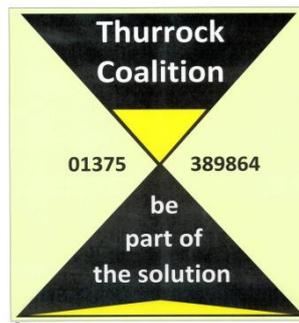


Thurrock Coalition



Informing the Thurrock Council Autism Strategy

Autism Strategy Consultation Event 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.

The Autism Consultation Event was held in order engage Citizens of Thurrock, people on the autistic spectrum, parents, carers and families and Council Officers to explore and discuss issues around appropriate service provision and availability, delivered in such a way so as to maximize choice and control for the individuals concerned. The issues were extracted and where necessary adapted (to make them specific to Thurrock) from the National Autism Strategy. The issues covered included: Health, Work, Social/Inclusion, Housing/Accommodation, Personalisation, Transition, Education

The event provided a valuable opportunity to explore what attendees found most useful for them in Thurrock currently, what they value and want more of in the future and finally what they would be noticing if their best hopes for the consultations were realized.

A consultation questionnaire was drafted by Thurrock Coalition in co-production with Thurrock Council officers; the consultation is open to individuals, parents, carers and families of anyone on the autistic spectrum.

The outcomes and themes identified on the day as well as the results of the Autism Strategy Consultation Questionnaire will help to shape and influence the work of the Autism Strategy Group (of which Thurrock Coalition is an active member) and the Thurrock Council Autism Strategy, which is expected to be published by the end of 2012.

Thurrock Coalition
Informing the Thurrock Council Autism Strategy
Recommendations and Next Steps

- a) This report will serve as the starting point for the format, content and objectives of the Thurrock Council Autism Strategy.
- b) Thurrock Coalition will work closely with Thurrock Council's People Directorate as an active member of the Autism Strategy Group to facilitate discussion, design and timely drafting of the Autism Strategy.
- c) Thurrock Coalition will work to ensure that the Autism Strategy effectively and accurately reflects the consultation feedback and includes the views of individuals on the autistic spectrum, their parents, families and carers.
- d) Thurrock Coalition will continue to support and strengthen the partnership between local government and the people of Thurrock.

Outcomes and cross-cutting themes

The following outcomes and cross-cutting themes were identified and extrapolated following the various table discussions throughout the consultation event:

Autism Strategy Outcome (adapted from the National Autism Strategy)	Cross-Cutting Themes (across all 6 Outcomes)
<p>A: People have accessed appropriate health services.</p> <p>B: People are in paid work or undertaking work related opportunities.</p> <p>C: People are living in a range of accommodation and included in a</p>	<p>i) Both the community and professionals are aware of Autism and some have received specific training.</p> <p>ii) There are a range of networks for support throughout Thurrock.</p>

<p>range of activities in the community.</p> <p>D: People have experienced choice and control in the planning and delivery of their individualised social care services.</p> <p>E: People have had appropriately planned and supported transitions.</p> <p>F: People have had supportive education and training opportunities.</p>	<p>iii) Universal services have access to specialist support.</p> <p>iv) Specialist support is available to people with Autism.</p> <p>v) Information about individuals is communicated and shared appropriately.</p> <p>vi) There is specific advice, information, and advocacy available to people with Autism.</p>
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Thurrock Coalition
Informing the Thurrock Council Autism Strategy
Format of the day

Thurrock Coalition invited residents, individuals, parents and service providers, council officers. We set the main hall up in a “café style” with group tables of 5-6 for the various delegates.

There were 7 tables, with 7 different topics drawn and adapted from the National Autism Strategy Outcomes. The event ran from 2pm to 7pm on Tuesday July 24th 2012 to maximize attendance and flexibility for contributions from individuals, parents and families who may not have otherwise been able to attend during normal office hours. All attendees had the chance to get involved with some Solution-Focused discussions and group work.

The consultation provided a prime opportunity for people to discuss their experiences, aspirations and best hopes for universal services, training and specialist support for individuals, families, carers and people on the Autistic Spectrum in Thurrock.

