

Oldham's Autism Strategy 2017 – 2020

Joined up commissioning

Diagnosis and post diagnosis support

Getting the right support at the right time

Better information and awareness



Oldham Clinical Commissioning Group



Oldham
Council

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Introduction

In Oldham we are committed to improving the lives of people with autism. We will do so by working with families, local and national autism groups and partner agencies to support people effectively.

We are committed to bringing our approach in Oldham in line with the Autism Act 2009, the first disability specific law to have been passed in England and Wales, and in conjunction with other relevant guidance such as NICE Guidance (National Institute for Health and Care Excellence) and Think Autism in 2014.

Oldham's Autism Strategy sets out a vision for all people with autism, whatever their age, to have the same opportunities as anyone else to live rewarding and fulfilling lives. This vision is shared by all public, voluntary and independent organisations that have worked in collaboration to develop the strategy.

Oldham continues to be committed a personalised approach ensuring support is formed around the person enabling them to take control and make real choices about how they lead their lives. This approach is seen to be a positive way for people on the autistic spectrum to receive the support they need empowering them to have more choice and control over how their needs are met.

Whilst the Autism Strategy does not have the benefit of additional financial resource, the strategy will enable partners to work together to support the people according to their individual needs. I look forward to seeing the difference the strategy will make to the residents of Oldham.

Councillor Susan Dearden, Chair of Oldham's Health and Wellbeing

Consultation

People with autism, their families and carers, and the professionals who work with them have been a central part of this strategy and its development. They will continue to be closely involved in order to achieve the aims and actions set out within this strategy.

To develop the strategy, a series of workshops were held with representative from a wide range of professionals, people with autism, parents, families, carers and local businesses. The workshops gathered information and ideas for key priorities for people with autism in Oldham. This information then led to the development of the areas for focus as well as the actions for improvement.

1. Understanding Autism

1.1 Understanding Autism

Autism is a lifelong, developmental disability that affects how a person communicates with and relates to other people, how they experience the world around them.

In line with the National Autism Strategy, this strategy uses the word 'autism' as an umbrella term to include all the conditions on the autistic spectrum. These include autism, autistic spectrum disorder, autistic spectrum condition, Kanner's syndrome, Asperger syndrome, high functioning autism, Rett syndrome, childhood disintegrative disorder, pervasive development disorder not otherwise specified (PDD-NOS), and neuro-diversity.

'Fulfilling and Rewarding Lives' (the strategy for adults with autism in England) defines autism as:

A lifelong condition that affects how a person communicates with, and relates to, other people. It also affects how a person makes sense of the world around them.

The extent to which people are affected varies from person to person. People with autism can have a wide variety of support needs and each individual with autism can have areas where they function well and other areas where they may need support (the term autistic spectrum is used to describe this). Some people with Autism are able to live independently, are able to interact well and be relatively unsupported while others may require specialist support.

Whilst people with autism vary greatly along this spectrum there are three main areas, known as the triad of impairments, which are common to all people with autism; they are:

- **social communication** – problems using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice
- **social interaction** – problems in recognising and understanding other people's feelings and managing their own
- **social imagination** – problems in understanding and predicting other people's intentions and behaviour and imagining situations outside their own routine.

Many people with autism prefer routine and structure, and may find change exceptionally difficult to deal with. It is also possible for them to experience some form of sensory sensitivity either hypersensitivity or hyposensitivity, for example to sounds, touch, taste, smells, light or colour.

Autism is a disability, and was recognised by the Equality Act 2010. Autism is not a mental health condition or a learning disability, although it is estimated that around

50% of those with autism also have a learning disability and 71% of those with autism may experience a mental health problem.

1.2 Why do we need an Autism strategy?

A key aim of the strategy is to increase awareness and understanding of autism across the whole borough, including across organisations, businesses, services, and the general public more broadly.

In developing this strategy it has been recognised that a lack of understanding of autism can lead to a variety of problems, from inappropriate responses, to poor services and provision for individuals, their families and carers. Developing an increasing the awareness of autism is therefore vital in building a better future for people with autism in Oldham, so that they are supported to be valued members of the community.

One of the ambitions running through this strategy is for Oldham to become recognised as an Autism Friendly Town. The action plan theme groups, referred to in Part 4 of the strategy will provide further information as to how we intend to gain this recognition.

1.3 Statutory responsibilities

[The National Autism Plan](#) for children was published in 2003.

This was followed by [The Autism Act](#) which was passed in 2009. The Autism Act placed a number of obligations on a range of public bodies to improve opportunities for people with autism.

