

## Autism Strategy Review Group Minutes

**Thursday 6<sup>th</sup> December, 11.00am – 3.00pm**

**Tweed Horizons, Newtown St Boswells, Scottish Borders**

**Approved**

**Present:** Arron Ashton, Scottish Government; Gillian Barclay (Chair), Scottish Government; Kabie Brook, Autism Rights Group Highland (ARGH); Fiona Clarke, Parent representative; Lesley Evans (minutes), Autism Network Scotland; Sonya Hallett, Autistic Mutual Aid Society Edinburgh (AMASE); Richard Ibbotson, The Richmond Fellowship Scotland; Thom Kirkwood, Aprex Associates; Prof Jean MacLellan, Autism Network Scotland; Fiona Milne, Annette Pyle, Scottish Government; Catherine Steedman, Autism Initiatives; Charlene Tait, Scottish Autism; John Urquhart, COSLA

**Apologies:** Anne-Marie Gallagher, NHS Greater Glasgow and Clyde; Stephanie Rose, Police Scotland, Marion Rutherford, Queen Margaret University; Nick Ward, National Autistic Society (NAS)

**Support Roles:** Eileen Keogh, Autism Network Scotland (note taker); Christine Collingwood, Autism Improvement Officer, Autism Network Scotland

**The agenda and accompanying papers provided by Scottish Government and the Scottish Borders were circulated to the Autism Strategy Review Group ahead of the meeting.**

Links were also provided to <https://www.gov.scot/publications/scottish-strategy-autism/>  
<https://www.gov.scot/publications/scottish-strategy-autism-outcomes-priorities-2018-2021/>

### **Welcome and Introduction**

**Rob McCulloch-Graham (RMG), Chief Officer, Scottish Borders Health and Social Care Partnership** welcomed everyone to the meeting, before introducing **Gillian Barclay (GB), Strategic Lead for Dementia, Autism and Learning Disabilities, Scottish Government.**

**GB** thanked **RMG** and welcomed everyone to the meeting. Introductions were made by the Autism Strategy Review Group members and NHS Borders representatives.

In summarising “**The national picture**” **GB** stated that during the refresh of the national strategy, a criticism of the public engagement consultation process<sup>1</sup> was that the autistic voice was not always heard. In recognition of this, Scottish Government and the Autism Strategy Review group will hold Strategy meetings in locations across Scotland, to get a flavour of how local strategies are being implemented and the issues and challenges being faced locally. It will also give autistic individuals the opportunity to ask any questions that may not have been addressed in the Outcomes and Priorities 2018 – 2021 document<sup>2</sup>.

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<sup>1</sup> <https://www.gov.scot/publications/scottish-strategy-autism-engagement-analysis-9781788516150/>

<sup>2</sup> <https://www.gov.scot/publications/scottish-strategy-autism-outcomes-priorities-2018-2021/>

**GB** highlighted some of the points which were raised against each of the four outcomes, namely:

- **A Healthy Life** – Responses from the consultations indicated that needs were not being met; there was a lack of consistency across the country regarding access to diagnosis and what could the Scottish Government do to help improve pathways?
- **Choice and Control** – Transitions were challenging, especially related to employment and higher education opportunities. To improve lives, better understanding of the condition is required.
- **Independence** – How are individuals with autism viewed? This will be addressed by introducing greater awareness campaigns and local initiatives to remove stigma. Housing and access to transport will also be prioritised.
- **Active Citizenship** – Recognition of the change in welfare benefit system and assessment process very difficult.

**GB** advised that the purpose of this meeting was to hear from the Scottish Borders as the first region to be visited and then invite questions.

