

**Thurrock Council  
Adult Autism Strategy  
2014-2018**

**Updated Version – March 2015**

## Foreword

**In April 2014, H M Government published their updated Autism Strategy called Think Autism. This revised strategy (Think Autism) contains 15 priorities that need to be met locally. These 15 priorities fall into 3 broad areas for people with autism;**

- An equal part of my local community (priorities 1 to 6)
- The right support at the right time during my lifetime (7 to 13)
- Developing my skills and independence and working to the best of my ability (14 and 15)

Web link to the revised strategy can be found at

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/299866/Autism\\_Strategy.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/299866/Autism_Strategy.pdf)

**We have refreshed Thurrock's autism strategy to ensure it reflects the priorities contained in Think Autism.**

**A new action plan at Part 8 which details any actions still outstanding (with a new deadline) or new actions which are a result of the changes in Think Autism or where Thurrock's scored either a red or amber in our Autism Self Assessment [the web link to the self assessment can be found at**

<http://www.improvinghealthandlives.org.uk/projects/autsaf2013/pdfs/thurrock.pdf> ].

**This action plan also captures additional actions that were seen as a priority locally during the public consultation**

<b>Contents</b>	<b>Page number</b>
<b>Where we are now</b>	3
Executive Summary	3
1. Introduction/Strategic Overview	7
2. Background	8
3. Autism in Thurrock	11
<b>Where do we want to be?</b>	
4. Thurrock aspirations	21
5. Thurrock goals	25
<b>How we are going to get there</b>	
6. Core strategy	26
<b>How will the strategy be implemented?</b>	
7. Resources	26
8. Action plans	27
<b>How will we know when we are there?</b>	
9. Monitoring	34
10. Review of strategy	34

## **Where are we now**

### **Executive Summary**

#### **Context**

Autism is a lifelong developmental disability, sometimes referred to as Autistic Spectrum Disorder (ASD) or Autistic Spectrum Condition (ASC). We have adopted the term Autistic Spectrum Condition. A spectrum condition, by definition, refers to people with a very wide range of needs. A significant proportion of people with autism will also have a learning disability. At the other end of the spectrum there are people with 'high-functioning' autism, which includes Asperger Syndrome.

Recent years have brought new statutory duties to local authorities and NHS bodies through;

- The Autism Act (2009)
- Fulfilling and rewarding lives - the national strategy for autism (2010)
- Statutory guidance for implementing the national strategy (DOH Best Practice Guidance, Gateway 15204, 2010)

This Strategy covers the Thurrock Council area and has been written in response to the above legislation and guidance. Initial consultation with people with an ASC and their family carers took place at a workshop on 24<sup>th</sup> July 2012 at The Beehive in Grays.

National and regional guidelines for the implementation of the Autism Act have formed the framework for the Strategy. It has been developed at a time of financial constraint, when it will be necessary to achieve outcomes by optimising the use of existing resources.

Thurrock Council outlines its own priorities which are as relevant for people with autism as the rest of the community.

- **Create** a great place for learning and opportunity
- **Encourage** and promote job creation and economic prosperity
- **Build** pride, responsibility and respect
- **Improve** health and well-being
- **Promote** and protect our clean and green environment

### **The need in Thurrock**

The need for support for people with ASC conditions varies considerably. A significant number of people with ASC will also have a learning disability, and some will also have other disabilities (learning, physical and/or sensory disabilities). Some people will need 24 hour support. At the opposite end of the ASC spectrum, people with “high functioning” Autism/Asperger Syndrome may need just a small amount of support or access to information, advice and guidance to enable them to live independently within their communities.

The exact number of people with ASC in Thurrock is not known, but estimates set the national prevalence at 1% (this is the incidence rate used in the national autism strategy). This gives an expected number of adults with ASC in Thurrock as 992. It is recognised that there are likely to be a number of adults with ASC who have not received a diagnosis. As young people with ASC reach the point of transition from Children’s Services to Adult Services they are very likely to have an existing diagnosis, so the number of undiagnosed people in the population will decline in future years.

It needs to be noted that the ASC population in Thurrock is expected to rise significantly over the coming years. This is due not only to the population increase but the provision of a specialist school with an excellent reputation for work with children with autism. Some families with children with autism are moving into the area in order to gain a place at the school. This will have a direct impact on adult services when these children reach transition and adulthood.

### **Existing Services in Thurrock**

Statutory services are currently delivered by the NHS and Local Authority, which provide support through either the Community Mental Health Teams, Community Learning Disability Team (Health) or Social Work Intervention and Transition and Locality Teams. A specialist Asperger’s diagnostic service is also available through South Essex Mental Health Foundation Partnership Trust (SEPT).

The voluntary sector offers valuable but limited services and support for people with ASC and their family carers, some of these are provided across the Essex County Council border.

### **What the Thurrock Autism Strategy hopes to achieve.**

The National Strategy focuses on five core areas of activity:

- Increasing awareness and understanding of autism among frontline professionals:
- Developing a clear, consistent pathway for diagnosis in every area, which is followed by the offer of a personalised needs assessment;
- Improving access to the services and support which adults with autism need to live independently within the community;
- Helping adults with autism into work, and
- Enabling local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities.

In 2014 this was expanded to fifteen priorities in the revised national strategy called Think Autism. These fifteen priorities fit into three areas of focus;

- An equal part of my local community (priorities 1 to 6)
- The right support at the right time during my lifetime (7 to 13)
- Developing my skills and independence and working to the best of my ability (14 and 15)

The Thurrock ASC Strategy has been prepared with the aim of addressing these objectives.

### **Thurrock Strategic Priorities**

The Goals for this strategy and the actions needed to achieve them are set out in the full Action plan

From consultation with local residents in July 2012, six priority outcomes were identified as follows: These are in line with the national strategy.

- 1:** People have accessed appropriate health services.
- 2:** People are in paid work or undertaking work related opportunities.
- 3:** People are living in a range of accommodation and included in a range of activities in the community.
- 4:** People have experienced choice and control in the planning and delivery of their individualised social care services.
- 5:** People have had appropriately planned and supported transitions.
- 6:** People have had supportive education and training opportunities.

