



# Living Well with Autism

A Joint Commissioning Strategy  
for Devon and Torbay

2015–2020



South Devon and Torbay  
Clinical Commissioning Group



Northern, Eastern and Western Devon  
Clinical Commissioning Group



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## Our Shared Vision

**To improve outcomes for people who are autistic, their families, and carers by providing the information and appropriate support required to be as independent as possible, and to create the conditions in which people with autism can lead fulfilling and rewarding lives with access to as many opportunities as possible.**

**We will achieve this through building a greater awareness of Autism, effective partnership working, and the best use of available resources.**

“Autism is a long term, lifelong condition, in a short term world.”

**Adult with autism**

## Introduction

The NHS and Local Authority bodies represented in this document, recognise their clear responsibility and legal duty regarding autistic people. This Commissioning Strategy sets out how we intend to meet these obligations and responds to the ‘National Autism Strategy - Fulfilling and Rewarding Lives’, ‘Think Autism’, and the accompanying statutory guidance.

Building upon previous work and services already in place, a set of priorities are established along with the key principles and organisational commitments which will shape their implementation. Further detail will be included in action plans that will reflect local need across Devon and Torbay.

The development of the national policy offers a major opportunity to raise the profile of Autism and to establish sustainable progress in how people are supported to lead valued lives as part of their communities.

These new duties and responsibilities are likely to increase demand and expectation at a time when resources are under significant pressure. Effective partnership working will be crucial to the delivery of timely and effective diagnostic assessments and care planning, which promotes independence, and personalised support for autistic people and their carers.

The Strategy is underpinned by evidence-based data and an initial needs assessment. People who are autistic tell us that often it is the small things that can make a significant difference to the way they are able to manage.

## Scope of this Strategy

The strategy relates to adults who are autistic but also makes reference to children and young people from the age of 14 who are included in transition planning and likely to require services on reaching adulthood. This strategy will also tie in with other strategies and approaches including 'Preparing for Adulthood', Learning Disability', 'Mental Health', 'Dementia', and 'Carers'.

<sup>1</sup> "Autism: recognition, referral, diagnosis and management of adults on the autism spectrum" June 2012

<http://www.nice.org.uk/guidance/cg142/resources/guidance-autism-recognition-referral-diagnosis-and-management-of-adults-on-the-autism-spectrum-pdf>

## Defining Autism

Autism is a lifelong neuro-developmental condition, the core features of which are persistent difficulties in social interaction and communication and the presence of stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests.

The way that autism is expressed in individual people differs at different stages of life, in response to interventions, and with the presence of coexisting conditions such as learning disabilities. People with autism also commonly experience difficulty with cognitive and behavioural flexibility, altered sensory sensitivity, sensory processing difficulties and emotional regulation difficulties. The features of autism may range from mild to severe and may fluctuate over time or in response to changes in circumstances.

A significant proportion of adults who are autistic across the whole autistic spectrum experience social and economic exclusion. Their condition is often overlooked by healthcare, education and social care professionals, which creates barriers to accessing the support and services they need to live independently. In addition, people with autism are more likely to have coexisting mental and physical disorders, and other developmental disorders. Some may have contact with the criminal justice system, as either victims of crime or offenders, and it is important that their needs are recognised.

'Autism' refers to 'autism spectrum disorders' encompassing Autism, Asperger's syndrome and atypical autism (or pervasive developmental disorder not otherwise specified). It is recognised, however, that different individuals and groups prefer a variety of terms for autism including autistic spectrum condition, autistic spectrum difference and neurodiversity (in recent Department of Health, National Audit Office and Public Accounts Committee documents, 'autism' is used to cover all of these terms<sup>1</sup>).

## Why Now? National Policy

The Government published the first strategy for adults who are autistic in 2010, accompanied by statutory guidance for local authorities and NHS bodies that set out their duties and how they should be supporting autistic people. The 2010 guidance requires that local councils and NHS bodies:

- Provide autism awareness training for all staff that come into contact with people with autism.
- Provide specialist training for key staff, such as GPs and community care assessors.
- Undertake community care assessments for adults with autism irrespective of their IQ and perceived ability.
- Appoint an Autism lead in their area.
- Develop a clear pathway to diagnosis and assessment for adults with autism.
- Commission services based on adequate population data and needs assessment.