The following topics (1 per table) were drawn from the 7 Outcomes for the Autism Strategy (adapted in order to be more Thurrock-specific):

1. Achieve better health outcomes (Health)
2. Be included and economically active (Work/Employment)
3. Live in accommodation that meets their needs (Social Inclusion)
4. Benefit from personalisation of care and services (Personalisation)
5. Be managed appropriately across the housing sector (Housing)
6. Be satisfied with transition services (Transition)
7. Be involved in their own service planning (Replaced with Education)

The following Solution-Focused questions were then addressed under each identified topic. This allowed attendees to think positively and creatively about current services and the potential for improvement in the future:

- 1) What do you find most useful to you in Thurrock right now? (Discuss peoples' experiences of the support they have received)
- 2) What do you value and want more of? (Services, activities, relationships...?) (Discuss what would have made individuals' experiences better).
- 3) Consider the question:

“Suppose your best hopes for this consultation were realised, what would you be noticing over the coming year?”

A summary of the key feedback is reproduced below (the complete set of table responses appears in the Appendix of this report).

1. *Overriding feedback was that there are not enough (if any) specialist services for people with Autism in Thurrock.*
2. *Huge lack of information for carers and often very limited knowledge of professionals on available services.*
3. *Senior professionals do not understand autism*
4. *Local and informal networks were really important, finding out what you don't know was key.*
5. *Using universal services is fine, as long as they understand autism and are*

good services to start with.

- 6. The Council should provide an enhanced UI&A service. Not just a service that signposts you where to go but helps you navigate the way and access the service too.*
- 7. People want empathy, honesty, understanding and advice from professionals -someone to help navigate everything. .*
- 8. Building up direct services (building and places) in the Borough will be expensive. Building up indirect services (navigation, family support, help line services, local networks, etc) might be less expensive. Building up indirect services will rely on people and process (training etc) People experience real anguish when that person moves on or changes roles. So, LA services (whatever they are) are heavily dependent on the people and their character. They are not robust enough*
- 9. Work needs to be done to ensure that there is increased awareness of services, personalisation, employment, transition, education, health and accommodation options*
- 10. A main concern for parents was that all such services must in place for their children for the future before they reach transition age.*

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 day are directly informed by the views and concerns of residents of Thurrock. The Outcomes and Themes identified during the Autism Consultation Event along with the accompanying Questionnaire will serve to inform the objectives and content of the Thurrock Council Autism Strategy going forward.

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)

Thurrock Coalition Informing the Thurrock Council Autism Strategy
Autism Strategy Consultation Event Appendices

Appendix A - Verbatim Feedback from the Discussion Tables

Table 1 – Health

1) What do you find most useful to you in Thurrock right now?
(Discuss peoples' experiences of the support they have received)

- *Thurrock paediatricians have been excellent from diagnosis to practical help from psychologists around sleeping, dietician for nutrition and occupational therapist for sensory help (deep-weighted blankets) easy hold cutlery and auditory processing*
- *Health have run “new beginnings” for parents of newly diagnosed children and drop in sessions with H.V./peds/O.T./SALT etc*

2) What do you value and want more of? (Services, activities, relationships...?) (Discuss what would have made individuals' experiences better).

- *I would like to see a course aimed at “adult autism” from individuals” physical needs to mental health needs to allow the individual to live an independent life!*
- *G.Ps and opticians need further training – do they know about autism?*
- *Not diagnosed – G.P.s not very helpful!*
- *G.P.s stopping melatonin*
- *Community dental unit – excellent.*
- *Service-user – 22 years old – No services for people with ASD or ADHD. Too high an I.Q for LD services. Getting directed to mental health services – not appropriate*
- *LD Services do not work with people with ASD*
- *ASD Requires a specialist service*
- *Children’s services link to adult services – who is filling the gap?*

3) Consider the question:

“Suppose your best hopes for this consultation were realised, what would you be noticing over the coming year?”

- *I would like to see a course aimed at “adult autism” from individuals” physical needs to mental health needs to allow the individual to live an independent life!*
- *G.Ps and other health professionals would receive extensive ASD awareness training.*
- *A specialist autism/ASD service would exist*

Table 2 - Work / Employment

1) What do you find most useful to you in Thurrock right now?
(Discuss peoples’ experiences of the support they have received)

- *Public transport – to get to work / college – world of work helped with my c.v*

2) What do you value and want more of? (Services, activities, relationships...?) (Discuss what would have made individuals’ experiences better).