There are a number of cross cutting outcomes which feature throughout as follows:

- Both the community and professionals are aware of Autism and some have received specific training.
- There are a range of networks for support throughout Thurrock.
- Universal services have access to specialist support.
- Specialist support is available to people with Autism.

These Thurrock priorities are in line with the National Strategy and are expressed clearly in HM Governments updated 2014 Think Autism strategy. These will be delivered through a three year action plan. During the life of the strategy we will continue to consult and invite feedback to ensure annual action plans reflect any changes to local or national priorities.

## 1. Introduction

### Why do we need a Thurrock Autism Strategy?

Adults with ASC and their families face many barriers in their everyday lives in accessing the support and services they require including:

- Their condition being misunderstood by professionals and society
- Difficulty with the support and services they need to live independently in the community
- Difficulties with gaining long term meaningful employment.

The Autism Act 2009 required the government to develop a strategy for meeting the needs of adults in England with autistic spectrum conditions by improving the provision of relevant services to such adults by local authorities, NHS bodies and NHS foundation trusts.

That requirement was met by *'Fulfilling and Rewarding Lives: The Strategy for Adults with Autism in England 2010'*.

Statutory guidance for implementing the national strategy was also issued in 2010.

Thurrock Council has worked in partnership with Thurrock Coalition, our user led organisation to co-produce a local response to the national strategy and statutory guidance. Please see Appendix 3 for full details

This document:

- Identifies gaps in provision of services for people with autism and actions to address those gaps.
- Sets out how the commissioners in Thurrock will work in partnership to improve services for people with autism.
- Sets out relationships and responsibilities of statutory organisations and partners involved in service provision for adults with autism to make the best and most effective use of resources.

In addition an event was held in September 2014 with Thurrock Coalition to explore key priorities – linked to Think Autism, for the Autism Action Group, once it is established. Please see Appendix 4 for full details



## **Thurrock Vision**

Thurrock's Community Strategy lays out the vision and priorities for Thurrock. The strategy is informed by what local people tell us are priorities for Thurrock.

The vision for Thurrock is:

*'Thurrock, A place of opportunity, enterprise and excellence where individuals, communities and businesses flourish',*

There are five strategic priorities to achieve this vision.

- Create a great place for learning and opportunity
- Encourage and promote job creation and economic prosperity
- Build pride, responsibility and respect to create safer communities
- Improve health and well being
- Protect and promote our clean and green environment

Thurrock Council's vision and priorities reflect the philosophy of the National Autism Act.

## **2. Background**

### **National and Local Policy Context**

A number of significant national policies and reports have emerged that are relevant to provision of services to people with an Autistic Spectrum Condition, culminating in the first disability-specific act of Parliament, The Autism Act 2009.

In response to The Autism Act 2009, the Department of Health published *Fulfilling and Rewarding Lives* in March 2010, a National Strategy for Adults with Autism. This guidance sets out the following vision:

*'...for all adults with autism to be able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis, and accept support if they need it, and they can depend upon mainstream public services to treat them fairly as individuals, helping them to make the most of their talents'*

### **National Prevalence**

Given that there is no prevalence rate for ASD in adults, the figure for the whole population is a very rough guide, but we estimate that there could be over 500,000 people who have an ASD. (*National Autistic Society*)

*'It is estimated that autism affects 1 in 100 adults and in a survey conducted by the National Autistic Society, 63% of adults with autism do not have enough support to meet their needs'* (Rosenblatt, 2008).

There is evidence that services provided by local authorities and health services are not always accessible. Adults with an Autistic Spectrum Condition can fall into the gap between learning disability and mental health teams, and this can be more problematic when local authorities and health services do not work closely together.

This is supported by a report by the National Audit Commission report identifying the difficulties in knowing if people have a recognised diagnosis

***'We are not confident that all people who may have ASD are recognised and recorded as having ASD.'***

*Local Authority Survey Respondent (Source: NAO)*

### **What is Autism Spectrum Condition (ASC)**

Autism Spectrum Condition (Autism) is the collective term for Autism, Asperger Syndrome, Atypical Autism and Pervasive Developmental Disorder – Not otherwise specified. Current thinking suggests that Autism is a lifelong developmental condition that varies in severity in its impact on individuals. The National Autistic Society defines Autism as: *a complex spectrum condition.*

*People on the autistic spectrum experience three main areas of difficulty:*

They are difficulties with:

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

As unique individuals, no two people with autism are the same. However, people with autism may show common traits such as strong preference for routine and rules, and some experience sensory sensitivity; for example in disliking loud noises. Around half of people living with autism also have a learning difficulty, and these people tend to receive a diagnosis of autism. Those with no learning disability have been referred to as having Asperger Syndrome, but impending changes in the definition of autism mean Asperger as a term is being used less.

Asperger syndrome is to be dropped from the psychiatrists' Diagnostic and Statistical Manual (DSM) of Mental Disorders, the American publication that is one of the most influential references for the profession around the world. The term Asperger disorder will not appear in the DSM-5, the latest revision of the manual, and instead its symptoms will come under the newly added Autism spectrum disorder, which is already used widely. That umbrella diagnosis will include children with severe autism, who often do not talk or interact, as well as those with milder forms.

People on the high functioning end of the autistic spectrum can experience anxiety and depression, especially if expectations cannot be achieved due to a variety of reasons.

It can be difficult for professionals to recognise that a person has autism when there is no learning disability present, so the condition frequently goes undetected. Awareness of autism is poor, even amongst experienced health and social care professionals and mainstream services often struggle to provide appropriate support.

Whilst it is possible for people with autism to live fulfilling and rewarding lives, with family, friends and meaningful employment, many on the spectrum experience significant challenges, including:

- Economic exclusion and unemployment

- Inconsistency in the availability of services with a common experience of falling between services as autism does not fit the traditional inclusion criteria for mental health or learning disability services.
- Increased risk of homelessness
- Increased vulnerability to all forms of exploitation

### **3. Autism in Thurrock**

Within Thurrock there is currently very little in the way of specialist community based or residential/supported housing services available for people on the ASC. This can result in people not accessing appropriate support, coming to the attention of mental health services or social care services at a later date and requiring in-depth support or going outside of the borough for specialist provision. It can be the case that people are pushed either towards mental health or learning disability services when neither of these are appropriate. This causes distress and problems to those families affected.

