

## Thurrock Coalition



### Informing the Thurrock Autism Strategy

#### Think Autism Workshop – Friday 26<sup>th</sup> September 2014

#### Report and Recommendations

#### Introduction

Thurrock Coalition offers advice and support for disabled and older residents of Thurrock and their carers. We are a wide network of individuals and groups aiming to inform people about their rights and entitlements and to improve the quality and choice of services that might assist them.

#### Background to *Think Autism*

*Think Autism* is the Government's new strategy for improving the lives of adults with autism in England, and was published on 2 April 2014. It is an update to the first Adult Autism Strategy, *Fulfilling and Rewarding Lives*, which was published in 2010. It is relevant to England only (the devolved administrations have their own strategies).

When *Fulfilling and Rewarding Lives* was published in 2010 the Government made a commitment to review this Strategy three years later. *Think Autism* is the result of the Government's review which sought the feedback and opinions from adults with autism, carers, and professionals in local authorities and the NHS about how well the 2010 Strategy has been implemented so far.

*Think Autism* does not replace the original Adult Strategy but builds on the themes and recommendations put forward by the 2010 Strategy because these remain the building blocks for creating better services and support for adults with autism.<sup>1</sup>

<sup>1</sup> National Autistic Society – Think Autism – A Supporter's Guide. Available at: <http://www.autism.org.uk/~media/NAS/Documents/News-and-events/News-from-the-NAS/Think%20autism%20-%20Supporter%20guide.ashx>

## **Thurrock's Autism Strategy**

Council Officers and Commissioners at Thurrock Council recognise that the current draft Autism Strategy in Thurrock needs to be updated to reflect the changes and recommendations contained within Think Autism and to more accurately reflect the needs of people with autism and their families, to recognise issues, anxieties and questions and plan accordingly.

### **The Workshop**

The workshop provided a valuable opportunity to explore the Thurrock specific issues, to identify relevant Actions and Priorities and to link these to the *Think Autism* Outcomes (see below).

The recommended Actions that emerged from the workshop will help to influence the Draft Strategy, the Action Plan and ultimately shape community solutions and services in Thurrock.

The implementation of the Actions will be overseen and Monitored by a User, Parent and Carer-Led Autism Action Group.

### **The Autism Action Group**

All workshop attendees were invited to join the new group. The wish to define the precise function, remit, size and terms of reference at the first meeting of the group was emphasised, as well as the need for person-centred and solution focused principles to be adopted and include people with autism in the group. Attendees agreed that initial membership should be between 6-10 individuals, to be reviewed periodically. The group to meet in November 2014.

### **The Key Themes**

Several key themes emerged from the workshop as well as issues specific to Thurrock, and link directly to Outcomes contained in *Think Autism* These have been captured and distilled as follows

- The importance of improving local community awareness & acceptance of Autism, developing User-Led training solutions for providers of goods, services, facilities, employers, health & social care professionals, commissioners and anyone working within the Criminal Justice System around Reasonable Adjustments (links to *Think Autism* Outcomes 1, 4, 9, 11, 13,15)
- The importance of a Local Offer - Individuals need opportunities to connect with other people and to be supported to develop local peer support groups offering low level support for individuals, families and carers. The

opportunities should emphasise participation, inclusion, involvement and to be able to affect big decisions in the local area increasing awareness of Community Safety (links to *Think Autism* Outcomes: 2, 3, 5, 10)

- The importance of an awareness of individuality & Protected Characteristics, an understanding of lived experiences of people with Autism and how this affects people differently throughout life, life events, and transitions (links to *Think Autism* Outcome 6)
- The importance of timely Diagnosis, ongoing information and support (links to *Think Autism* Outcome 7)
- The importance of Personalisation that adapts with individuals and support is tailored to additional specific needs using person-centred principles (links to *Think Autism* Outcomes 8, 12).
- The importance of equality of opportunity to be independent and support to develop skills, knowledge, experiences to improve chances of finding and keeping employment (links to *Think Autism* Outcomes 14, 15).