The government reviewed the strategy after feedback from all stakeholders including autistic people and their carers. A new strategy, '**Think Autism**', was subsequently published in April 2014. 'Think Autism' includes commitments to significant developments in addition to those in the original strategy including:

- That local authorities will need to use new guidance on the use of national data agreed by National Autistic Society to inform their commissioning and delivery strategies.
- Autism will be a priority for the training and awareness of GPs over the next three years.
- Autism training will be rolled out to all Disability Employment Advisors at Jobcentres.

Autism is also included as part of the national 'Transforming Care' initiative underlining the expectation that correct levels of support should be provided locally in relation to mental health needs, and also support people with behaviour that challenges and their families.

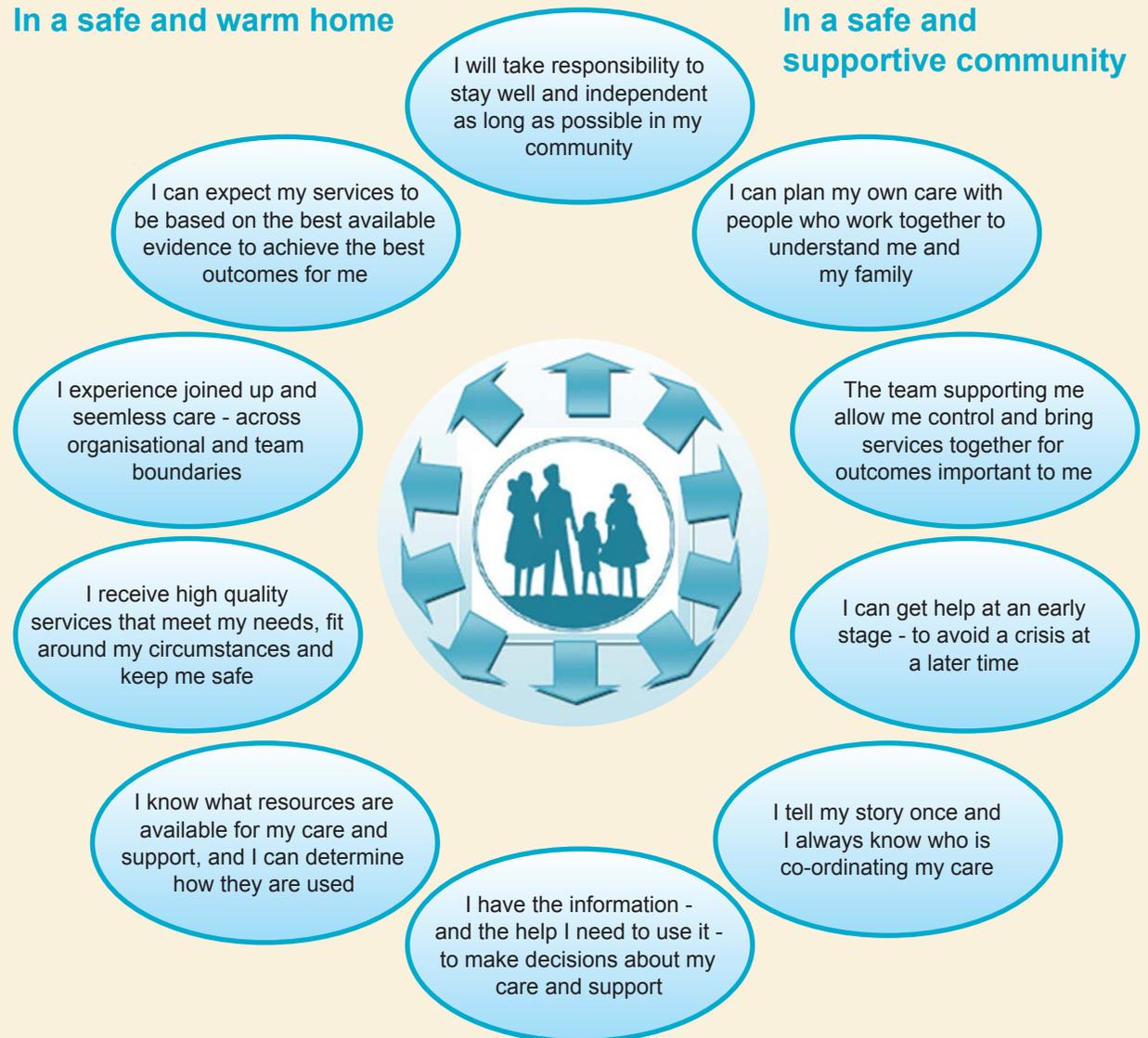
# Our Principles

- A person who is autistic has the same rights and responsibilities as any other citizen and should have the same opportunities and access to all mainstream or universal provision.
- Any autistic person that experiences problems or barriers to accessing such provision has a right to expect a service, or an organisation, to make 'reasonable adjustments' in order to meet their needs.
- In circumstances where mainstream provision is unsuitable, then any specialist autism-specific service should be of a type, quality, and sufficiency to meet local population needs.
- Every young person or adult has a right to live free from abuse in accordance with the principles of respect dignity, autonomy, privacy and equality.
- We recognise the importance of access to advocacy for people who are autistic and the increased demand for this service as people get older.
- People who are autistic and their carers should be listened to and have the opportunity to co-design and implement local plans.
- We will keep it personal through person-centred planning leading to personal budgets for people who are eligible for funded support.
- We will provide information that is relevant and useful.
- We will work with people who are autistic to help them find and stay in employment.

These principles are linked to the Integration Plan 'I Plan' for Health, Wellbeing and Care in Devon which are joint commissioning principles agreed by Devon County Council, NEW Devon and South Devon and Torbay Clinical Commissioning Groups.

## In a safe and warm home

## In a safe and supportive community



## With access to education and employment

# Why Now? National Context

In developing this strategy an Autism Prevalence report representing the most recent Public Health information was produced.

The report summarised that UK prevalence of autism spectrum conditions is approximately 1%, ranging from 89 to 157 per 10,000 in children and young people and from 98 to 110 per 10,000 in adults. The similar prevalence rates in children and young people and in adults indicates that the increase in prevalence seen over the last 10 years is due to increased awareness and diagnosis, rather than an increase in incidence.