#### **What is the level of need in Thurrock?**

There are no local sources of information that record incidence and prevalence of autism across Thurrock. For this reason, estimates based on those used in the National Autism Strategy have been used. These estimates indicate that prevalence is higher among men (1.8%) than women (0.2%), and rates change slightly between different age groups.

It is recognised within the National Strategy that current best estimates are based on a small study, which had a secondary aim of developing a robust methodology for undertaking such research.

A quote from the author reinforces the need to treat these rates with caution:

*“This small base means that great caution is required in interpreting the population distribution of ASD (particularly among women).”* Brugha et al, 2007

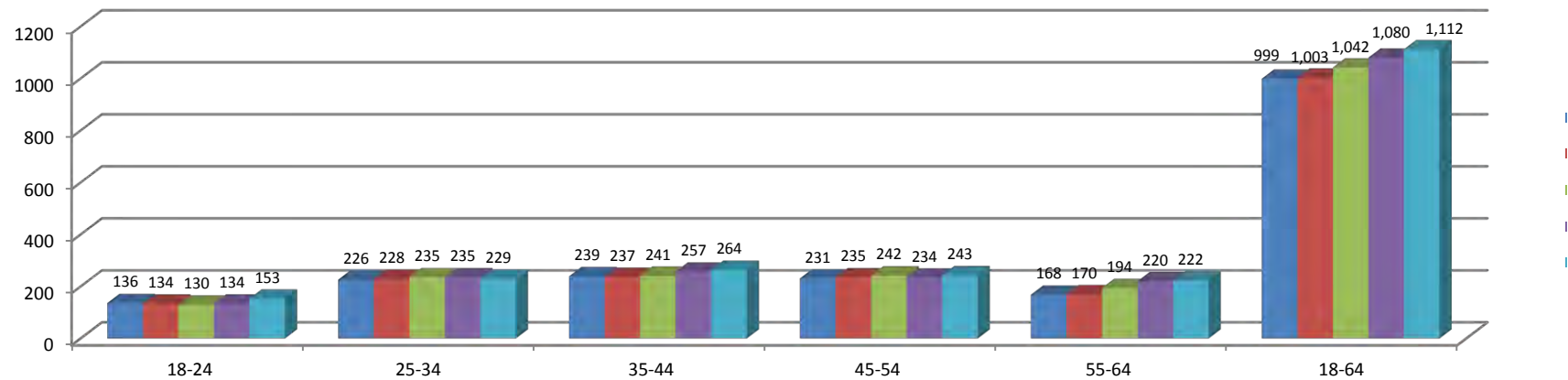
However, this study has been cited widely and in the absence of more accurate data, we have chosen these rates to estimate population of people with autism in Thurrock.

The following charts show the population by age and gender, and a key finding is the disproportionate number of males with autism. Again, it is worth viewing these findings with caution as these figures are based on the national study described above.

If we are to take the national prevalence rate in Thurrock, this equates to a predicted population of just under 1000 adults.

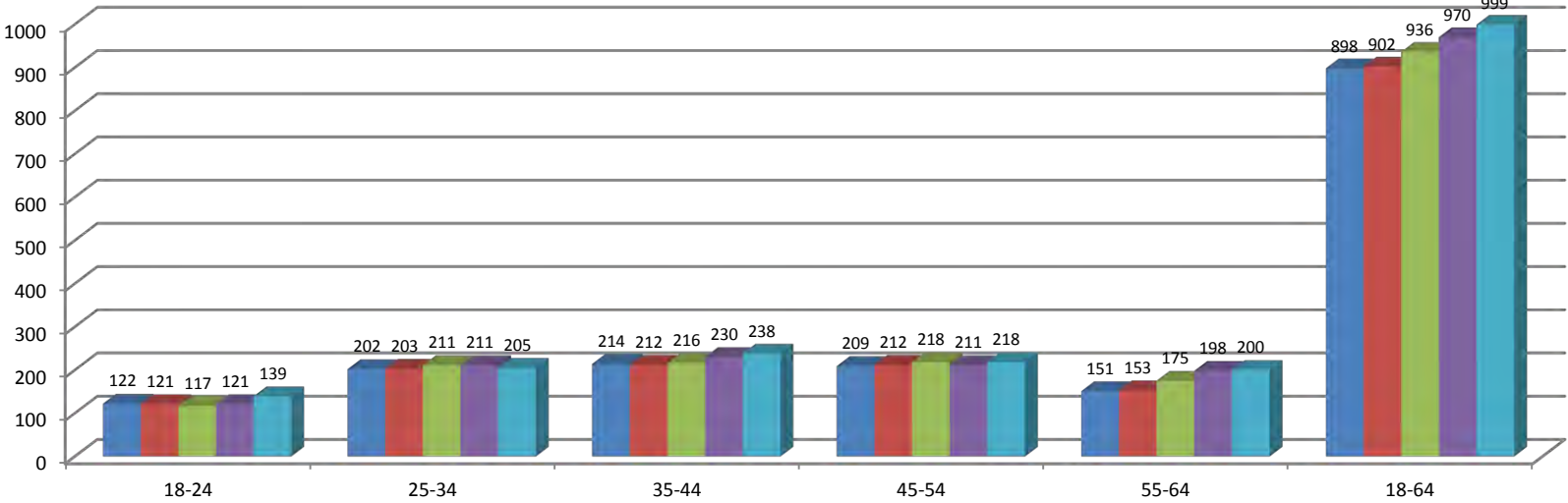
Using the data available from Projecting Adult Needs and Service Information System (PANSI) total population aged 18-64 predicted to have autistic spectrum disorders is 999 and this is set to rise.