- *Services – work placements – budgeting – good service could do more help in budget plans*
- *Activities – not enough – would like to play football or rugby*
- *Relationships – I have a girlfriend already from outside of Thurrock In paid employment, able to plan to buy a house, make new friends be able to save for holiday. Feel like I would need to be supported to begin a new job especially if it’s full time but slowly withdraw support*
- *Need supported employment*
- *For educating employers*
- *Spectrum support group*
- *My son to have paid employment*
- *Would like to see more employment agencies specialising in employment opportunities for disabled adults – autistic adults!*
- *Would like to see assessments of yr. 11, 12 + 13 when leaving school to determine if young person would wish to work / able to*

work then referred to correct service to assist them

- *As a provider – exceptionally disappointed to come across a “high functioning” autistic 18 yr. old, who is able to drive, has 9 GCSE’s and IQ of 142 – made appointment at job centre to discuss employment – adviser offered 2pm appointment following day On arrival at 1.15pm the following day advisor had already left!! – No phone call / email / apology, extremely upsetting for young man, parents!!*
- *Rose Project (Realistic Opportunities for Supported Employment) in Havering at the moment, needs to be brought in to Thurrock to give young people the skills to maintain part time employment Independence is the key!!*
- *Working in a shoe factory and used to work in chocolate Thornton’s*

3) Consider the question:

“Suppose your best hopes for this consultation were realised, what would you be noticing over the coming year?”

- *Multiagency working*
- *Multiagency plans / reviews working towards wk. / employment*
- *Improved communication*
- *Improved vision / planning*
- *Interviews easy*
- *No service after 18*
- *Employability course good idea! Need to do training*
- *Help in a shop or leisure centre – help the lifeguard*
- *Learn about money – meet more people*
- *Make me feel better as a person*
- *No work – completed a work placement but didn’t get a job*
- *Need supported employment*
- *Educating employers*
If my son left the house - Independently (supported by someone other than family)
- *Women voices would be easier to hear*
- *There would be Inclusive assessments*

Table 3 - Social Inclusion

- 1) What do you find most useful to you in Thurrock right now?
(Discuss peoples’ experiences of the support they have received)

- *Direct Payments/Personal Budgets – as a parent of a younger child, this has allowed me to purchase services to benefit my son, including social integration sessions to help my son with social interaction leading to social inclusion with his peers. As a provider specialising in mainstream inclusion and for the young adults (18-25 years) they are asking for Travel Training to access social groups, pubs and activities to increase independence. Life is for living.*
- *If I wasn't aware of what is available in Thurrock, I would've struggled to get the help I needed from health services.*

2) What do you value and want more of? (Services, activities, relationships...?) (Discuss what would have made individuals' experiences better).

- *Hospitals should let people know about the facilities that are available to patients with mental health issues/disabilities*
- *Better signposting to facilities*
- *Support services should be more accessible as there should be more services available in the community*
- *G.P.s surgeries that know and understand mental health and does not just give pills.*
- *Less disability-specific and more integration from organisations in setting up future services. Need to be more customer led than organisation led*
- *Chances to see more of my boyfriend*
- *More activities in Thurrock – discos, clubs, gyms and snacks in Thurrock*
- *Meet a girl – have a meaningful relationship*
- *Not enough evening/weekend flexible hours of support*
- *Bonus to be able to use the locality base during holidays before my son has left school*
- *Mental Health/Disability/Autism are not dirty words*
- *There needs to be more social inclusion for ASD and bring all impairment types together and avoid segregation*

- *“Independent to buddying groups – Thurrock Council was evil and not as to is a money to out life and as to my mum not same life”*

3) Consider the question:

“Suppose your best hopes for this consultation were realised, what would you be noticing over the coming year?”

- *More autism-specific services in Thurrock*
- *Inclusion re: environment i.e. hearing (soundboard) consideration of lighting – where it is placed/colour*
- *More advertising/high profile for autism to avoid a lack of education. Should be able to go into schools, businesses, colleges and hospitals to talk about autism*
- *People in the same position as yourself opening up to their illness*
- *There would be established signposting, social networking, volunteering, setting up groups in the community by the community including “Buddying” groups*
- *Somebody coming to me instead of me finding services*
- *Why do we have to wait? Some children need help to become independent ready for becoming 18*
- *There would be a Young Adults Service for 14-18 year olds to encourage independence.*

Table 4 – Personalisation

1) What do you find most useful to you in Thurrock right now?
(Discuss peoples’ experiences of the support they have received)

- *Sunny Side (school) – Care plan, communication book includes a person’s likes and dislikes – who the person is. There is a service user meeting every week – they set the agenda*
- *Going out in groups – activities and friends*
- *Having a Direct Payment – allows some flexibility and the freedom to choose how and when. There is nothing autism-specific in Thurrock so a Direct Payment allows access to other things*
- *Unit at Harris Academy – transport works well but is not flexible – this effects learning and independence*
- *Taxis work ok, but come out of the person’s budget*

- *Treetops (school)*
 - *Some good people within limited services (despite what is available)*
 - *Hamlin Respite*
 - *Autism Anglia (Parent Group)*
- 2) What do you value and want more of? (Services, activities, relationships...?) (Discuss what would have made individuals' experiences better).