1. Q: *When was the meeting planned?*  
A: At least 5 – 6 weeks ago.
2. Q: *Where is the next meeting to be held?*  
A: Highland.
3. Q: *Has the group considered running local council led events rather than regional events?*  
A: If the meetings work at this level, they will continue, if not, the group will consider more localised meetings.
4. Q: *Re housing, as a stock transfer council, how can social housing landlords be registered?*  
A: Scottish Government appreciate the complications of housing and are currently working on a pilot in Ayrshire to provide training to housing officers.
5. *Regarding resource allocation, will there be recognition of additional resources required?*  
GB stated trying to bolster the capacity within partnerships, however, to resolve this is quite complicated. It is a priority and currently working with colleagues across mental health to address.
6. Q: *What local initiatives will be introduced to reduce stigma and will the Borders hear about them?*  
A: The initiatives have not been launched yet, but hoping to do so in the next 2 months. £1m has been set aside by Scottish Government to support awareness raising campaigns. The Scottish Government is currently consulting with Inspiring Scotland to ensure the bidding process will be open and transparent. The fund will

**be administered nationally with projects delivered locally. Further information will be distributed through national networks once available.**

**7. Q: When will there be an investigation into restraint in schools?**

**A: Children in Scotland, Scottish Autism and NAS recently produced a report, titled “Not Included, Not Engaged, Not Involved”<sup>3</sup>, the findings of which were debated in the Scottish Parliament with John Swinney on Tuesday 4<sup>th</sup> December, who said he will revisit the issue, focussing on exclusion.**

A brief discussion followed highlighting the human rights element as well as an ongoing need for improved teacher training. **GB** spoke of the successful SCERTS<sup>4</sup> training, which took place in September 2018 for which 500 complementary places were offered nationwide. 70% of attendees represented the education sector and it is hoped another SCERTS training offering a further 500 complimentary places will take place in 2019.

The topic of PDA (Pathological Demand Avoidance) was raised, however, as the specific details related to a personal case it was agreed that the group were unable to address the concerns at this forum.

One parent highlighted that although the diagnostic pathway had been a challenge for their children, a positive outcome was experienced for her daughter, which led to a discussion on The Right Click service and SWAN. The “Under Our Wing” project which aims to provide autistic women the opportunity to participate in a holistic, experiential learning programme underpinned by autistic led peer support, to build skills, confidence, and feelings of empowerment was also highlighted.

Due to travel disruptions causing speaker delays, it was agreed to cancel the two Autism Strategy Review Group talks and amend the agenda accordingly. It was also agreed that the agenda item, **Review Group Terms of Reference** would be held over until the group’s next meeting in January 2019.

The Chair then introduced **Haylis Smith (HS), Strategy and Commissioning Manager, NHS Borders** to present “**The local picture**”.

The Borders Autism Strategy was launched in 2015, developed in consultation with Autistic people, parents, carers and a range of professionals from NHS Borders, Scottish Borders Council and 3<sup>rd</sup> sector groups. An Autism Strategy Group was then formed to lead development of Strategy with an Autism Strategy Coordinator employed through the Integrated Care Fund from February 2017 for a period of 2 years to drive forward activity relating to the delivery plan.

There is no consistent way of recording data nationally, however, with a 1% prevalence rate, there is an expectation of around 1,200 autistic people in the Borders.

- 90 children and young people known to Education and/or CAMHS (2015)

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<sup>3</sup> <https://www.notengaged.com/download/SA-Out-Of-School-Report.pdf>

<sup>4</sup> <http://scerts.com/the-scerts-model/>

- 167 adults who had received an assessment or service from LD or CMHT, or had an inpatient episode (2015)
- 97 adults registered with Autism Initiatives (2017)

There may be some duplication due to the way the data is collected and there is currently no data available on individuals not in receipt of the services mentioned above.

The delivery plan was wide-ranging and ambitious covering all sectors and ages, with the 9 outcomes identified now aligned to the 4 national outcomes (see Appendix 1). **HS** discussed the 9 outcomes in turn and advised that the Autism Strategy Group does not have oversight of them all.

In November 2018, a survey relating to the 9 agreed outcomes was circulated to approximately 150 people, including parent carers and autistic individuals in the Borders as well as contacting individuals directly and via a range of organisations. 12 responses were received (6 parent carers of autistic child or young person; 1 parent carer of autistic adult; 5 people both autistic adult and parent carer).