## The Key Themes, Issues and Actions

Each of the above *Themes* has corresponding *Issues* and *Actions* that link to the *Think Autism* Outcomes

<b>Key Themes</b>	<b>Issues</b>	<b>Actions</b>	<b>Think Autism Outcomes</b>
The importance of improving local community awareness & acceptance of Autism, developing User-Led training solutions for providers of goods, services, facilities, employers, health & social care	<ul style="list-style-type: none"> <li>• Public facing staff need training, unsure how to act/behave.</li> <li>• Looking “Normal” can be difficult. Staff not aware that people are disabled which can lead to misunderstanding and confrontation</li> <li>• Providing signs asking people to disclose/self-refer are not appropriate. Individuals may not identify as Autistic</li> <li>• Transition (leaving</li> </ul>	<ul style="list-style-type: none"> <li>• Training content, standards and actions to be agreed by parents and experts</li> <li>• Training to be led by people with Autism who are experts by lived experience.</li> <li>• Train children to be “Autism Aware” from an early age and involve staff in schools, colleges and universities.</li> <li>• Establish mobile workshops visiting schools and all other</li> </ul>	1, 4, 9, 11, 13,15

<p>professionals, commissioners and anyone working within the Criminal Justice System around Reasonable Adjustments</p>	<p>school) is often hard.</p> <ul style="list-style-type: none"> <li>• Too much emphasis on the diagnosis, need to focus on ongoing support</li> <li>• Do not pressurise parents to accept provision just because its “cheap”</li> <li>• Sometimes specialist provision is needed and the local offer is not enough.</li> <li>• Need greater police and Courts Service awareness, as perhaps haven’t broken the law</li> <li>• Police to attend meetings and meet the peer support groups. Build on positive relationships with PCSOs.</li> <li>• There needs to be greater awareness of Autistic body language in relation to crime/witnessing – lack of eye contact won’t necessarily indicate evasiveness</li> <li>• There are currently not enough opportunities for individuals with ASD.</li> <li>• Employment is still hard to find. 1 in 10 adults with ASD are employed.</li> <li>• There is currently no education/council-run apprenticeship scheme to introduce the idea of work at a</li> </ul>	<p>providers (listed), to deliver User-Led training &amp; awareness</p> <ul style="list-style-type: none"> <li>• G.P.s to sign up to Annual Health Checks for people with ASD</li> <li>• Flag people with ASD for priority at surgeries.</li> <li>• Develop “Autism Aware” training, similar to “Dementia Friends” – deliver to the Hubs, Employers, Police, PCSO, HIRCs and wider community</li> <li>• Autism Section to be written into new CCG Commission</li> <li>• Transport companies – liaise with Passenger Transport Unit to deliver training</li> <li>• Involve individuals/parents/carers in the contracts commissioning process</li> <li>• Introduce 999 Cards in schools</li> <li>• Thurrock Council to produce a clear Autism Communication Strategy – publicise plans etc.</li> <li>• Recruit an Autism Specialist Social Worker with a team to support families and young people to signpost and co-ordinate services/professionals</li> <li>• Develop a Local Kitemark for “Autism Friendly” providers, businesses, etc.</li> <li>• Basildon Hospital needs its own Autism Strategy, to include, for example: <ul style="list-style-type: none"> <li>- Quiet room</li> </ul> </li> </ul>	
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	younger age.	<ul style="list-style-type: none"> <li>- Specialist nurse</li> <li>- Interpreter</li> <li>• Increase awareness and uptake of the Hospital Passport and SEN Nurse</li> <li>• Better staff consistency, throughout life and transitions</li> <li>• Learn from existing good practice, e.g. SEPT BTUH Asperger's Service</li> <li>• Provide support and signpost to realistic opportunities for employment in the borough.</li> </ul>	
<p>The importance of a Local Offer</p> <p>- Individuals need opportunities to connect with other people and to be supported to develop local peer support groups offering low level support for individuals, families and carers. The opportunities should emphasise participation, inclusion, involvement and to be able to affect big decisions in the local area increasing awareness of Community Safety</p>	<ul style="list-style-type: none"> <li>• Should get in touch with parents and ask views, email, meetings, etc. Don't ignore us, we want to help.</li> <li>• We need to be consulted as we have the real story.</li> <li>• Lack of understanding of Autism</li> <li>• Lack of access to information on groups for people with Asperger's – people don't know what provision is available.</li> <li>• Paediatricians do signpost, but parents still inform other parents</li> <li>• Not enough social clubs for ASD, or who will allow ASD</li> <li>• Individuals ex: Computers, car club, train enthusiasts, film making, cinema, pub</li> </ul>	<ul style="list-style-type: none"> <li>• Create the Autism Action Group and ensure User-Led membership</li> <li>• Involve group in consultations decisions and processes that affect them, co-produce all strategy documents relating to Autism</li> <li>• Ensure all information is shared, communicated to all interested parties and is accessible</li> <li>• Link to existing inclusive social/sports clubs and peer support within Third Sector Networks, consider community based solution for new club/peer support/social activities as needed.</li> <li>• Help young people to access "mainstream" groups as well as providing specialist peer support groups.</li> <li>• Encourage groups to</li> </ul>	2, 3, 5, 10