- *Need an informed choice – across the ages*
- *Not knowing*
- *Needs to be easier to find stuff*
- *Autism-specific service has more experience – full of enriched education*
- *There needs to be a better understanding of autism*
- *Value school networks*
- *Provision of more activities/clubs*
- *Need to be listened to more – “He is happy” – Structure/routine*
- *Local networks*

3) Consider the question:

“Suppose your best hopes for this consultation were realised, what would you be noticing over the coming year?”

- *Services will be timely and responsive – when I know what I want, I need it now!*
- *Consider moving!*
- *Having it local*
- *Empathetic service*
- *A telephone helpline (at any time) would be ideal*
- *Balance of choices in personalisation*
- *Professional befrienders – trained and experienced*
- *I wouldn't need to worry about meeting criteria – I would be happy with support*
- *Lack of personalisation in Thurrock*

- *Adults would have access to housing and meaningful employment based upon interests*
- *Find out what is available and to know what's what from diagnosis*
- *Help to navigate me through it*
- *Navigate my child to help his independence from me*
- *There would be flexible choice in transport options e.g. minibus*
- *Balance of choices in personalisation*
- *The process of funding wouldn't be a battle. It would be constant at each stage*
- *Wouldn't worry as much about Local Authority boundaries (no postcode lottery)*
- *Having a plan B or C*

Feedback from Personalisation Discussion Table Lead:

- At first my table had less traffic. When people did come it was a bit sheepish. They all asked "what is personalisation?". I asked them to tell me what they thought first.
- Most of the time people didn't even guess. Some thought it was about personal care or things that are done to the person. One woman did get it. Lucy (Autism and Downs) clearly articulated that it was about her care plan and how she and her mum made it.
- Personalisation for people with Autism needs to be different. Lots of examples given to me about their loved one not doing a task while in the care of a service. When the parent challenges why the reply is, "Its his/her choice". Carers understood the service was for and about the person and applaud that but, despair at the lack of common sense. People often needed to be prompted even goaded to make sure they did their personal hygiene tasks, eat sensibly etc. The balance of personalisation for these people needs to be redressed.
- I didn't have many people saying great things about services they used, in fact most agreed services are sparse in Thurrock.
- Most understood there were pressures on budgets.
- 2-3 people used DP's and they thought them useful but wanted them to be more flexible. "I can use it for a day centre for my daughter but I can't use it to get her there."
- Local and informal networks were really important, finding out what you don't know was key.
- Finding who the right person to talk to was also key.
- Anglia Autism was mentioned more than once as very good. How

can we leverage that?

- Transition service didn't come out good. people said that they new more than the worker did. One example was around LPA's.
- We do have some good people in our limited services and very helpful despite our criteria and processes (not because of them).
- Most people said finding the right person to help them is key (not the right service, the right person). Real anguish when that person moves on or changes roles. So, our services (whatever they are) are heavily dependant on the people and their character. They are not robust enough.
- Senior figures don't understand autism (especially at panel)
- Most people said it was a real battle. Not just with coping with a child with autism but getting heard and going through the system.
- Challenges with the spectrum, some said their child had Asperger but fell between the cracks because she wasn't "severe" enough. "Sorry cant help you now, come back when things are really bad".
- Most people said it was a real battle. Not just with coping with a child with autism but getting heard and going through the system.
- Most people just wanted empathy, honesty, understanding and advice. Someone to help navigate everything.
- Many examples given to me were almost centres of excellence. So, one lady sends her daughter to Gravesend for an NAS centre (which is excellent but costly). It strikes me that this has nothing to do with the services the LA provides but more a happy geographic accident. If that centre happened to be this side of the QE2 bridge people would feel that Thurrock had a great service?? Look at Treetops. People move into the area for that school. Why has the school developed here? I don't think there was a conscious effort to create a centre of excellence in Thurrock from scratch, I think it was a school that existed in Thurrock already that evolved into a centre of excellence.
- I think Treetops brings its own challenges with it. people move here for the school. This means we have more people with Autism in the Borough if we didn't have the school. This means we will have more adults with Autism in the Borough!!
- Employment opportunities are poor, work placements are poor.

Some possible suggested changes (based on the collective feedback from the day).