The 157 per 10,000 rate is higher for children and young people as it incorporates the identification of unknown cases, and can be used as an upper limit for expected cases. For every three known cases, two unknown cases would be expected. This is supported by the National Autistic Society estimation that around 700,000 people may have autism in the UK, or more than 1 in 100 of the population.

“Diagnosis has confirmed all of the struggles I have been aware of for a long time but didn’t understand why I struggle as I do.”

**Adult with autism**

It is evident that there is likely to be a backlog of cases for adult services to continue to diagnose as a result of the increased awareness of autism that has occurred over the last 10 years, the changes in assessments as a result of the Care Act and the gap between prevalence rates and our current diagnostic rates.

Autism often co-exists with learning disabilities/difficulties, physical disabilities and conditions, and mental health problems. Around 50% of people with autism have a learning disability. National figures estimate that 70% of individuals with autism also meet diagnostic criteria for at least one other (often unrecognised) mental and behavioural disorder, and 40% meet diagnostic criteria for at least 2 disorders, mainly anxiety, attention deficit hyper activity disorder) and oppositional defiant disorder.

Autism appears to be more common among men than women. This could be because of genetic differences between the sexes, or that the criteria used to diagnose autism are based on the characteristics of male behaviour. Locally, an increase in the number of families known to services with more than one autistic member has been noted.

While the overall life expectancy of people with autism remains lower than for other individuals, their life expectancy is increasing along with the general population<sup>2</sup>. For people over 75, the demand for service should already be known - people who have reached this age without specialist services will generally continue without them.

<sup>2</sup> “Towards a Better Quality of Life – The Rights of Aging People with Autism”  
<http://www.autismeurope.org/files/files/ageing-report-en-sml.pdf>

## Local Context

Based on the estimated national prevalence for autism, there are currently just over 8,500 people in Devon and Torbay, including approx 380 young people aged 14–18.

As part of the Joint Strategic Needs Assessment, an autism topic summary page is available here: <http://www.devonhealthandwellbeing.org.uk/?p=830>

Since the introduction of the EQ-CL (Equalities and Classifications) framework, in November 2013, autism is identified by social care services from the ‘Reported Health Conditions’ captured at assessment or review. As the data is currently only capturing those people who have had an assessment or review since November 2013 current figures are under reported, however, Devon will continue to build a more robust profile over time as directed by this strategy.

DCC figures for people assessed by adult social care during 2014/15 and identified as having autism indicate that the total number of people meeting social care eligibility criteria with autism was 394. Of those, 365 (93%) also have a learning disability and 11 (3%) have a mental health problem.