### Total number of adults in Thurrock predicted to have Autism Spectrum Conditions

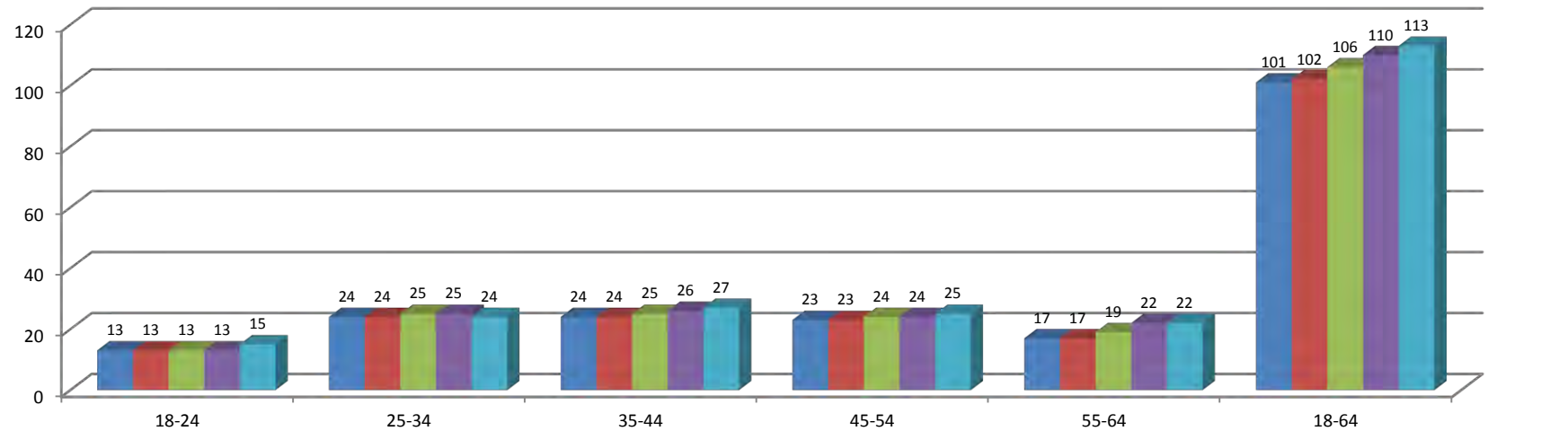


**Conclusion 1: Available data indicates that total number of adults with autism in Thurrock area is 999 in 2014, with a projected increase to 1,112 by 2030.**

**Total number by gender – Males**



## Total number by gender – Females



Various studies, together with anecdotal evidence, have come up with male/female ratios ranging from 2:1 to 16:1. Whatever the true ratio, clinical referrals to a specialist diagnostic centre such as The National Autistic Society's Lorna Wing Centre have seen a steady increase in the number of girls and women referred. Because of the male gender bias, girls are less likely to be identified with autism, even when their symptoms are equally severe. Many girls are never referred for diagnosis and are missed from the statistics.

National Autistic Society (2011) identified the different way in which girls and women present under the following headings; social understanding, social communication, social imagination which is highly associated with routines, rituals and special interests. Some examples cited in the paper are:

- Girls are more able to follow social actions by delayed imitation because they observe other children and copy them, perhaps masking the symptoms of Asperger syndrome (Attwood, 2007).
- Girls are often more aware of and feel a need to interact socially. They are involved in social play, but are often led by their peers rather than initiating social contact. Girls are more socially inclined and many have one special friend.
- In our society, girls are expected to be social in their communication. Girls on the spectrum do not 'do social chit chat' or make 'meaningless' comments in order to facilitate social communication. The idea of a social hierarchy and how one communicates with people of different status can be problematic and get girls into trouble with teachers.
- Evidence suggests that girls have better imagination and more pretend play (Knickmeyer et al, 2008). Many have a very rich and elaborate fantasy world with imaginary friends. Girls escape into fiction, and some live in another world with, for example, fairies and witches.
- The interests of girls in the spectrum are very often similar to those of other girls – animals, horses, classical literature – and therefore are not seen as unusual. It is not the special interests that differentiate them from their peers but it is the quality and intensity of these interests. Many obsessively watch soap operas and have an intense interest in celebrities.

The difficulties in the diagnosis of girls and women arise if clinicians continue to use the narrow definitions set out in the International Classification Systems. An assessment takes time and detailed evaluation is necessary to enable a clinician to systematically collect information which not only provides a diagnostic label, but more importantly, a detailed profile of the person.

Many women with ASC are not being diagnosed and are therefore not receiving the help and support needed throughout their lives. Having a diagnosis is the starting point in providing appropriate support for girls and women on the spectrum. A timely diagnosis can avoid many of the difficulties women and girls with an autism spectrum disorder experience throughout their lives. (Dr Judith Gould and Dr Jacqui Ashton Smith, Good Autism Practice, May 2011).

**Conclusion 2: There is a disproportion in diagnosis between males and females. Because of male gender bias, females are less likely to be identified with autism. There may be a rise as gender diagnostic bias is taken into account**



### **Transition from Childhood to Adulthood**

A National Audit Commission report in 2009 recommended that *the NHS and local authorities needed to do more to collect information on the numbers of people with autism who are receiving support from mental health and learning disability teams to begin to understand the extent that needs are being met* (NAO, 2009). In terms of future demand, more should be done to analyse the number of pupils with statement of special educational needs and at school action plus who have autism and are approaching school-leaving age.

It should be noted that as well as being supported within mainstream schools, Thurrock has an outstanding special school that provides the Applied Behavioural Analysis/Verbal Behaviour (ABA/VB) approaches with children with ASC and learning disabilities. This has proved to be an extremely effective method of teaching and has resulted in some families moving into Thurrock in order for their children to access this valuable resource.

In addition information provided by Children's Social Care on children known to their service indicates that there is a likelihood of 57 children aged between 14 & 18 that would transition to Adult Social Care. Of those there are 31 children with ASC, 54% of the total numbers known.

Both factors will have a direct impact on Adult Social Care when they reach transition and adulthood. It is therefore likely that the numbers of adults with ASC in Thurrock will rise in the coming years.