- Have a separate panel process or, once a diagnosis is gained, have a protocol that minimises the burden of proof needed to express the persons issues. Almost lowering FACS to include

moderate or low (unofficially)

- Either build up services in the borough (most people would like things local) or make it easier for people to access good services around us (LA)
- We could build a college, Treetops II. This college continues my education but concentrates on helping me be independent. The MyLife programme but on a much bigger scale.
- Provide a navigator. Someone that works with the family through their life. A different family support officer or something. Maybe even a real paid job for an adult with autism?
- Provide a befriending service for young people (trained and experienced service) that can help people try out and gain skills to help them be independent. Current services are too inflexible so the person has to use universal services, they need someone to help them do it. A 14 year old boy doesn't want his mum coming on the bus with him to school in front of everyone.
- Using universal services is fine, as long as they understand autism and are good services to start with. Maybe we concentrate there?
- Provide an enhanced UI&A service. Not just a service that signposts you where to go but helps you navigate the way practically too. For example, I might get signposted or directed to understand how to apply to the Court of Protection. We not only do that but we help you download the forms and fill them in too. We not only tell you about access to work but we talk to them on your behalf (if needed), help you with the forms and any queries. We don't just point you in the right direction and give you a push, we walk alongside for as long and as close as you need us too (all the time focusing on making you, your family, self-sufficient as much as we can. We don't want to hold your hand every step of the way but we are happy to if you need it).
- Get rid of transitions service for people with Autism. Allocate an adult case worker early at 12-14. Allow them to work with the family from 14 and into adult. Or get rid of Children and Adults services all together and just rally have People Services.
 - It seems to be like we have 3 steps. children's, transition, adults. For people with a condition that will have some impact on them all their life its 2-steps too many.
- Building up direct services (building and places) in the Borough will be expensive. Building up indirect services (navigation, family support, help line services, local networks, etc) might be less expensive. Building up indirect services will rely on people and process (training etc) and we can't be too dependent on the

people. We can't get to a position where we have a great support service but, when Sharon leaves, all of a sudden it's rubbish one.

- If we can't be good at the direct services, let's get really good at the indirect ones.

Table 5 - Housing/Accommodation

1) What do you find most useful to you in Thurrock right now?
(Discuss people's experiences of the support they have received)

- *People with Autism/Aspergers are not considered in the banding system for council housing the same as people with L.D or M.H.*

2) What do you value and want more of? (Services, activities, relationships...?) (Discuss what would have made individuals' experiences better).

- *Housing / accommodation need to be assessed on individual basis, residential opportunities for those who need / want them community supported living (more – please) make them part of their own communities!*
- *Sheltered accommodation – warden controlled, carers available to teach life skills bill paying / shopping / cooking!*

3) Consider the question:

“Suppose your best hopes for this consultation were realised, what would you be noticing over the coming year?”

- *There should be more available housing for people with mental health / learning difference supported living / floating support*

Feedback from Housing/Accommodation Discussion Table Lead:

1. Overriding feedback was that there are not enough (if any) specialist services for people with Autism in Thurrock.
2. Huge lack of information for carers and often limited knowledge of professionals on available services.
3. Services are in place for children but there is nothing when they move on into adult services.
4. Main concerns for parents were ensuring that services and accommodation options were in place for their children for the future.

Q1 – What works well at the moment?

- Treetops school is fantastic – staff are well trained and knowledgeable but the school has become a victim of its own success with people moving into Thurrock just to ensure that their children could attend the school. There is now a waiting list for the school.
- Staff at the school are great but they could be more flexible. Some parents stated that staff often take on second jobs to supplement their salary. A group of parents who are in receipt of Direct Payments would like to use this money to buy extra hours of staff time to support their children but would like to know if this is possible and if so, how this could be co-ordinated.
- Direct Payments work well for some carers but some carers had difficulty in finding out information about them or getting them
- Social workers in children’s services have provided fantastic support but there are concerns about the support available as children move into adult services.

Q2 – What are the issues?

- There is no specialist residential accommodation in Thurrock. Children have to attend residential schemes in other areas. This can put huge strain on the parents and siblings and parents don’t want to have to leave the area just to ensure that their children are appropriately supported.
- Adult services are not specialised and there is not enough personalised support. Moving through from children’s to adults’ services there is a huge difference. Once children are 18, then they are virtually on their own with parents having to often trying to find activities and/or services to support them. Would like to see more structured, personalised activities made available including skills training in order to ensure that they can be occupied and have meaningful activities to carry out. Day activities are time limited and have poor choice of activities. People have to fit into the service rather than the service fitting around them and this often does not work.
- Some carers would be interested in Direct Payments but do not take them up because they can’t find activities or services that their child would be interested in.