Torbay figures indicate there were 15 clients aged 18+ receiving long term support in 2014/15 with the reported health condition of ‘Autism (excluding Asperger’s Syndrome / High Functioning Autism)’ or ‘Asperger’s Syndrome / High Functioning Autism’. Of these, 6 (40%) were receiving long term support due to Learning Disabilities and none were receiving support for Mental Health conditions<sup>3</sup>. See also ‘Autism in Torbay’ (JSNA survey<sup>4</sup>).

### Prevalence of Autism 2015–2030



### Predicted Prevalence of Autism in Devon (DCC and Torbay)

	2015		2020		2025		2030	
	Devon	Torbay	Devon	Torbay	Devon	Torbay	Devon	Torbay
0 to 13	1,122	194	1,185	202	1,197	204	1,187	201
14 to 17	334	58	329	56	367	60	376	63
18 to 24	625	98	584	90	577	86	637	94
25 to 34	785	134	819	144	805	144	767	136
35 to 44	800	133	790	126	857	136	899	144
45 to 54	1,063	186	985	168	880	145	874	140
55 to 64	993	172	1,087	190	1,147	199	1,075	185
65-74	995	177	1,031	181	1,004	177	1,114	197
75 and over	769	142	915	168	1,136	207	1,265	230
<b>Total 14 and over</b>	<b>7,486</b>	<b>1,294</b>	<b>7,725</b>	<b>1,325</b>	<b>7,970</b>	<b>1,358</b>	<b>8,194</b>	<b>1,390</b>

<sup>3</sup> These figures may be under-reported due to these particular conditions being reported from 2014.

<sup>4</sup> <http://www.southdevonandtorbay.info/media/1467/autismintorbay.pdf>

## Consultation

A consultation was carried out during 2014 with user groups, carers and professionals. This was commissioned by Devon County Council and the two Clinical Commissioning Groups and undertaken by the National Autistic Society (NAS) and local Healthwatch team.

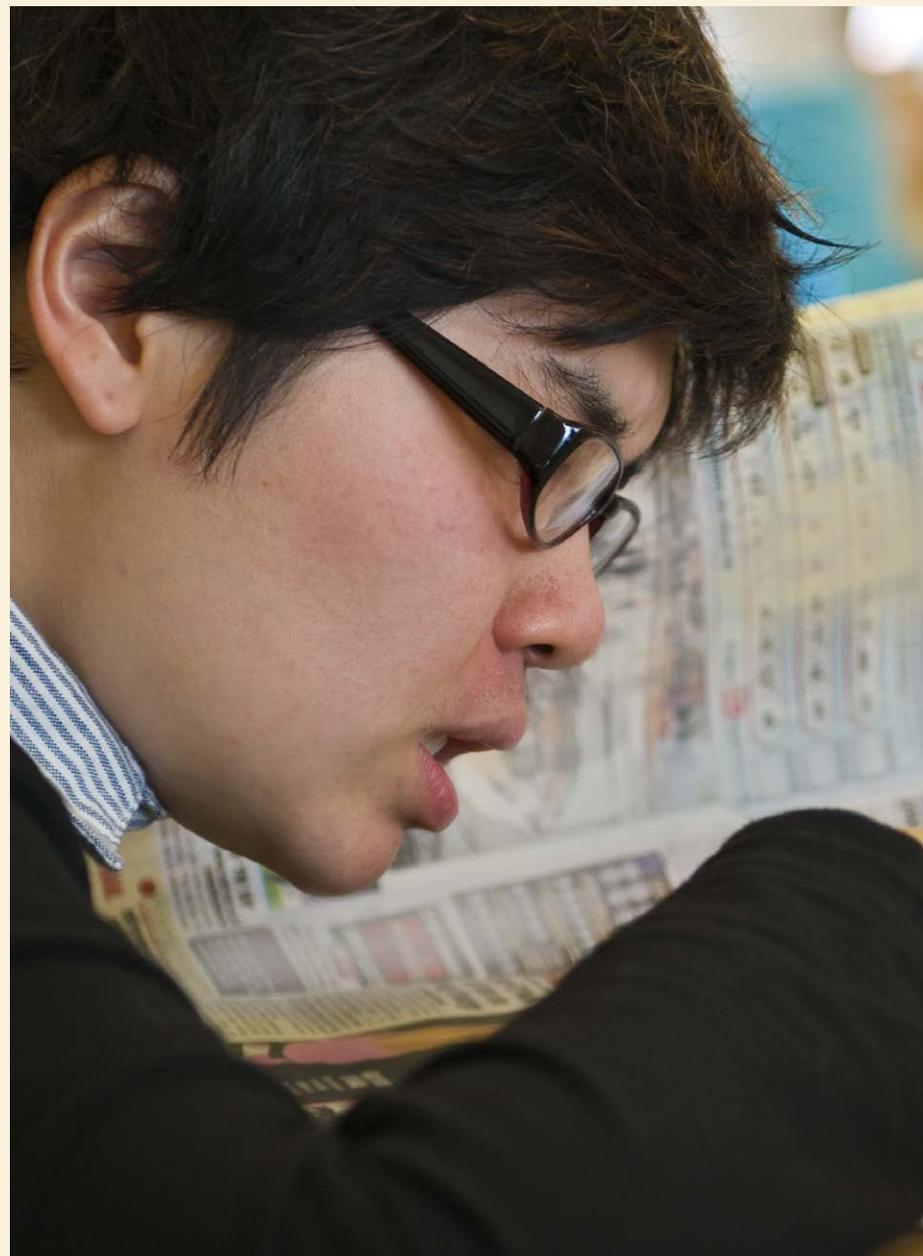
The recommendations within the report 'Listening locally: Developing autism provision in Devon' provides further opportunity to learn from families how best to improve services and the key recommendations will form part of the local Action Plan.

