?clip\\_start=12:14:26](https://www.scottishparliament.tv/meeting/public-petitions-committee-december-16-2020?clip_start=12:14:26)

Here is a short video explaining the petition: <https://youtu.be/SQaTozSDTlc>

The video gives the wider context of why having autism associated with a learning disability is a dangerous policy move.

I would ask you to reflect that the petition was also lodged on the change.org platform, and it gathered over 1,000 separate signatures and comments about the lack of influence the autism strategy has had. I would ask you to reflect on this as part of your report. The petition can be found at: <https://www.change.org/p/social-care-autism-support-time-to-get-it-right>

I would be more than willing to discuss any of this with you should you wish.

Yours faithfully

### **Email received on 16 February**

Thanks for the 'visual minutes' arising from the discussions on autism services and Strategy on 27<sup>th</sup> January. This is a large topic to cover in the time we had, although it was focussed more on 'what works well and what does not work well' and 'what is required at local and national level to help make these improvements happen'. If we had more time I would have liked to make a few other observations:

- The Scottish Government's Strategy on Autism although well intentioned has clearly failed many autistic individuals and their families as frequently recorded in presentations made to the Scottish Parliament's Cross-Party Group (CPG) on Autism. The failure of any significant progress in supporting autistic individuals over the past 10 years of the Strategy is documented in the CPG's report of October 2020: "[The Accountability Gap](#)", which looks in details at how the four strands of the Strategy have impacted on the lives of those with autism. It is a damning report which exposes the lack of project management and accountability in improving services to those who desperately need them. To those families who support autistic individuals this will come as no surprise as they are exhausted by the endless cycle of being let down by local authorities and support services which either do not have the resources or who do not understand the nature of autism. In essence, the weakness of the Strategy is the very fact that it is a strategy, with vague aims and objectives and no long-term resourcing for issues, by their very nature, require long-term support.
- We have seen many commissioned reports which have had no impact on autism services, which should if nothing else, highlight the fact that another report on what autistic people require is not yet another report. In 2001 The Public Health Institute of Scotland (PHIS) published a report "Autistic Spectrum Disorders- Needs Assessment Report" which accurately described in detail the services that people with autism require ([https://www.scotphn.net/wp-content/uploads/2015/11/Autistic\\_Spectrum\\_Disorders.pdf](https://www.scotphn.net/wp-content/uploads/2015/11/Autistic_Spectrum_Disorders.pdf)). Twenty years later and we still seem to be talking about the lack of appropriate services. A copy of the PHIS report should be on the desk of all those policy makers and

those commissioning autism services as a reminder of what needs to be in place.

- I mentioned at our workshop the urgent need for more Community Psychiatric Nurses (CPNs) within the local mental health teams. The NHS Lothian's leaflet on Community Mental Health Services in Edinburgh (<https://edinburghcarerscouncil.co.uk/sites/default/files/booklets/Community-Mental-Health-Services-Booklet1.pdf>) emphasises the importance and services which can be offered by the CPNs. My Locality in Edinburgh does not have a CPN, despite the local GP desperately needing one.
- At the Workshop I asked the specific question "Will Blake Stevenson have access to the reports from the Scottish Government to the Cross Party on Autism as described in the Government's "Outcomes and Priorities 2018-20121". The answer they provided and which you passed on did not answer my question. The answer: "The Scottish Government regularly provides updates to the Cross-Party Group on Autism. Details of these are available in the minutes of meeting which are available at: <https://www.parliament.scot/msps/autism.aspx>. The CPG meetings are free for all to attend." referred to minutes of meetings, not reports. I have scanned all the minutes on the CPG website and there is nothing which answers the Government's own question "How Will We Know the Scottish Strategy for Autism has Made a Difference?" Or have I missed something?

There are many other outstanding issues to be addressed, many have already been described by the autistic community and their families so I do not need to repeat them here. Government and local authorities cannot pretend they have not been told, we are still waiting answers. I hope you find this helpful.

Kind regards,

**Email received on 3 February**

Dear X

This may be reflective of some of the failures of the SSA. Consultation only happens with people who are readily available to be consulted. The likes of me are ignored. This is precisely why Scottish Autism are able to claim that they are doing a good job. You don't hear from people like me who are being structurally failed by them.

APOs only exist in areas of existing good practice. This is not an accident, but as I learned the hard way they are unwilling to jeopardise their existing relationships with groups that allow them to access this good practice. In private they will admit that the situation elsewhere is "a shitshow", but are unlikely to say so in public.

With reference to the Accountability Gap report, I have read this document, and it is clearly a means by which the big charities can dodge accountability while foisting all accountability for the failures of the SSA off on to local authorities. Some of the responsibility for the disaster that the SSA has proved to be no doubt lies with local authorities, and I have much more to say about this, but they are certainly not alone.

I have around a thousand words of views that I wrote this morning which I can edit in order to align with your questionnaire.

I live in Fife, and might be willing to consider joining one of your focus groups, but fear being shouted down by the usual suspects, by which I mean the big charities and the more vocal parents. The phrase "autistic people and families" is something of a red flag, because families rarely have the same goals as adult autistic people, and at least one of the big charities, Scottish Autism, an organisation I despise just as much as they despise me, openly align themselves with the former and in opposition to people like me (see, for example, their proposals for an Autism Commissioner - in principle an excellent idea, but certainly not as they want to implement it).

With best regards

NB: This person attended the workshop in Fife. He did not submit the additional 1,000 words he mentioned in his second email, although he may have responded to the (anonymous) online survey.

### **Email received on 4 March**

Dear X,

Excuse me expressing myself quite bluntly.

Quote undernoted "This is an opportunity to feed into this evaluation and share your views of the existing strategy, local services and future improvements"

The statement above is a delusional and a fabricated perceptual lie, What existing strategy? What local services ? What improvements... these do not exist in Renfrewshire. See attached letters from the council.