The strategy for adults with autism '[Fulfilling and Rewarding Lives](#)' followed in 2010 and provided a clear direction in terms of how public services must transform to better address the needs of adults with autism.

More recently, '[Think Autism](#)', published in April 2014 shared detailed consultation and research into the views of people with autism and their families on how progress has been taken forward in implementing the 2009 Autism Act.

In March 2015 '[Statutory Guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#)' was also published.

The Government has also recently introduced a major transformation of the way services for children and young people with special educational needs and/or disabilities (SEND) are delivered. Some of the key changes are outlined below:

- Replacing statements of SEN with Education, Health and Care plans
- Personal budgets
- Services working together
- Birth to 25

- Local Offer
- Engaging parents, children and young people
- Resolving disputes

1.4 National Autism Strategy for adults

The National Strategy '[Fulfilling and Rewarding Lives](#)', the first ever strategy for adults with autism in England was published in March 2010 and sets out the long-term vision and ambition to improve the lives of adults with autism. The strategy gives clear direction in terms of how public services must transform to better address the needs of adults with autism.

Fulfilling and Rewarding Lives represents a shared approach towards a common goal, a society that not only accepts and understands autism, but also provides real opportunities for adults with autism to live fulfilling and rewarding lives.

The Vision:

All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents.

Department of Health (2010)

The National Strategy focuses on five outcomes of activity:

- **Outcome 1** – increase awareness and understanding of autism among frontline professionals
- **Outcome 2** – develop a clear, consistent pathway for diagnosis in every area which is followed by the offer of a personalised needs assessment
- **Outcome 3** – improve access to services and support which adults with autism need to live independently within the community
- **Outcome 4** – help adults with autism into work
- **Outcome 5** – enable local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities.

The guidance states that local authorities and the NHS **must**:

- appoint an autism lead who has the responsibility for the implementation of the National Autism Strategy in their area
- involve people with autism, their families and carers in the planning of services
- provide autism awareness training to all staff involved in the delivery of services in the public, private and voluntary sector
- provide specialist training for key staff such as GPs, care staff and community care assessors
- develop a plan on how to commission local services for adults with autism
- appoint a lead professional to develop diagnostic and assessment services for adults with autism in their area
- commission services for adults with autism based on adequate understanding of the local population
- use guidance from the National Institute for Health and Clinical Excellence (NICE) to help develop a pathway to diagnosis
- improve the transition process for young people with autism leaving school and should have transition procedures in place for those using mental health services.

2. Delivery of the Strategy in Oldham

2.1 Delivery of the Strategy in Oldham

To ensure a consistent approach across health and social care the strategy for meeting the needs of people with autism in Oldham also needs to be linked to other local approaches, strategies and initiatives.

Oldham Council's ambition is to develop a **Co-operative future for the borough**; one where citizens, partners and staff work together to improve the borough and create a confident and ambitious place to live. Put simply, **becoming a co-operative borough is about everybody doing their bit and everybody benefitting.**

The overall Vision for Social Care in Oldham is to ensure as many people as possible are enabled to stay healthy and actively involved in their communities for longer and delay or avoid the need for targeted services. This strategy is a key part of our vision in Oldham to improve the outcomes for people with autism.

The Vision and Values of Oldham's NHS Clinical Commissioning Group (OCCG) is to improve health and healthcare for the people of Oldham by commissioning the highest quality healthcare services provided near to the patient, in an integrated fashion and representing best value for money.

2.2 Theme groups

In order to deliver Oldham's Autism Strategy action plans have been developed that have stemmed from the Department of Health's Autism Self-Assessment Framework (known as the 'Autism SAF').

Local areas are required to submit an annual autism self-assessment. This is to enable areas to review their progress and support future planning with partners including people with autism and their families. Oldham carries out its autism self-assessment via the Autism Way Forward Partnership Board.

The theme groups for Oldham's Autism Strategy have been adapted from self-assessment priorities and are:

- Joined Up Commissioning
- Better Information and Awareness
- Getting the Right Support at the Right Time
- Diagnosis and Post Diagnosis Support

This strategy focuses on laying the foundation for the changes needed in local services and builds on some improvements which have been made in services and support for people with autism in Oldham.