The themes and priorities identified through this engagement process have informed the direction of travel set out in this strategy. Ongoing inclusion of people who are autistic, their carers, and key professionals remains a key commitment in developing the Action Plans.

### **#AutismFact:**

Including families, autism touches the lives of over two million people every day

[www.bit.ly/hpbNPQ](http://www.bit.ly/hpbNPQ)



# Where are we now?

As we look at our strategic plans for the future it is important to recognise the progress that has been made so far and identify where we need to priorities our future budgets and resources:

## County-wide

An Autism Awareness Card Scheme

The Devon Autism and ADHD Service (DANA<sup>5</sup>) provide a diagnostic and advisory service.

<sup>5</sup> The Devon Autism and ADHD Service provides a diagnostic and advisory role for the assessment of high functioning autism/Asperger's disorder and Attention Deficit Hyperactivity Disorder (ADHD).

[http://www.devonpartnership.nhs.uk/Service-Display.60.0.html?&tx\\_svcdirectory\\_pi1%5Bmode%5D=summary&tx\\_svcdirectory\\_pi1%5Bvalue%5D=303&tx\\_svcdirectory\\_pi1%5Bback%5D=abclist%3Aabc%3Aall%3A71&cHash=b2416c78a81fa1f79488c9a871b61a57](http://www.devonpartnership.nhs.uk/Service-Display.60.0.html?&tx_svcdirectory_pi1%5Bmode%5D=summary&tx_svcdirectory_pi1%5Bvalue%5D=303&tx_svcdirectory_pi1%5Bback%5D=abclist%3Aabc%3Aall%3A71&cHash=b2416c78a81fa1f79488c9a871b61a57)

## Devon

- A Devon Autism Partnership Board has been set up.
- A Specialist Autism and Attention Deficit Hyperactivity Disorder service (DANA) has been established by Devon Partnership Trust (DPT). In addition to diagnostic assessment, the services supports adults diagnosed through DANA via post diagnostic course and a monthly support group. Similar support exists for family/friends of those diagnosed through the service. The service also provides training for DPT staff.
- DANA ran pilot courses on 'Living with Autism' and 'Relationships & Sexual Health' that support NICE initiatives.
- Staff in the DCC Community Enabling Teams have received training to support people with autism.
- Devon Partnership Trust (DPT) has a delegated role to support people who have a primary mental health need and autism.
- A care management function to support people who are autistic and require social care services is provided by DCC who are responding to the increased numbers of people who are autistic requiring social care assessments.
- Diagnostic Care Pathway for children established by Integrated Children Services.

## Torbay

- An Autism Partnership Board has been set up.
- Reasonable adjustments have been made to improve access and support for people with Autism in employment services and health care settings.
- Torbay Council is working with Devon and Cornwall Police and the voluntary sector to develop improvements for keeping safe. Materials have been developed to support people with autism to feel safer in their community.
- A 'Festival of Ideas' took place in Torbay which showed a range of daytime, evening and weekend opportunities to people with Learning disabilities and autism, this event enabled Torbay to develop provider services to meet the needs of people with autism.
- iPads and smart watches have been purchased to be loaned to people with autism. iPads will include apps that help people to have a greater understanding of issues such as hate crime, and the smart watches will be used to promote healthy lifestyles.