Against each objective, the questions asked was “From your experience, to what extent is this true in the Scottish Borders?” From the limited responses it was noted that the Scottish Borders is failing to both meet the needs of the autism community, and to make people aware of the services that are available.

**There are challenges implementing the strategy due to:**

- No singular agency is responsible for providing services for autistic people, therefore, the responsibility for delivering successful services is widespread.
- Creating consistent access to services and social or employment opportunities is hindered by the rurality of the Borders.
- Delivering to a national strategy with no additional resourcing available.

**Lessons learnt include:**

- The scope of the strategy and delivery plan raised expectations beyond what was achievable.
- Need to be more realistic with SMART objectives.
- Need an identified lead at Chief Officer level in Adult and Children’s Services
- Need to rethink the role, membership and reporting structures of the Autism Strategy Group.
- Need more formal routes for consultation and inclusion in service planning and delivery for greater community involvement.

**HS** was receptive to having more autistic involvement in their services and keen to make it happen.

The Chair thanked **HS** for an open and honest presentation and invited questions.

**Anita Hurding**, Autism Strategy Coordinator, joined **HS** for the Q & A session.

- 1. Q: The Autism Strategy Co-ordinator was asked why a training framework was being developed when the NHS Education Scotland (NES) national training framework<sup>5</sup> was available. Why was it not meeting local needs?**

**A: Although the NES Framework is great, it is huge. This will be a stripped down version with local resource.**

A discussion then followed regarding the Borders Autism Strategy Group and its ongoing struggle to implement the strategy due to gaps in meeting attendance, inconsistent membership and the recent reduction in hours of the Autism Strategy Co-ordinator's post until March 2019, after which the post will not be replaced due to a lack of funding. **RMG**, Chief Officer, Scottish Borders Health and Social Care Partnership advised that £23m is allocated across the entire Scottish Borders Health and Social Care Partnership and that following a review of all works, the Integrated Joint Board (IJB) had decided to no longer continue to fund this post and to re-prioritise funds. The IJB will continue to look at ways of using existing resources to implement the strategy.

- 2. Q: Which organisations is the Autism Champions (outcome 3) training aimed at?**

**A: Initially Health and Social Care staff. Autism Initiatives will assess, train and roll out. This is deliberately starting small to maintain sustainability of the programme.**
- 3. Q: Can Children's Services be included in Autism Strategy Group and Autism Champion Training?**

**A: There is recognition that there is a number of gaps in the strategy group membership and further work is required around representation.**

The Chair introduced **Dr Anne-Marie McGhee (AMM)**, Child and Adolescent Psychiatrist, CAMHS, NHS Borders, **Peter Old (PO)**, Assistant Team Manager, Learning Disability, NHS Borders and **Dr Amanda Cotton (AC)**, Associate Medical Director / Consultant Psychiatrist, NHS Borders, to present "Diagnosis and post diagnostic support".

The speakers described the current Borders Diagnostic Pathway for Autism for Children and Young People as well as the Borders Diagnostic Pathway for Autism for Adults.

**Borders Diagnostic Pathway for Autism for Children and Young People** has two routes to the Borders Assessment Team, i.e. under 5 years old and 5 years and above.

Under 5 years old, a professional referral to the Early Years Co-ordination and Assessment Team is the first step, then once assessed, if there is concern re possible Autism Spectrum Disorder, a referral is made to the Borders Autism Team (BAT), who meet monthly.

For 5 years and above a professional referral is made directly to CAMHS then passed to BAT if there is concern re possible Autism Spectrum Disorder.

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<sup>5</sup> <http://www.knowledge.scot.nhs.uk/media/9595218/asd%20web%20final%20%282%29.pdf>

There is a minimum 3 component assessment in both cases:

1. Autism focussed history
2. Observations
3. Individual Assessment (ADOS)

Once complete, BAT reconvene and reach their conclusion.