	<ul style="list-style-type: none"> <li>• The biggest issue is who to trust when you are new to area;</li> <li>• One main area to collate all info on groups etc...(or to find) info is required.</li> <li>• Parents are not the right person to accompany young person to social groups/clubs/services</li> <li>• Disability Hate Crime is more recognised but prosecutions remain low in %</li> <li>• Safeguarding individuals from physical, mental, sexual or financial abuse</li> <li>• Awareness for parent/carers of managing finances for adults with autism</li> <li>• “Particularly” vulnerable to fraud/deception</li> <li>• Sexual awareness. Prone to abuse – boundaries not known</li> <li>• Online threats/abuse – often very tech aware.</li> <li>• Learning about safety awareness needs to start early 5+ repetition needed for learning.</li> <li>• The I.Q. issue - under 70 discrimination</li> <li>• Can feel isolated and frightened after receiving ASD</li> </ul>	<p>make reasonable adjustments for young people</p> <ul style="list-style-type: none"> <li>• Introduce 999 Cards: Blue – Under 18. Red – Over 18.</li> <li>• Offer Hate Crime Ambassador Training to individuals, parents, families, carers.</li> <li>• Provide information on L.P.A (Lasting Power of Attorney) to peer support groups.</li> <li>• Provide clear signposting and ongoing support to families</li> <li>• Ensure equality of access to services across Thurrock</li> <li>• Provide a Community based Autism Co-ordinator for each “tier” level of young person to access local groups</li> </ul>	
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	<p>diagnosis – clearer signposting and ongoing support are needed</p> <ul style="list-style-type: none"> <li>• Access into services varies dependent upon original access point e.g. Health, Social Care, Education.</li> </ul>		
<p>The importance of an awareness of individuality &amp; Protected Characteristics, an understanding of lived experiences of people with Autism and how this affects people differently throughout life, life events, and transitions</p>	<ul style="list-style-type: none"> <li>• Public awareness. Perception this needs to be more widespread.</li> <li>• Awareness of using facilities such as disabled toilets – no physical disability – peoples judgement</li> <li>• Autism that is ignored as not always visible.</li> <li>• Training – this should not just be in a room but people actively participating with individuals, parents, carers to make it real.</li> <li>• Early intervention at school even to prevent the heavy use of services when they get older.</li> </ul>	<ul style="list-style-type: none"> <li>• Provide advice on relationships for people with autism especially at key times such as puberty.</li> <li>• Within schools – tailored to suit individuals, such as role plays around Protected Characteristics.</li> <li>• Work to ensure dignity for individuals i.e. discussing issues about individuals with parents of teenagers</li> </ul>	6
<p>The importance of timely Diagnosis, ongoing information and support</p>	<ul style="list-style-type: none"> <li>• Not enough staff for child – waiting list (long)</li> <li>• Diagnosis → Service but took 2 ½ years to get appointments and then diagnosis.</li> <li>• Process for services is too long</li> <li>• Access to a trained professional too long</li> </ul>	<ul style="list-style-type: none"> <li>• Develop a clear pathway for diagnosis and services (available) with timescales at each stage.</li> <li>• Provide clearer advice and information to be accessed which professionals are aware of and can signpost to, that provide activity led (structured) activities.</li> </ul>	7