The summary below describes what is already happening in Oldham:

- We have an established a Partnership Board for autism called ‘Autism Way Forward’. Autism Way Forward reports to Oldham’s Health and Wellbeing Board.
- Oldham Council has appointed an Autism Lead, who as Head of Service for Mental Health and Learning Disabilities has the responsibility for the implementation of the National Autism Strategy in Oldham
- Oldham Council has appointed a commissioning lead for mental health and learning disabilities who, working alongside colleagues in the CCG supports Oldham’s Autism Lead.
- Oldham CCG has a diagnostic pathway in being developed

2.3 The Vision – what do we want to achieve in Oldham?

The Oldham Vision is that all people with autism, whatever their age, have the same opportunities as anyone else to live rewarding and fulfilling lives. This Vision is shared by all public, voluntary and independent organisations that have been working collaboratively to improve service for people with autism, their families and carers.

We have four ambitions for children, young people and adults in Oldham; for people to:

1. **receive seamless support** with all agencies working together commissioning services
2. **have a clear diagnosis pathway**
3. **get the right support at the right time** during their lifetime
4. **have better information** and awareness of autism

This strategy will improve the planning and development of appropriate services for children, young people and adults with autism by working better together with all public services, people with autism, their families and carers, the community and local business to:

- ensure services are of a **good quality and commissioning is joined up** wherever possible to ensure a seamless journey by evaluating and ensuring outcomes are measured so they can be continually improved

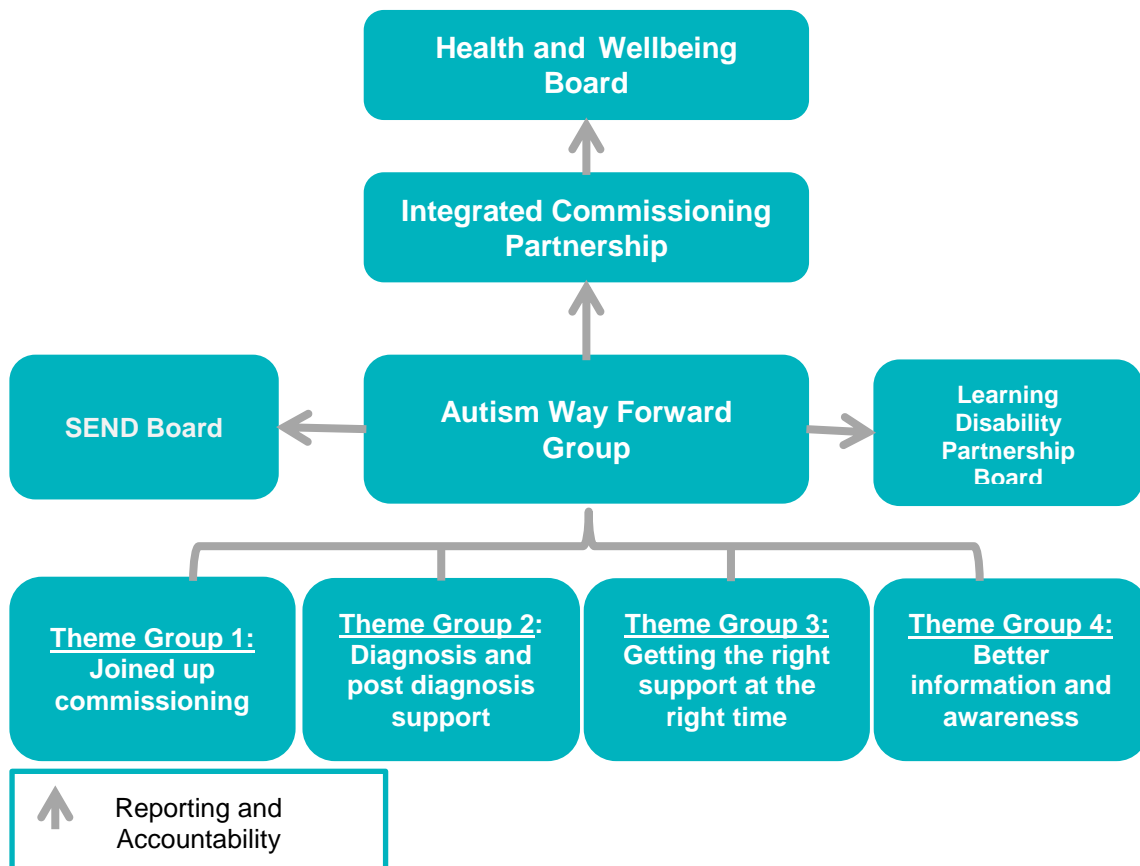
- develop a clear, consistent, timely **pathway for diagnosis** and post diagnosis support
- **improve access** for people with autism to the services and support they need – including people who have **not received a formal diagnosis**
- increase **awareness of autism** among frontline professionals and in the community – working together to make Oldham an ‘Autism Friendly Town’
- improve the availability of **information, signposting and support** for people with autism and their families and carers.