If initial assessment is inconclusive then a 6 month - 1 year review follows to allow development. Once a conclusion is reached, this is fed back to the family. A post diagnosis appointment will be arranged within 2 – 3 months with the child having a tailored input. The biggest concern being the 6 – 8 months it takes to complete a diagnosis.

The team continue to work to reduce waiting list times.

**Borders Diagnostic Pathway for Autism for Adults** is two-fold, accessed either with a learning disability or with no learning disability. With a learning disability, the referral stems from learning disability team or GP, there is then a screening by the learning disability team and if there is concern re possible Autism Spectrum Disorder, a referral is made to the Borders Adult Autism Diagnosis Service (BAADS), who meet monthly. If no learning disability, the referral stems from a GP, there is then a screening by the community mental health team and if there is concern re possible Autism Spectrum Disorder, the pathway suggests referral is made to the Borders Adult Autism Diagnosis Service (BAADS). In practice the assessment is undertaken by professionals within the community teams and usually discussed at BAADS to ensure multidisciplinary and quality oversight.

Currently the process is working well with referrals being addressed in a timely manner.

There have been significant moves forward within adult diagnosis, although, retaining and/replacing the skills within the team is difficult which can result in a degree of inconsistency between the health teams skill mix. Post diagnostic support can also feel inadequate.

The Chair thanked the speakers and invited questions.

1. Q: ***What would you like to see regarding post diagnostic support?***

A: **At present it feels impersonal to only give the families a link to an external resource, it would be preferable to be able to have a person discuss individual needs.**

Autism Initiatives said they currently offer this service and can adapt it for the Scottish Borders

2. Q: ***The completion of a diagnosis taking 6 – 8 months was queried, with the questioner asking how they could get better support to mental health services?***

A: **As the specific details related to a personal case it was agreed that the group were unable to address the concerns at this forum.**

**3. Q: Will autism be a distinct category with a specialism in that area rather than under the umbrella of mental health?**

**A: Not a straightforward area as there is such a breadth to how autism presents. Those with a diagnosis of Autism may not require ongoing mental health care but the diagnosis process should sit within Mental Health services who have the relevant skills. Comorbidity also needs to be borne in mind.**

In the afternoon, the group heard from **Kate Wrigley, parent and representative from the Borders Additional Needs Group (BANG)**, a parent led charity who work with other organisations to provide social opportunities for young persons. From a recent survey, the respondents were particularly positive about occupational therapy services, Leader Valley School, Aberlour, Sleepy Heads Respite Services and the increase in awareness regarding public spaces.

Regarding challenges and what could be different the survey highlighted:

- Difficulties in getting a diagnosis; waitlists; private diagnoses not recognised locally; PDA
- post diagnostic support – don't know how to best support your child; receiving the right services
- education (seclusion, restraint, safe guarding) – lack of policies
- transport - unpredictability of arrangements
- parent/carer engagement – concerns that parents are not believed or recognised, difficulty connecting with local policy makers to engage in the strategy

Parents are realistic. They know there are systemic problems, however, all they want is to do their best with the resources available, not have the current disconnect between themselves and services.

The Chair thanked the speaker for her thought provoking presentation, then welcomed **Graeme Nisbet, autistic self-advocate**, who shared his story, his artwork and experiences, highlighting the difficulty in accessing sustainable services as well as a lack of peer led initiatives. The Chair thanked the speaker for his positive presentation and re-iterated the importance of the autistic voice being heard and at the centre of discussions. Regarding the lack of peer led support group members of the Autism Strategy Review Group offered their help.

The Chair summed up the day by re-iterating that this first meeting was an opportunity to hear and reflect on what we need to do to support services. The lack of notice to attend was recognised as was the lateness of the final agenda.

Members of the Autism Strategy Review Group thanked the speakers and the audience for their openness and honesty.