# Our three priorities

On the basis that 'much has been achieved but much more needs to be done', establishing priority areas for implementation is seen as providing a manageable starting point to help focus efforts and resources, and to this end we will focus our efforts on three priorities: Diagnosis, Information and Training, and Person Centred Support. These will be at the core of Locality Action Plan.

## 1. Diagnosis

**When the diagnostic assessment process works well, professionals, the person with autism and their family, partner or carer(s) communicate right from the start and the person with autism is involved in the decisions relating to their care. This lays the foundation for a long-term understanding between the person with autism, their family, partner or carer(s) and the professionals supporting their needs.**

Although autism is a lifelong neurodevelopmental condition, it is not always the case that it is clearly identified and diagnosed in childhood. National guidance on autism and the Care Act 2014 emphasise the need and value of clear and effective diagnosis in eliminating other conditions as an explanation of an individual, and establishing a care pathway, and this is seen as providing a good starting-point for people to access services. Whilst the need to avoid unhelpful labelling is acknowledged, it is helpful to identify which group of people is being referred to for any care pathway or commissioning strategy such as this. The 'Listening Locally' initiative recommended the development of 'improved clear communication about diagnostic pathway waiting times'.



## 2. Information and training

**‘Improving training around autism is at the heart of the autism strategy for all public services staff, but particularly for those working in health and social care’. Adult Autism statutory guidance Department of Health.**

Information and training needs are required at different levels:

At a general population level, a wide range of general awareness-raising would be of benefit, much in the same way that dementia awareness has been developed to include dementia friendly communities.

Organisations that have experienced particular problems in accommodating people who are autistic such as employment or the criminal justice agencies should be the focus of targeted input so that people’s specific needs can be understood and provided for.

Any provider organisation that is commissioned to provide services for people who are autistic is responsible for providing sufficient information and training to its staff to ensure that a person’s needs are understood, and that best practice is followed.

People who are autistic should have the opportunity of providing training and shaping its content.

## 3. Person-centred support

**Support and care should take into account peoples’ needs and preferences. People with autism should have the opportunity to make informed decisions about their care, in partnership with their healthcare professionals. NICE guidelines on autism 2012 <sup>6</sup>**

The wide range of abilities included in the spectrum indicates that individual need will vary greatly. Some people will manage their life with little or no support, others will require 24 hour care and support. Services will range from advocacy, help with life-skills through to behavioural management and personal care. Where specific services are commissioned or provided for a person with autism, the services should be person-centred and relevant to the individual needs and wishes of the person receiving them.

It is the responsibility of commissioning organisations to ensure that any autism-specific service is able to deliver the quality of service required. Commissioning organisations will need to further develop the market place particularly where there are gaps in provision.

Not all people with autism will need, nor be eligible for social care, but in cases where they are, they will need access to both mainstream and specialist providers.

<sup>6</sup> <https://www.nice.org.uk/guidance/cg142/resources/guidance-autism-recognition-referral-diagnosis-and-management-of-adults-on-the-autism-spectrum-pdf>

# Our Commitments

Devon and Torbay will both publish a supporting, detailed, action plan to describe how they will implement the strategy and meet their statutory requirements based upon the shared commitments of:

- Promoting health and well-being for people who are autistic through work with all health agencies to implement the strategy and improve training and communication with GPs and Health Professionals.
- Keeping vulnerable people safe by working with police on preventing, reducing and reporting hate-crime, providing effective support and full access to any appropriate safeguarding processes.
- Improving the Diagnostic Pathway so that people who are autistic are able to receive a timely diagnostic assessment with the aim of reducing waiting times so that they are as close as possible to NICE guidelines of an assessment starting within three months of referral.
- Improving access to post-diagnosis intervention and support.
- Developing a range of information and training opportunities so that a better understanding of autism is established, access is improved and people who are autistic are not disadvantaged. This should include identifying specific local priority organisations such as housing, employment or criminal justice agencies.
- Ensuring access to assessments and care planning for people who are autistic and their family carers in a way that is sensitive to specific needs.
- Further developing the market so that there is available local service provision of suitable quality and cost to meet local need.
- Supporting young people and their families who are entering adult services from children services to have a smooth transition with any specific needs arising from autism included as part of any planning.
- Improving Data; we will keep an updated record to evidence how many people with autism live in our community and how many receive support through information, advice and advocacy as well as funded support.