**Number of children and young people within Thurrock schools receiving additional support who are identified as having Autism Spectrum Conditions as their primary area of special educational need. There may be other children in school who are identified as having autism at a later stage in their education or following on from an earlier identification of speech and language disorder. 133 children are supported within mainstream schools with 117 students within our specialist school. NB: this figure does not include 6<sup>th</sup> Form colleges**

Year	SA+	Statemented	Total
Nursery 2	4	2	6
Reception	1	16	17
NC Year 1	1	14	15
NC Year 2	2	13	15
NC Year 3	4	24	28
NC Year 4	4	14	18
NC Year 5	2	14	16
NC Year 6	1	14	15
NC Year 7	4	27	31
NC Year 8	1	15	16
NC Year 9	4	16	20
NC Year 10	1	20	21
NC Year 11	3	18	21
NC Year 12	1	5	6
NC Year 13	0	3	3
NC Year 14	0	2	2
Grand Total	33	217	250

**Conclusion 3: There is evidence to suggest that there has been an increase in families accessing specialist childhood provision within Thurrock. Current numbers of those that will transition from Children's Social Care to Adult Social Care with ASC represents 54% of the total. This will have a direct impact on Adult Social Care when they reach transition and adulthood.**

### **Population growth and BME Groups**

Thurrock's population is growing rapidly and becoming more diverse. The population at the 2011 census was 157,700. It is predicted to rise to 207,200 by 2033. There is no evidence to suggest that autism is more prevalent in any particular ethnic group but it needs to be recognised that the population of the borough is changing. School census data shows ethnicity in some schools with non white students at 22.7% and a shift in the largest BME group from Asian/Asian British to Black African. The number of National Insurance registrations within Thurrock by overseas nationals in 2011 was 1260 (DWP Dec 2011).

**Conclusion 4: As the general population within Thurrock grows, the expected number of people with Autism Spectrum Conditions is also likely to rise. Culturally sensitive and personalised services need to be considered when implementing this strategy.**

### **Summary of conclusions from Thurrock Data**

Conclusion 1: Available data (predicted) indicates that the number of adults with autism in Thurrock is around 999, with a projected increase to 1,112 in 2030. We currently do not have exact data of people with autism in Thurrock. One of our actions suggests we need to get better at understanding our local numbers, thus moving away from estimates as much as possible towards empirically based local data.

Conclusion 2: There is a disproportion between the diagnosis between males and females. Because of the male gender bias, females are less likely to be identified with autism. There may be a rise as gender diagnostic bias is taken into account

Conclusion 3: There is evidence to suggest that families are moving into the Thurrock area to access specialist childhood provision. Current numbers of those that will transition from Children's Social Care to Adult Social Care with ASC represents 54% of the total. This will have a direct impact on Adult Social Care when they reach transition and adulthood.

Conclusion 4: It is important this strategy does not overlook people with autism who come from BME groups and ensure that culturally sensitive services are considered.

## **Existing Services for People in Thurrock with an Autistic Spectrum Condition**

This section maps out existing local service provision for adults with an Autistic Spectrum Condition in Thurrock. Services in Thurrock are provided by both the National Health Service and Local Authority (Statutory Services) and the Independent and Voluntary sectors (Non Statutory Services)

### **Statutory Services**

#### **Health**

There is no separate structure for the delivery of autistic services within statutory organisations in Thurrock. Adults on the spectrum who have a learning disability are supported through the Community Nursing Learning Disability service and those on the higher functioning end of the spectrum may be involved with the Community Mental Health Teams. South Essex Mental Health Foundation University Trust (SEPT) is the significant provider for Mental Health and Learning Disability health services in Thurrock.

#### **SEPT Asperger's 18-30 Diagnostic Service**

SEPT operate a diagnostic service for those aged 18-30. Access is via the Clinical Assessment Service or referral by a Psychiatrist. They do accept people aged over 30 if referred to the service by a Psychiatrist.

The assessment includes the use of the Diagnostic Interview for Social and Communication Disorders (DISCO). The DISCO is recognised by the National Autistic Society as a reliable assessment tool in the diagnosis of ASC.

This service is primarily a diagnostic service; however it does offer limited post diagnostic support such as psychology, family counselling and referral to voluntary sector groups.

#### **Adult Social Care**

Thurrock Adult Social Care provides assessment and support for adults and those coming through transition on the ASC and carers. The provision of services is dependent on Fair Access to Care (FACS) criteria. Thurrock continues to support those individuals who meet critical and substantial need. People meeting this criteria can be offered a commissioned service or more personalised support through a Direct Payment or Personal Budget.

#### **Residential Services**

There are currently no long term residential care or supported housing services specifically for autism in Thurrock. This results in people needing to move into specialist provision some distance away from their families and communities.

### **Voluntary Sector**

#### **Thurrock Lifestyle Solutions TLS – Spectrum**

Spectrum is a recently formed support group for adults diagnosed on the Autistic Spectrum.

#### **Supporting Asperger's Families in Essex (SAFE)**

SAFE is a support group for people on the autistic spectrum and carers.

It was set up in 1997 by a group of parents of children with Asperger's. They provide parent support group meetings, run regular social skills training programmes, two adult support groups, two youth groups and social events for all ages. SAFE campaigns for better services and understanding for people with Asperger Syndrome and their families around the county.

**Please see web link to the mapping exercise undertaken by Thurrock Coalition, the local user led organisation at:**

<https://consult.thurrock.gov.uk/portal/tc/asc/aasc/aasc>

## **Training**

In 2012 Thurrock Council surveyed staff on how confident they felt working with people with ASC. Whilst many had experience the majority were keen to learn more and update their skills. Whilst most professionals know something about autism, they do not necessarily understand how autism affects a person. This makes it hard for them to recognise autism and communicate appropriately. It also means they may have little idea how to adapt their behaviour or services

At the current time staff working across the Council and Private and Voluntary Sector have been able to access an on-line e-learning package provided through The British Psychological Society. This consists of three modules as follows:

- Building awareness of autism
- Supporting adults with autism
- Working with adults with autism

Recognising and having an understanding of autism is important and at present many staff feel they lack in these skills, for these reasons we have identified training as a specific area within the action plan as in line with the national strategy

## **Resources**

### **Financial mapping and analysis**

Our current expenditure on supporting people with ASC is £2,692,944.32 per annum.