2.4 Governance

The Autism Way Forward Partnership Board will monitor and review the action plan and ensure the targets are met with regular updates being provided to the Health and Wellbeing Board. This will ensure that people can find out about how we are doing, and what has changed for people with autism in Oldham.

The success of the strategy and implementation of the action plans will be overseen and monitored by the Autism Way Forward Partnership Board. Autism Way Forward will report according to the governance structure set out below:

Governance and Delivery of the Autism Strategy



2.5 Co-production

The key tasks of Autism Way Forward will be to oversee the implementation of the strategy and to monitor progress of the action plan. Action Plan Theme Sub Groups are in place to:

- oversee the development and implementation of the action plans
- monitor, review and ensure targets set in the action plan are met
- ensure co-production with service users, families and carers in the development of the Autism Action Plans and implementation of the Autism Strategy.

3. The Need in Oldham

3.1 The Need in Oldham

Autism is more common than many people think. The National Autistic Society (NAS) estimates that there are **535,000 people in the UK with autism**. NAS states that if their families are included, **autism touches the lives of over two million people** every day.

NAS has reported a 61% increase in autism cases between 2005 and 2010. Recent studies have reported increased prevalence and the condition is currently considered to occur in at least 1 per cent of people.

3.2 What do we know?

Taken from the 2011 Census figures, Oldham has an estimated population of 228,700. Of this 134,900 are aged between 18 and 64 years and 35,900 people are aged 65 and over. The population is projected to grow by 7 per cent to 235,900 by 2020 (18 to 64 years), whilst the older population will increase by 13% to 38,900 nearly 17% of the whole population of Oldham.

Taken from the 2014 Learning Disability Joint Strategic Needs Assessment, the following table provides information on the predicted numbers of people with ASD aged 18 to 64 in Oldham by 2020:

Table 10: Numbers predicted to have ASD aged 18 – 64 in Oldham by 2020

	2012	2013	2014	2015	2016	2018	2020
18-24	205	205	205	205	203	199	195
25-34	292	298	302	304	309	315	316
35-44	301	296	288	286	282	281	285
45-54	299	301	305	307	307	307	296
55-64	243	239	241	243	248	251	262
TOTAL	1340	1339	1341	1345	1349	1353	1354

Projecting Adult Needs and services Information (PANSI) and the Projecting Older People Population Information (POPPI) (2012)

Population growth trends show in the table above suggests that there will be an increase in the numbers of people requiring more specialist support due to complex challenging behaviours, complex manual handling needs or carer breakdown resulting from dementia, stroke, autistic spectrum disorders and/or substance misuse and other dependencies. It is therefore important to have a strategy in place for Oldham to be able to manage the projected and potential demands on services.

4. Oldham's Autism Action Plan

4.1 Oldham's Autism Action Plan

The action plan sets out how Oldham Council and the CCG will implement the Autism Strategy, in particular, what we will do to respond to what people told us during the consultation.

In line with the national guidance and our commitment to improving services for people with autism in Oldham, our three year action plan will include the following actions:

- continuing to raise and improve awareness and provide information about autism in Oldham
- continuing to improve services for people with autism, their families and carers
- supporting adults with autism into work and training
- improving the way we plan and prioritise the services for people with autism
- improving access to services to facilitate independent living
- continuing identifying and responding to the needs of families and carers for people with autism
- working with professionals to ensure people with autism, their families and carers are listened to and are involved in the shaping of service
- close monitoring of progress and future development.

4.2 Themes of the Strategy

There have been four theme groups established that focus on the areas of the action plan.

These are:

1.

Theme 1: Joined up commissioning

- Health and social care working better together to deliver more effective, joined up care
- A better understanding of current and future needs
- Better health and wellbeing
- Meaningful engagement and consultation

2.

Theme 2: Diagnosis and post diagnosis support

- Improving access to diagnosis
- developing a clear, consistent pathway for diagnosis and post-diagnostic support
- Strengthening the role of education settings in early detection, intervention and support

3

Theme 3: Getting the right support at the right time

- Employment, volunteering, training and finances
- Relationships
- Housing
- Life transitions
- Support for carers

4

Theme 4: Better information and awareness

- Community acceptance and awareness of autism
- Being safe in the community
- Awareness and training in services and professionals
- information, signposting, advice, advocacy and training

4.3 Measures of Success

The success of this strategy will be measured against the outcomes set, and the progress made with implementing actions. Progress reports for each of themes will be submitted to the Autism Way Forward Partnership Board to provide details of the direction of travel aimed at improving services for children, young people and adults with autism.