“There needs to be a consistent pathway that is known by GPs, healthcare providers etc.”

**Carer of adult with autism**

## Reviewing our progress

The Autism Partnership Boards were established in 2014 to bring together key organisations and representatives of people who are autistic and their carers.

Joint agency partnerships will take this Strategy forward and be responsible for ensuring that the key priorities and commitments, identified are implemented. There will be subgroups created, as required, to take forward the action plans.

The partnerships will establish a communication plan to ensure we inform key stakeholders and the general public on the progress and implementation of the Strategy.

The Autism Partnership Board will report to the Joint Commissioning Coordinating Group who will be asked to support the content of this strategy and its implementation.

In addition to reviewing the implementation of the strategy, we will also complete the yearly Public Health England self assessment which is published for public scrutiny.

This strategy has been written to be delivered over the next 5 years however in addition to the governance arrangements for ongoing monitoring, in line with the other joint strategies, an update will be completed in 2017.

“Networking among carers is a great way to share information.”

**Carer of adult with autism**

## Action Plans

The detail of how both Devon and Torbay will implement this strategy will appear in their respective Action Plans. These will set out what it is that will be specifically delivered in the two areas, and in addition to the commitments to focus on the three priorities they will reflect local needs from their respective populations.

Each plan will include clear timescales for the completion of each action and progress in Devon and Torbay will be overseen by the respective partnership boards.

The respective authorities in Devon and Torbay will be required to address the challenge of how delivering the action plans will be resourced in the context of high demand and competing priorities.

## Summary

The Autism Act 2009 remains the first and so far the only condition-specific legislation of its type in England. This demonstrates the importance Parliament has attached to ensuring that the needs of people with autism are met.

Over 100 adults with autism in Devon and carers shared their views, ideas and experiences during the consultation that has shaped this strategy. They have expressed gratitude and thanks for individual professionals and services that have been supportive, and at times they have been frustrated and demoralised by the lack of understanding and appropriate care. However there is a belief from many that things can improve, that the changes that need to happen (including improved understanding, better training for professionals, a better range of accessible support services), are possible.

The development of this autism strategy, and the accompanying action plans, will start to address many of the recommendations made in the consultation report with the statutory guidance that supports the strategy 'Fulfilling and Rewarding' and the updated 'Think Autism'.

We recognise that Local Authorities and the NHS need to work in collaboration with local partners to take forward the key priorities in Think Autism which is why this strategy is a joint document which will be steered by a Partnership Board.

## Getting involved

Autism Partnership Boards are responsible for ensuring that people who are autistic, and their carers', voices are heard. This will ensure that all service commissioning and provision is sensitive to them, and benefits from their input.

Each local plan to deliver this strategy will include opportunities for people with autism, carers, service providers and other interested parties to be involved.

### Contacts:

**Devon County Council**, Topsham Road, Exeter EX2 4QD

**Torbay Council**, Town Hall, Castle Circus, Torquay TQ1 3DR

### #AutismFact:

**People with autism  
may demonstrate  
above average levels of  
concentration, reliability  
and accuracy**

<http://bit.ly/Rr2JiJ>

# Supporting documentation

**Autism Act 2009** <http://www.legislation.gov.uk/ukpga/2009/15/contents>

“Fulfilling and rewarding lives” The strategy for adults with autism in England (2010) [http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_113369](http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369)

**Think Autism.** Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update (2014)

<https://www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy>

**Children and Families Act 2014** <http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted>

**Care Act 2014** <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>

‘Listening locally: Developing autism provision in Devon’ NAS report.

**Devon Health and Well being Joint Strategic Needs Assessment (JSNA)** <http://www.devonhealthandwellbeing.org.uk/?p=830>

**Public Health Devon Autism Prevalence Report April 2015**

**Public Health England Autism Self Assessment returns** <https://www.improvinghealthandlives.org.uk/projects/autsaf201415>

**NAS #AutismFact Campaign** <http://www.autism.org.uk/about-autism/myths-facts-and-statistics/myths-and-facts.aspx>

## Acknowledgements

We acknowledge with thanks photographs from the NHS photo website.

We acknowledge with thanks the generosity of people who are autistic, and their carers, from across Devon who worked with NAS and Health Watch to produce this strategy.

This guide is also available in Braille, large print and other languages on request.