This is to support around 42 adults with Autism as follows:

Service provision	Percentage of cost
Residential Care	65.2 %

Short Breaks	23.79 %
Homecare	11.19 %

## **Where do we want to be?**

### **4. Thurrock's aspirations for autism support**

Thurrock's aspiration will be focused on the national vision and the five core areas of activity

#### **National vision and strategy**

The National Strategy focuses on five core areas of activity.

- Increasing awareness and understanding of autism among frontline professionals
- Developing a clear, consistent pathway for diagnosis in every area, which is followed by the offer of a personalised needs assessment.
- Improving access to the services and support which adults with autism needs to live independently within the community
- Helping Adults into work, and
- Enabling local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities

#### **Specific areas for action**

##### **Increasing awareness and understanding of autism**

It is essential that at the very least, autism awareness training is available to everyone working in social care and those services in the voluntary sector who support people with autism. Without appropriate training, staff are unlikely to know how to adjust the way they deliver services.

Many professionals have some knowledge of autism and how to support people with autism, but frequently admit their knowledge is severely limited in terms of how autism affects people. Poor understanding of autism amongst practitioners can lead to the condition being overlooked.

A further consideration for adults with autism is that many of the most effective advocacy and buddy schemes are delivered through the voluntary sector and volunteer groups, who have a real insight into the challenges faced by adults with autism. However, funding is often a significant issue for such groups which makes it hard for them to increase their capacity. Given how valuable these services can be for individuals, Thurrock believes that more should be done to support volunteer and third sector groups to deliver these kinds of services.

Thurrock aim's to:

- Improve access to information for people with autism and their families
- Commission autism awareness training for front line staff in all areas
- Multi agency training plan - where both the local criminal justice system and the CCG are engaged in the training agenda
- Make people aware that reasonable adjustments must be made to universal services (the type of services available to all people across the borough e.g. libraries, transport, cinemas etc) to improve access and support to people with autism.
- Develop an Autism Champions programme led by the Autism Action Group

### **Improved access to diagnosis and assessment services**

Adults with autism need to be able to get access to appropriate and timely assessment and diagnosis. This is not an end in itself and needs to be linked to community care assessments to enable people to access support if they need it.

People who have complex needs associated with autism continue to be supported by community learning disability services. Clear pathways are needed and professionals need to be aware of these.

Thurrock aim's to:

- Health colleagues to lead on the development of a clear local diagnostic pathway. As part of this pathway a diagnosis should trigger a community care assessment.
- Improve the way the Council carries out eligibility assessments and reviews
- Ensure that carers are fully aware of the right to an assessment in their own right
- Ensure Thurrock's Carers Strategy and Autism Strategy are linked and that carers are represented on the AAG

### **Transitions**

During transition a young person is on a gradual continuum from being a child being cared for, to becoming an adult, making decisions about their own life, with support, if necessary

The aim of the transition process is to minimise disruption, and to enable young people to realise their potential for independence.

Thurrock aim's to:

- Ensure that statutory duties around transition planning are followed and the local area meets the minimum standards in transition planning. This strategy links to the recently developed Transition Strategy and Pathway
- Transition plans for young people with autism include meaningful employment as a key outcome

### **Improved access to services: Facilitate independent living for adults**

Following diagnosis, adults will be entitled to an assessment by Thurrock Council to establish whether they are eligible to receive services. The eligibility criteria is designed to ensure equity and consistency in the way resources are allocated across all groups of people.

We recognise that people with autism have not always been well serviced by the standard approach to assessment, as their needs may not be identified by practitioners not knowing how to communicate effectively. Thurrock has ensured that practitioners carrying out assessments within the locality teams have received Autism Awareness Training.

In line with the national social care policy of personalisation, people can now exercise choice and control about how their needs can best be met by contributing to their self directed support plan. For many people this includes managing a personal budget to purchase their choice of help and support services. We would like to see more people with autism taking up this opportunity.

Thurrock aims to;

- Develop a single identifiable contact point where people with autism (whether or not in receipt of a statutory service) can get information, signposting and autism-friendly entry points for a wide range of local services. (this may be through the council run LAC service)
- Make information available about local support easily accessible to people with autism

### **Housing**

People with autism have varying levels of support and housing needs with some being able to live completely independently.

Exercising choice and control over where and with whom people live with is a fundamental part of life and independence for most adults. Thurrock shares this vision and our aim is to support people with autism to live as independently as possible.

Adults with autism need a range of living environments. Those who require intensive support have historically been referred to residential accommodation outside of Thurrock. Whilst this is still appropriate for some cases, others benefit from choice, control and independence with support, either alone or with others,



Thurrock aims to:

- Support people to access mainstream housing where they can have a tailored package of support from a provider of their choosing, using a personal budget
- Build on existing projects to enable people with autism to have access to housing projects that have suitable support with staff having specialist knowledge on ASC
- Continue to encourage the development of a range of new and innovative local housing options offering care and support
- Include the need of people with Autism in the housing strategy

### **Employment**

15% of adults with autism in the UK are in full time paid employment.

46% of all people living with a disability are in full time paid employment.

71.2% of adults of the general population of working age are in full time employment.

People with autism are capable of making a positive contribution to the work place and some people with the condition have traits that can make them particularly valuable to employers in specific roles. Thurrock aims to promote greater awareness amongst potential employers about these benefits, as well as making reasonable adjustments to achieve compliance with disability discrimination legislation.

People with autism need clear information and support in their journey to work.

Thurrock aim's to:

- Increase awareness to employers
- Ensure access to supported employment opportunities
- Ensure Job centre plus Disability Employment Advisors have specialist knowledge around ASC
- Promote apprenticeship schemes
- Setting the example locally by becoming an autism friendly place to work.

### **Improving the way we plan and prioritise services for adults.**

Thurrock Council and NHS systems do not currently record information related specifically to ASC. This shortcoming has been identified and the need to adjust these systems to enable information to be included has been actioned.

Through this process Thurrock will also seek to clarify how many people with autism also have additional conditions such as learning disabilities and or mental health difficulties.