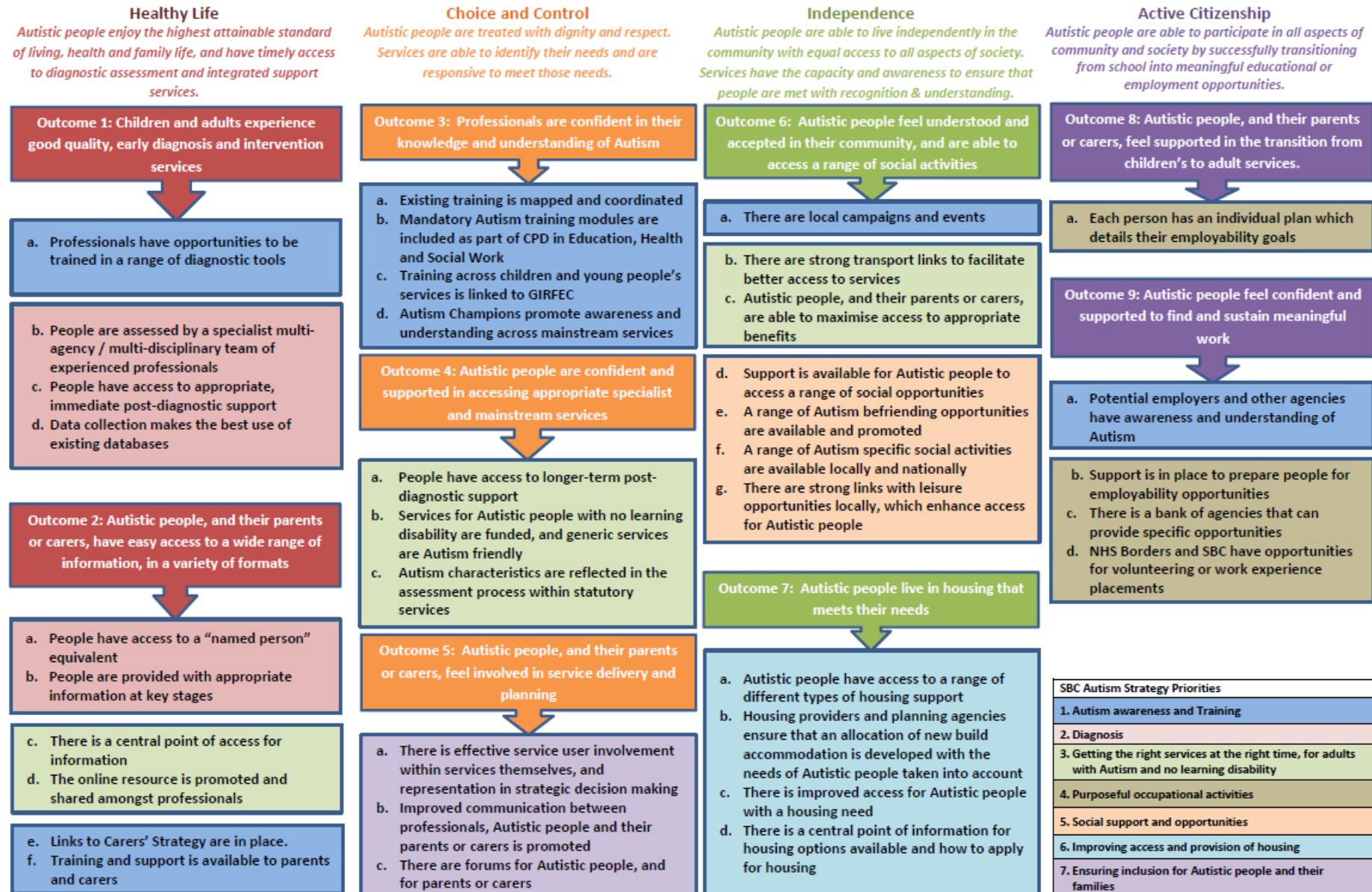
**Rob McCulloch-Graham, Chief Officer, Scottish Borders Health and Social Care Partnership** closed the meeting by thanking all attendees and speakers. He stated that there were positive benefits in linking up professionals and the local council. With over 110,000 residents in the Scottish Borders, **RMG** was keen to see what can be done as a community and to develop peer support groups. In summation, **RMG** acknowledged

this meeting was a springboard and added he is determined to do more, do better, listen to people and engage them further.