- Some Autism support groups are good but there is generally a lack of information about specialist support that is available locally- nearest support groups is Shenfield. Would like to see a Thurrock group set up and representation on a Partnership Board.
- Some carers are frustrated as often, they are let down by respite services. If staff are on leave or are sick, then they are not offered replacement staff which means that they cannot have respite.
- Would like to see day services operate at weekends and bank holidays as these often are the times when carers need support – need to be much more flexible and fit in with the needs of service users. Some carers willing to pay for this and extra hours by using Direct Payments, if possible.
- With reference to future housing, one parent said that she is so frustrated at the lack of services that are available to support her child that in the future she wants her to go into residential care (even though she does not need this) as then at least she can be guaranteed of a home and activities and support.
- With regards to housing options, there needs to be a range of accommodation options available locally which include residential care, supported living and specialist floating support. People in the Council Housing Dept need to understand that someone with Asperger's has a disability and need to understand how this affects their need for specific housing. At the moment, there appears to be little understanding and one parent has fought very hard to try to obtain a priority banding for her child to enable him to be housed. Staff need training on disabilities and how this affects not only them but their families as well.
- Most parents coming to the table feared what the future held for their children and wanted to be able to plan for them but feel that they are unable to do so because of the lack of services locally.
- One parent had a child with Asperger's . when he was in children's services, he had a social worker and very good support. However when he became old enough, the mother was told that his file would be passed to Adult services and a social worker would contact her. This never happened, the mother assumed that she was not entitled to any help and she and her husband have been coping ever since. (She was assisted to apply for a new assessment).
- Support networks are not in place – tend to be informal with parents getting together- would like to see some formal support networks in place.

Q3 – What’s needed for the future?

- A range of accommodation services within Thurrock including residential, supported living and floating support
- Review of adult services – more money available and more structured, personalised services that meet service user needs at the times they want and offering personalised activities including lifeskills training.
- Information source on services available in Thurrock which is easily available to carers. Support groups and partnership board representation to have a say and input into developing services
- Council to take a lead in this and involve carers in developing the services that are required.
- Training for staff to understand disabilities and the impact on the need for services when living with someone with Autism.

Table 6 - Transition

1) What do you find most useful to you in Thurrock right now? (Discuss peoples’ experiences of the support they have received)

- *Tracey Smith Thurrock transition support group!! Liaised some excellent considerations this year!*
- *My child is nearly 5-for him I hope by the time he reaches transition people with autism are treated as individuals regardless of age by services that support them*
- *It would be useful if more “professionals” were aware of autism i.e. Doctors, a & e, statutory, voluntary, dentists*
- *Finding somewhere to move into (tempory Hathaway Rd)*
- *Taster days for college*
- *People choosing my preferences for housing - my choices – living independently or with others*
- *Would be helpful if – new tenants could be introduced to existing tenants, so initial living together would be supported i.e. Likes / dislikes / name / age*
- *Grays school support! – heads of years*

2) What do you value and want more of? (Services, activities, relationships...?) (Discuss what would have made individuals’

experiences better).

- *Children's and adult services to know more about each other seems very disjointed*
- *Extension of ABA*
- *Support of other parents – sharing information but reliant on parents finding out for themselves – no central point for info*
- *Some local respite care not autism specific depends whose on shift*
- *Consistency of professionals supporting the individual that know about the individual*
- *Make sure professionals know about the individual*
- *Transition support to be open and transparent – share with carers and family information sharing*
- *Police recognition autistic child- a card that provides a photo and information about how your child communicates and gets added to their system if your child runs away / goes missing – similar to 999 cards for LD.*
- *Professionals that have “good” knowledge about what neighbouring boroughs offer*
- *Grays school supporting person by being a teaching assistant and has opened up his idea to becoming a teacher – is there support for “professional” roles for those with learning difficulties?*
- *If someone achieves “mainstream” schooling there should be some provision to extend education so they don't have to attend Treetops for one remainder of their education*
- *Support to stay in their own home / into the borough*
- *More services locally – residential – community support*
- *More of a service that is arranged to meet those coming through transition to cope with future*
- *Look at how to support individuals skills when people move, change hours, take a carer break, have family, child care*
- *Support with budgeting and shopping advises on amount of money so it lasts dislikes money handling support helps not to get frustrated*
- *Person-centered support place as much emphasis on life skills as educational skills – long lead into transition to extend services*
- *Adult services integrated into sign supported sign language such as signing to assist and support communication*
- *Getting the right training course that would suit me – bringing employers more together with the colleges – couldn't be full time course and full time training, also can only work so many hours*

before I would lose benefits

- *Education for professionals on sensory issues and the complex nature of autism – person centered / people as individuals – parents need support with these issues too .*
- *Day services improved – would mean less need for residential – meaningful activities – life skills structured and delivered for the individual – with opportunities to connect to ABA*
- *More support for carers with professionals – carers needs (holistic for the family) peers to peer support for carers – better services and information sharing*
- *Money and resources*
- *Advertising around transition team – CWD – Bosa – surgeries for Thurrock transition group – support to be identified before age 13 to increase choice of full independent life*
- *More support through transition – for people to know their rights to do with transition.*