Thurrock aims to:

- Improve collection and analysis of information and trends to clarify how many people in Thurrock have the condition. This includes recording data about the number of people who meet adult social care eligibility criteria but do not receive a service.
- Need to record more accurately the number of people with Autism who are also identified as having a learning disability or mental health problem (dual diagnosis)
- Autism is included in the Joint Strategic Needs Assessment
- A mechanism for adults with autism and carers to oversee the implementation of this strategy through the development of an Autism Action Group (AAG)
- Ensure Older People with Autism are considered in the planning of services.
- Ensure that Thurrock's Clinical Commissioning Group (CCG) are engaged and a full partner in the development of this strategy.

SCIE encourages local authorities to explore how to support volunteer and third sector groups in planning and commissioning services locally.

One key route to do this may be through working with user-led organisations for disabled people such as Thurrock Coalition.

## **5. Thurrock Goals**

In July 2012, a workshop was held in Grays to begin to establish the scope of the strategy for Thurrock. This involved people with ASC, carers, professionals from health, social care and the voluntary sector.

One of the main aims of the day was to achieve a consensus around the outcomes that the local strategy should seek to achieve for people with ASC in Thurrock. These were identified as:

- 1:** People have accessed appropriate health services.
- 2:** People are in paid work or undertaking work related opportunities.
- 3:** People are living in a range of accommodation and included in a range of activities in the community.
- 4:** People have experienced choice and control in the planning and delivery of their individualised social care services.

**5:** People have had appropriately planned and supported transitions.

**6:** People have had supportive education and training opportunities.

There were a number of cross cutting outcomes which feature throughout as follows:

- Both the community and professionals are aware of Autism and some have received specific training.
- There are a range of networks for support throughout Thurrock.
- Universal services have access to specialist support.
- Specialist support is available to people with Autism.

All of the above outcomes were mentioned in the National Autism Strategy and they will form the basis of the Thurrock Autism Strategy.

These areas were selected as it was considered that access to a diagnosis was key to enable people to be assessed/signposted for future support; having trained staff across agencies would help with accessing key services such as housing and healthcare; increased public awareness would ease and promote integration into mainstream education, meaningful employment and leisure; specialist housing and employment support would address two key areas of peoples' lives.

**How are we going to get there?**

## **6. Core strategy**

It is a requirement that Thurrock has an Autism Action Group (AAG) which includes adults with autism and their carers. This board must also include representatives from social care, health, education, housing and the criminal justice system. This board will monitor and report progress to the Disability Partnership Board

There is the need to focus on building capacity and capability at local level to enable local partners to develop relevant services for adults with autism to meet identified needs and priorities

**How will the strategy be implemented?**

## **7. Resources**

The current expenditure on autism services is not specified as such and currently sits within mental health or learning disability budgets. As with most areas of expenditure Thurrock is looking at delivering better value from a reduced allocation. It is unlikely we

will be able to allocate significant additional resources towards this strategy in the short to medium term but it will be how we can use our existing spend better.

## 8. Action Plan

This action plan is based on both the National Strategy (including Think Autism) and local outcomes that Thurrock residents highlighted during consultation.

Priority	What do we want to achieve?	How are we going to do it?	Who is going to do it?	When are we going to do this by?
An equal part of my local community	Reasonable adjustments must be made to improve access and support for people with autism (universal services)	Task and Finish group to be established as part of the AAG to deliver	Autism Action Group (AAG)	December 2016
	Explore the development of the Autism Champions programme in Thurrock	Task and Finish group to be established as part of the AAG to deliver	AAG	April 2016
	Autism Action Group must be in place. AAG must have sign up of social services, health, education, housing and criminal justice as well as people with autism and their carers.	Commissioning Team & Thurrock Coalition to identify members and convene initial meeting	Commissioning Team & Thurrock Coalition	December 2014 <b>Completed, meeting quarterly</b>
	Information on local progress is made available locally (e.g. self assessment) so that local communities can hold the local authority and other	<ul style="list-style-type: none"> <li>Autism self assessment is published on Thurrock Council's website.</li> </ul> <a href="https://www.thurrock.gov.uk/healthy-living/autism-self-assessment">https://www.thurrock.gov.uk/healthy-living/autism-self-assessment</a>	Commissioning Team (Allison Hall)	<ul style="list-style-type: none"> <li>Completed for 2014, to be updated annually</li> </ul>

	partners to account.	<ul style="list-style-type: none"> <li>Autism Strategy to be published when approved through Health &amp; Well Being Board</li> </ul>		<ul style="list-style-type: none"> <li>July 2015</li> </ul>
	A single identifiable contact point where people with autism (whether or not in receipt of a statutory services) can get information, signposting and autism-friendly entry points for a wide range of local services	Possible Task and Finish group to be established as part of the AAG to deliver	Commissioning Team & Thurrock coalition	December 2015
	Information available about local support easily accessible to people with autism	See above	See above	As above
	Those people who do not meet adult social care eligibility criteria have access to low level preventative support e.g. buddying schemes	Look for external resources and capacity to support the development of this service. E.g. – Thurrock Lifestyle Solutions, SAFE & Autism Action Group	Commissioning Team	December 2016
	Include the need of people with Autism in the housing strategy	Review the strategy	Housing	<b>Completed.</b> The Housing Strategy is currently being consulted upon, officers have been involved in providing information

				on the needs of people with autism to Housing colleagues during its development
	Quality autism awareness training should be included within general equality and diversity training programmes across the council	Review training programme to ensure autism awareness is included	Organisational Development Team	September 2015
The right support at the right time during my lifetime	Health colleagues to lead on the development of a clear local diagnostic pathway (with clear performance indicators or timescales). As part of this pathway a diagnosis should trigger a community care assessment.	Thurrock CCG to develop pathway (good practice guidance to be issued September 2014)	Learning Disabilities Commissioning Manager - Thurrock CCG	31 <sup>st</sup> March 2016 (to complete review of current pathway)  31 <sup>st</sup> March 2017 (to complete any actions following review)
	People with Autism to be flagged as a priority in GP practices Annual Health checks to be completed by GP practices for those with Autism	Thurrock CCG to develop a process for health checks and system for the flagging of people with autism, jointly with GP's	Thurrock CCG	31 <sup>st</sup> March 2016
	Ensure that data collected can record <ul style="list-style-type: none"> <li>• The number of people with autism</li> <li>• Those that meet ASC</li> </ul>	LAS system to be updated and guidance provided to staff to enable data to be recorded and reported upon	Strategic Lead for Performance. Quality & Business Support	September 2015