	<ul style="list-style-type: none"> <li>• Not enough information/support provided to parents/carers</li> <li>• Not enough training or information around ASC for frontline staff in health (including nursing and GP staff) and schools and care</li> <li>• Too much gate keeping from different organisations preventing access to services (health and education)</li> </ul>	<ul style="list-style-type: none"> <li>• Commitment to provide basic and specialist training dependent upon level of involvement</li> <li>• Utilise Person-led/Centred planning – in partnership with professionals – not led by professionals.</li> </ul>	
<p>The importance of Personalisation that adapts with individuals and support is tailored to additional specific needs using person-centred principles</p>	<ul style="list-style-type: none"> <li>• Basic Human Right to be included in a service that is designed around/for them</li> <li>• Question the Joint Statement and its effectiveness?</li> <li>• Lack of Counselling/Therapy targeted to ASD/Autism/Asperger's as the areas aren't being addressed.</li> <li>• Personalised treatment in the long term as well as diagnosis</li> <li>• Services should network between themselves and not just wait for this group to push.</li> <li>• A high % of individuals with ASD have accompanying co-morbidities including mental health issues</li> <li>• All behaviours are a</li> </ul>	<ul style="list-style-type: none"> <li>• Ensure that there is an active, open, transparent, inclusive Multi-Disciplinary Team, involving Experts by Experience</li> <li>• Focus on treatment in the long term, not just the diagnosis</li> <li>• Need better networking and information sharing between services</li> <li>• Provide one Keyworker/Specialist who remains responsible for a person with autism so there is continuity even if the support required is from a new team – or a good transition from one worker to another.</li> <li>• Open up all services to people with Asperger's.</li> <li>• Adapt current LD/Autism Services</li> </ul>	8, 12



	<p>form of communication</p> <ul style="list-style-type: none"> <li>• If individual has a support worker and a mental health issue is identified, the case can be transferred over to a new team – continuity is needed</li> <li>• Transition from children’s services to adult services is “diabolical”</li> <li>• Need to improve joint working: Children’s &amp; adults social work. Should work together with young person and parent for the good of the child/individual in a timely fashion – not last minute</li> <li>• People with Asperger’s cannot access some of the same services as people with autism (due to IQ issues)</li> </ul>		
<p>The importance of equality of opportunity to be independent and support to develop skills, knowledge, experiences to improve chances of finding and keeping employment (links to <i>Think Autism</i> Outcomes 14, 15</p>	<ul style="list-style-type: none"> <li>• Need more employment opportunities and Equality Awareness</li> <li>• Information is empowerment. How can choices be made when we are not told about services?</li> <li>• There are currently not enough opportunities for individuals with ASD.</li> <li>• Employment is still hard to find. 1 in 10 adults with ASD are employed.</li> <li>• There is currently</li> </ul>	<ul style="list-style-type: none"> <li>• Provide diversity awareness training &amp; Community training to local employers</li> <li>• Improve communication, training. Attitudes need to be changed</li> <li>• Employer training and awareness (Proctor and Gamble and Wincanton)</li> <li>• Young people need realistic opportunities which schools should be sourcing and supporting.</li> <li>• Develop closer working relationships with Lakeside, DP</li> </ul>	<p>14, 15</p>

	no education/council-run apprenticeship scheme to introduce the idea of work at a younger age.	World or any local business to organise work experience with or without a carer.	
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## Conclusion

As the User-Led Organisation for Thurrock, Thurrock Coalition helps to provide input in a comprehensive and strategic manner and to ensure that the actions from the workshop are directly informed by the views and concerns of residents of Thurrock.

We will work closely with individuals, parents, carers and their families, alongside Thurrock Council to support and facilitate the new Autism Action Group to help to ensure that the identified Actions are implemented wherever possible. To work to improve local community awareness & acceptance of Autism by developing User-Led training solutions along with developing a Local Offer for people with Autism and their families in a way that takes the needs for equality, diversity, timely diagnosis, ongoing support, Personalisation as well as opportunities for employment into account.

For more information on the work of Thurrock Coalition, including latest news, consultation and engagement events, projects and reports please visit:

<http://www.thurrockcoalition.co.uk>

You can also follow us on Twitter: [@thurrockULO](https://twitter.com/thurrockULO)

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