**The meeting closed at 14.45hrs**

**Appendix 1**

## Scottish Borders Autism Strategy Delivery Plan 2015 – 2025: Overview



Scottish Borders Autism Strategy: Priorities	Healthy Life	Choice & Control	Independence	Active Citizenship	National Health and Wellbeing Outcomes	Healthy Life	Choice & Control	Independence	Active Citizenship
1. Autism Awareness and Training (ICF Outcomes: Awareness of Autism / Improved access to Autism training)	X	X	X	X	1. People are able to look after and improve their own health and wellbeing and live in good health for longer	X		X	
2. Diagnosis (ICF Outcomes: Improved access to diagnostic assessment across the lifespan / Improving information and resources pre and post diagnosis)	X				2. People, including those with disabilities or long term conditions, or who are frail, are able to live as far as reasonably practicable, independently and at home or in a homely setting in their community			X	X
3. Getting the right services at the right time for adults with Autism and no learning disability (ICF Outcomes: Improved access to information on local services / Improved access to services)	X	X	X		3. People who use health and social care services have positive experiences of those services, and have their dignity respected	X	X	X	X
4. Purposeful occupational activities (ICF Outcomes: Improved access to employment support services, education, training and volunteering)				X	4. Health and social care services are centred on helping to maintain or improve the quality of life of people who use those services		X	X	X
5. Social support and Leisure opportunities (ICF Outcomes: Increased access to a range of social opportunities within the community)			X		5. Health and social care services contribute to reducing health inequalities		X		
6. Improving access and provision of housing (ICF Outcomes: Improved awareness of the needs of Autistic people, and as a consequence, improved housing provision)			X		6. People who provide unpaid care are supported to look after their own health and wellbeing, including to reduce any negative impact of their caring role on their own health and wellbeing	X			
7. Ensuring inclusion for Autistic people and their families (ICF Outcomes: Improved inclusion and involvement for Autistic people and their families in development and delivery of services)	X				7. People using health and social care services are safe from harm				
					8. People who work in health and social care services feel engaged with the work they do and are supported to continuously improve the information, support, care and treatment they provide	X	X		
					9. Resources are used effectively and efficiently in the provision of health and social care services	X	X		
Scottish Autism Strategy: Best Practice Indicators	Healthy Life	Choice & Control	Independence	Active Citizenship	SBC Local Objectives	Healthy Life	Choice & Control	Independence	Active Citizenship
1. A local strategy	X	X	X	X	1. We will make services more accessible and develop our communities	X	X	X	
2. Access to training and development	X	X	X	X	2. We will improve prevention and early intervention	X	X		X
3. Easy access to useful and practical information about Autism	X	X	X	X	3. We will reduce avoidable admissions to hospital				
4. An Autism training plan	X	X	X	X	4. We will provide care close to home			X	
5. A process for data collection which improves the reporting of how many Autistic people are receiving services and informs the planning of these services	X				5. We will deliver services within an integrated care model	X			
6. A multi-agency care pathway for assessment, diagnosis and intervention	X			X	6. We will seek to enable people to have more choice and control	X	X	X	X
7. A way to get feedback to inform service improvement and encourage engagement		X			7. We will further optimise efficiency and effectiveness	X	X		
8. A multi-agency coordinated focus on meeting the needs of Autistic people	X	X	X		8. We will seek to reduce health inequalities		X		
9. Clear transitions at each important life stage			X	X	9. We want to improve support for unpaid carers to keep them healthy and able to continue in their caring role.	X			
10. A self-evaluation framework to ensure best practice implementation and monitoring.	X								