3) Consider the question:

“Suppose your best hopes for this consultation were realised, what would you be noticing over the coming year?”

- *Things I would notice: Safe, happy, healthy, independence! Choice!*
- *For my child to progress through transition “seamlessly”*
- *(Carers) people would be happier as their issues would have been addressed before it got to crisis*

Table 7 – Education

- 1) What do you find most useful to you in Thurrock right now?
(Discuss peoples’ experiences of the support they have received)
- *2 year check by health visitor*
 - *ASD Champion in each school*
 - *Work experience opportunities pointing in the right direction*
 - *Transport to school*
 - *The Unit at Harris Academy Chafford Hundred*
 - *National Autistic Society*
 - *Supporting parents at home – too much to cope with to have time to research services and help*

- *Opportunities to meet others with Aspergers – doing activities that interest them (focus)*
- *Parental requests for E.Ps*
- *Post diagnosis support*
- *Not searching for a “cure”*
- *Travelling/DLA information*
- *Belmont nursery*
- *Treetops Portage Service*
- *Sunshine Centre Support Workers*
- *Without the 3 services (above) my son would not hve achieved the high level he has.*
- *Autism Anglia*

2) What do you value and want more of? (Services, activities, relationships...?) (Discuss what would have made individuals' experiences better)

- *Make the Autism representative at Thurrock Council easily known and easily contactable*
- *Website for parents to access re: services/professionals available to help*
- *Courses for Adults – extra help*
- *Specialist service for ASD – mental health difficulties need - CBT*
- *Learning to cope – more places at ASD unit*
- *More training for parents*
- *Closer and wider links between families and agencies*
- *Listening*
- *Systems for identification and support in school*
- *Multi-agency working to support child*
- *Eclectic approach to interventions is needed. Reduce a “one size fits all approach”*
- *Teachers understanding behaviour and communication*
- *Dr. Carol Toogood (Educational Psychologist)*
ctoogood@thurrock.gov.uk
- *Value senior school provision, but we need it in primary schools.*

- *Teachers who understand and listen*
- *Understanding! Teachers to gain the same understanding of special needs as their SENCOs*
- *Treetops Rocks! For younger children 2-19 years.*
- *Teaching qualifications – whilst it would have been fine a while ago for special needs to be an option in teacher training with the improved diagnosis and people being recognised with special needs, this should be reflected and the optional unit should now be mandatory*
- *Good beginnings – moving on together*
- *Prejudice from teachers (Naughty) “No such thing as (insert condition)”*
- *Aspergers children fall between the gap unless they are picked up by good teachers and put forward for assessment, they suffer. If they are assessed the process takes too long and parents get no support.*

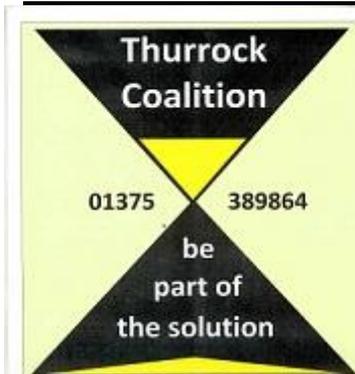
3) Consider the question:

“Suppose your best hopes for this consultation were realised, what would you be noticing over the coming year?”

- *Services to mainstream*
- *Computers*
- *S.A.FE. for Thurrock*
- *Experts available to talk to – tips in managing behaviour in school and at home*
- *Sunnyside House Rocks!*
- *Support with break times and lunch time is urgently needed*
- *A Primary (School) ASD unit*
- *Support Groups that operate outside of school hours and that can be reached on public transport*
- *Train all teaching staff to understand problems faced by children with ASD*
- *Teach the staff to be aware and to help children with ASD*
- *It’s not always behavioural difficulties, it’s behavioural communication and it’s not always personal.*

Appendix B

Thurrock Coalition



Mapping the support provided to people on the autistic spectrum in Thurrock

Thurrock Coalition is a company that has been set up to ensure that people who live in Thurrock have access to all the information they may require to get the support and care that they need. We are a User-Led Organisation (ULO) for Thurrock working to uphold the rights and entitlements of disabled people, older people, their families and carers. Thurrock Coalition is an 'umbrella' company that consists of 4 organisations, all of which follow the Social Model of Disability and aim to improve the lives of disabled and older people living in Thurrock by seeking to remove environmental, attitudinal and physical barriers that exist in society.