	<p>eligibility criteria but do not receive a service</p> <ul style="list-style-type: none"> <li>• Those with autism also identified as having a learning disability or mental health problem</li> </ul>			
	Autism is included in the Joint Strategic Needs Assessment (JSNA)	To be actioned at next JSNA re-write	Strategic Lead for Performance. Quality & Business Support	Draft to be published in 2015
	Commissioning plan for services for adults with autism, to be developed and reviewed annually	<p>To review the following and attach as an appendix of the Market Position Statement</p> <ul style="list-style-type: none"> <li>• The number of adults known to have autism in the area;</li> <li>• The range of need for support to live independently;</li> <li>• The age profile of people with autism in the area – including those approaching;</li> <li>• 65 or above working age and the number of children approaching adulthood</li> </ul> <p>How adults with autism are able to access personal budgets and benefit from personalisation</p>	Commissioning Team	<b>Completed</b> Included within the Market Position Statement
	Basic autism training should be available to all staff	Achieved and ongoing for 2015/16	Workforce Development Team	<b>Completed</b>

	working in health and social care. Specialist training for those in roles that have a direct impact on access to services for adults with autism.			
	Thurrock Council to develop an approach to becoming an Autism Friendly Council	Initial discussions to be held with Thurrock Councils Community Development Team to discuss approach	Commissioning Team	April 2016
	<ul style="list-style-type: none"> <li>Multi agency training plan to be developed, ensuring that we engage with partners, all public services (including CCG and the local criminal justice system) in the training agenda</li> <li>Training programme to be user-led approved around content &amp; delivery, and approves organisations as Autism Friendly upon completion</li> </ul>	<ul style="list-style-type: none"> <li>Task Group to be established</li> <li>Review training with AAG</li> <li>Consider developing on-line fact sheets and refresher training programmes</li> </ul>	AAG & Workforce Development Team	April 2016
	Ensure Thurrock's Carers Strategy and Autism Strategy are linked and that carers are represented on	Amendments to be made to the Carers Strategy through the Carers Partnership Group	Carers Strategy Officer	December 2015 The Carers Partnership Group is not currently



	the AAG			meeting, this will be raised as an action once it is formally re-established
	Promote apprenticeship schemes. Setting the example locally by becoming an autism friendly place to work.	Explore potential for apprenticeship schemes (and if do-able develop a programme)	Learning & Skills Manager	December 2015
	Person centred care planning reflects the needs relating to LD, MH or PH issues as well as specifically to their autism.	Current practice to be reviewed and awareness raising with practitioners to be undertaken to ensure appropriate recording. Regular file auditing to evidence compliance	Strategic Lead for Safeguarding, Complex Care & Social Work, Team Managers	Completed and ongoing through file audits
	Ensure that the actions which come out of Transforming Care – the DH report following its review of the abuse exposed at Winterbourne View hospital	<p>The Winterbourne view agenda has progressed well in Thurrock. We had a very small original cohort of people. We now have 3 people who need to move on. They are part of a national review programme to ensure they are moved on as soon as is appropriate.</p> <p>The wider winterbourne agenda for change is being led by a steering group across health and social care ensuring that local provision is available wherever possible. This links to the Market position statement and work being</p>	Strategic Lead - Commissioning and Procurement	The timescale for each person will be individual but will be monitored closely by the national winterbourne team.

		undertaken within social care around developing the local market		
	Implement good practice from the British Psychological Society's current Autism and the criminal justice system project (not reporting until March 2015)	Review actions in 2015, discuss initially with CJS	Commissioning Team	Report not published, dates to be set once report seen
	Implement the outcome of the National Autistic Society brokerage/personalisation project reporting in March 2016.	Review report in 2016	Commissioning Team	March 2016 to commence review
	Transition plans for young people with autism include meaningful employment as a key outcome	<ul style="list-style-type: none"> <li>• Current practice to be reviewed to ensure compliance</li>   <li>• Engage with <ul style="list-style-type: none"> <li>○ Provider Services (e.g. – Thurrock Lifestyle Solution</li> <li>○ Thurrock's User- led Organisation</li> <li>○ Education Dept.</li> <li>○ Education colleges</li> <li>○ Adult Community College</li> <li>○ Specialist schools</li> <li>○ Key local employers</li> </ul> </li> </ul>	Strategic Lead for Safeguarding, Complex Care & Social Work	November 2015

		To develop opportunities for internships, work experience and volunteering		
	<p>Care planning process for adult social care considers meaningful employment as a key outcome and looks particularly at whether personal budgets can be used to support adults with autism to become work ready</p> <p>Ensure the assessment process includes signposting, as appropriate to Access to Work</p>	<ul style="list-style-type: none"> <li>• Current practice to be reviewed to ensure compliance</li> <li>• Engage with <ul style="list-style-type: none"> <li>○ Provider Services (e.g. – Thurrock Lifestyle Solution</li> <li>○ Thurrock’s User- led Organisation</li> <li>○ Education Dept.</li> <li>○ Education colleges</li> <li>○ Adult Community College</li> <li>○ Specialist schools</li> <li>○ Key local employers</li> </ul> </li> </ul> <p>To develop opportunities for internships, work experience and volunteering</p>	Strategic Lead for Safeguarding, Complex Care & Social Work	November 2015

**How will we know when we are there?**

**9. Monitoring**

In line with policy guidance, it is proposed that progress in the implementation of this strategy and the future development of detailed joint commissioning plans, should be overseen by the Autism Action Group reporting to the Disability Partnership Board.

## **10. Review of the strategy**

This strategy will be reviewed throughout its lifetime to ensure relevance and ensure it includes any developing national or local policies or drivers. It is anticipated that the action plan will be reviewed on an annual basis to note progress and include areas of red and amber on each annual Autism Self-Assessment.