Success means...

We will have joined up services.

We will improve access to diagnosis with a clear pathway in place.

We will have services in place for people to access the right support at the right time.

We will have better information on and people will have an improved awareness of autism.

4.4 Action Plans

Theme 1: Joined Up Commissioning

***Ambition:** people with autism will receive seamless support with all agencies working together commissioning services*

***Success will look like:** we will have joined up services*

The Joined Up Commissioning theme group will work on the following action points:

- Making sure that **both health and social care services work together better** and are working to identify areas of health and social care service delivery that can be integrated so that that people experience more joined up, effective care.
- Getting a better understanding of **the current and future needs** of people with autism and the demand on services
- Developing a better understanding of the **services that are currently delivered** and what the gaps are.
- Getting a better understanding of the **suitability of the care provider market** to respond to current and future needs of people with autism in Oldham
- Making sure that services **are sustainable and value for money**
- Supporting people with autism to have better **health and wellbeing**, including the prevention of ill health, having good mental health and getting the right support to get better when they become ill.
- Making sure that **meaningful engagement and consultation** is carried out by:
 - increasing the involvement of parents / carers and people with autism in service planning and delivery
 - increasing the involvement of people with autism in making decisions that they are affected by
 - ensuring consultation is meaningful and done in an accessible way

Theme 2: Diagnosis and Post Diagnosis Support

Ambition: people will have a clear diagnosis pathway

Success will look like: we will improve access to diagnosis with a clear pathway in place

The Diagnosis and Post Diagnosis theme group will work on the following action points:

- **Improving access** to autism diagnosis services by **developing a clear, consistent pathway** for diagnosis and post-diagnostic support for both adults and children, early years right through to adulthood.
- Strengthening the role of **education settings** in the early detection and intervention of autism, and making sure that schools are providing children and young people with autism with the right support
- Developing **awareness, support and training** for people who might have a role in the early detection and intervention of people who might have autism

Theme 3 – Getting the Right Support at the Right Time

***Ambition:** people with autism will get the right support at the right time throughout their lifetime*

***Success will look like:** we will have services in place for people to access the right support at the right time*

The Getting the Right Support at the Right Time theme group will work on the following action points:

- Developing better support for people with autism to get into **volunteering, training, further education or employment**
- Developing ways to support people with autism to become more **financially independent** and to understand the benefits they are entitled to.
- Supporting people with autism to develop **meaningful (and safe) relationships**
- Helping people with autism to maintain their own independence as much as possible by having **housing** that they want and that is suited to their needs
- Providing the right support for young people to help them make the **changes from childhood to adulthood** and to ensure a smoother transition for young people with autism into adult services
- Developing support for **transitional stages of life for adults** with autism, such as getting older
- Ensuring **parents and carers have better support**, and can have short breaks away from caring responsibilities when they need it

Theme 4 – Better Information and Awareness

Ambition: people will have better information and awareness of autism

Success will look like: we will have better information and people will have an improved awareness of autism

The Better Information and Awareness theme group will work on the following action points:

- Developing a range of **training packages** for carers, families, provider services and professionals, making sure service users and carers are involved in developing training packages
- Encouraging communities and the general public in Oldham to develop **a better awareness and acceptance of autism** – working together with partners to make Oldham an ‘Autism Friendly Town’
- Ensuring people with autism are **safe in the community** and free from the risk of discrimination, hate crime and abuse
- Increasing **awareness and understanding of autism across all services and professionals**, for both adult and children’s services and in wider support services
- Developing better **information, signposting, advice, advocacy and support** for people with autism and their families and carers

References

National Autism Plan for Children (March 2003)

The Autism Act (2009) placed a duty upon the Government to produce a strategy by April 2010. The strategy was published as:

- Fulfilling and Rewarding Lives: The Strategy for adults with autism in England (March 2010)

Towards 'Fulfilling and Rewarding Lives': The first year delivery plan for adults with autism in England (April 2010)

Implementing Fulfilling and Rewarding Lives: Statutory Guidance for local authorities and NHS organisations to support implementation of the autism strategy (December 2010)

Transforming Care: A National Response to Winterbourne View Hospital (December 2012)

SEN (Special Educational Needs) Green Paper

Children & Families Act (2014)

The Care Act (2014)

Transforming Care – the next steps (Jan 2015)