As an autistic adult living in Renfrewshire I report that:

There is no local autism strategy, autism committee nor autism services (out-with a learning disability with co-morbid autism) in Renfrewshire

How can you review that which does not exist? Renfrewshire council did a page exercise years ago without any input from autistic people and they dropped the idea under the guise of no money. I have many letters from Peter McCulloch and Peter McLeod stating same. They defuncted the autism committee which would have delivered any change and not once invited any autistic people onto the committee or created any sub-committee for autistic people. Autistic people in Renfrewshire have been made voiceless in all manner of events, excluded. How can you have a local autism strategy without the foundation and priorities of autistic people involvement at the core. Some one made the decision in the council not to involve autistic people from the start and it continued that way. Who decided autistic people had no worth ?

So let's stop socially pretending there was ever was a working strategy or autism direct support for the autism community in Renfrewshire. (LD is not the flagship nor category for autism, that is what the council hides behind, which discounts 70% of

the autistic community and promotes a false narrative of autism as a learning disability.)

The autism strategy is a total sham, the central government and local authorities have been total disingenuous to the autism community. There should be an enquiry into the 10 years of wasted opportunity and a learning disability IS the same as autism false narrative in Renfrewshire, so unless you have the two magic conditions you do not get any autism support.

Sorry to sound so affective but the true autism community lives in a deliberate grey zone created policy.

How can you evaluate that which has not been operational nor existence in Renfrewshire ? An enquiry of failure would be more necessary and welcome than an academic social professional partnership feedback exercise. Can I request as there is no autism strategy framework operational in Renfrewshire that the event be cancelled until an enquiry is carried out. I feel the feedback event is more smoke and mirrors which the council can use as a tick box exercise event.

It seems a total insult to now ask autistic people at the end of the day for their input. I wish to engage but given my lived experience of disappointment of the local autism strategy plan, which is dead donkey from the start. I really what to just cry as the lack of an effective autism strategy in Renfrewshire has been traumatic and created more isolation of the autism community.

Can you also take my email as an individuals skeleton evidence in your pseudo review as the autism strategy has no operational context in Renfrewshire, and those who say it does are blatant liars !

In disappointment and sadness,

### **Email received on 21 March**

Dear X and any concerned parties,

Could I ask for your support to ask for an external inquiry into the failure of the local autism strategy in Renfrewshire.

As far as I am and others autistic persons are concerned there will be no lessons learnt unless there is an inquiry by say a QC into the failure of the strategy and the risk this has placed upon the life of me and my family and others in the autism community. There has been no betterment in the lives of autistic people in Renfrewshire via a national and local autism strategy which has ignored by nefarious minded do-nothing policy of the Renfrewshire council and the health partnership under the guise of no funding, no hope.

As a result of a failure of their social duty and responsibility, **the lack of an enacted** local autism framework for the autistic community in Renfrewshire has resulted in the following situations for me personally:

No statutory autism support given, (unless you have a learning disability, which 70% of the Autistic people do not have).

Not treated equally before or by the law

No right of legal representation

No right of appeal

My right to private and family removed because it was decreed I had autism as grounds for their removal.

Autism seen as a mental health disorder automatically by court and as such automatic ruling of incapacity given and all human rights removed.

Sheriff decrees because my son is autistic and am I autistic we have no right to family life. That is totally unconscionable.

Given an incapex (incapacity) ruling without legal or medical test by a discriminatory bias sheriff on a whim.

Absolute, Inherit and human rights removed on the sole premise of being autistic.

Local Authority allows third party others to sign documents and displace me without any legal court interlocutor to do so.

Forced into council social housing not fit for autism purpose nor human habitation resulting in a dance with death and months in hospital with sepsis.

**Conclusion:** Basically, living In Renfrewshire with Autism sets a precedence that you have no legal rights, right of representation and you are automatically made a ward of state without legal nor medical test and as a ward of state and therefore you have no right of appeal due to pretext of incapacity. This status allows others to rob your estate for personal enrichment as you are made into a non-person by evil construct just for being autistic.

You subsequently have your assets stripped and stolen by third parties with the unlawful assistance of the local authorities. You then have your right of family removed., and you are put into a slum council house and are left to rot and nearly die in a construct of Social detention. A system of being isolated and disenfranchised by third parties without any autistic support to counteract any of this evil situation.

The national and local autism strategy should have provided a protective shield to me as a vulnerable autistic person, but I was given to these wolves and sharks without anyone on my side. If anything the local council and health care partnership assisted in there evil.

I cannot forgive the Renfrewshire council and health partnership for that, as they are complicit by a policy of DO NOTHING !

Until an external inquiry is set up to review the total failure of the autism strategy and the put at risk vulnerable autistic people status in Renfrewshire and how we are put at risk systematically by Renfrewshire Council and that there will be continued high risk to autistic community unless there is an external inquiry to fact gather and close the gap.

Can I call for this external inquiry with immediate effect.

**Email 12 March**

Hi X,

As the Blake Stevenson team approach the deadline for an inclusive and comprehensive evaluation and consultation process for the 10 year-long Scottish Strategy for Autism, I would wish to reiterate one of my concerns that when I asked if a collective lead officers feedback event could be arranged on 7th January 2021, I was informed by X that after consulting with the Scottish Government this “could not be accommodated” (email reply dated 13th January 2021 refers)

This came as a particular surprise as a written ministerial reply (attached) clearly indicated that any local authority wishing to take part in the review process “should contact Blake Stevenson directly”...

I believe that the omission of a Lead Officer consultation is a significant diminishment in the veracity and inclusiveness of the review process and would be grateful if this matter to be noted when your final report is published in May 2021



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