Thurrock Council asked Thurrock Coalition to assist with informing and writing the Council's autism strategy. This was achieved through a consultation and engagement event held in July 2012, followed by designing an online survey for individuals, parents and carers.

In addition to the above we wanted to map the support provided to people on the autistic spectrum in the borough. In order to achieve this, we set up an online survey and contacted services providers asking them to complete a series of 9 questions (see below).

The survey can be found here: <http://www.surveymonkey.com/s/N8652KV>

The deadline for completing the survey was 5pm on Friday 9th November 2012

The information gathered from the survey will help to inform the autism strategy and commissioning.

For more information on the work of Thurrock Coalition, please visit our website: <http://www.thurrockcoalition.co.uk>

The collected survey results and responses can be found on the following pages.

Thurrock Coalition - Collected Survey Results and Responses from Service Providers in Thurrock:

1. What type of service do you currently provide?

Answered questions: 12
Skipped questions: 2

<u>Type</u>	<u>Response %</u>	<u>Response Count</u>
Day opportunities	16.7%	2
P.A. Support	16.7%	2
Residential Care	75%	9
Supported Living	33.3%	4
Parent/Carer Support	25%	3
Other (please specify)		5

Showing 5 text responses

- Thurrock Stroke Project, NHS continuing care
- Respite
- Respite
- We will offer supported living in the future and domiciliary care from January 2013
- Domiciliary care

2. Do you currently support people on the autistic spectrum?

Answered questions: 12
Skipped questions: 2

<u>Answer</u>	<u>Response %</u>	<u>Response Count</u>
Yes	58.3	7
No	41.7	5

3. If you have answered "Yes" to Question 2, what type of support do you provide for people on the autistic spectrum?

Answered question 9
Skipped question 5

<u>Answer</u>	<u>Response %</u>	<u>Response Count</u>
Yes	100	9

Showing 9 text responses

- We offer independence training services within a residential care environment so we help to teach them daily living skills to ultimately help them live in a lower support environment. so things like personal hygiene, cooking, communication techniques, relationships etc
- Residence and activities
- N/A
- Support would be provided based upon the contents of the Individual Support plan
- When they come to use our service, depending upon how long they stay with us. the staff are trained to support people on the spectrum
- 24/7 residential
- N/A
- N/A
- We currently support someone who is borderline autistic (displaying traits) He is with us but they are moving on soon. The client group that we currently mainly support is around mental health

4. Would you be interested in supporting people on the autistic spectrum?

Answered question 12
Skipped question 2

<u>Answer</u>	<u>Response %</u>	<u>Response Count</u>
Yes	91.7%	11
No	8.3%	1

Showing 9 text responses

- We are working on some training now with NAS through Thurrock council and we have set up an autism team for our specialist autism flat that has just been completed. we would be interested in any training on offer to help our team understand autism and aspergers syndrome specific techniques and challenges
- Through our service provision
- Individual support plan would identify the individual's needs, and we would then identify relevant training for staff. Staff have received basic training Wider training would be good dependent upon need and would thus be Needs led
- We would like specialist training. we only have basic awareness at the moment The training happens at least once a year
- Yes, we would be happy to support more people on the Autistic Spectrum
- Ongoing training please would be good [for people] on the spectrum
- Our staff are based at Long Lane and Bellmaine. We would need awareness

- training on issues such as communication etc
- Yes, we are registered for both LD and MH, we would happily support people on the autistic spectrum We would require training on: Communication and understanding their needs
 - Care and support work

5. How many people on the autistic spectrum do you support?

Answered question 12
Skipped question 2

<u>Type</u>	<u>Response Average</u>	<u>Response Total</u>	<u>Response Count</u>
Number of people with Asperger's supported	1.73	19	11
Number of people with Autism supported	1.6	20	12
Total number of males on the autistic spectrum supported	2.09	23	11
Total number of females on the autistic spectrum supported	0.18	2	11

6. What is the age range of the people on the autistic spectrum that you support?

Answered question 12
Skipped question 2

Showing 12 text responses

- 18-30
- 24 to 28 years old
- Adults - up to end of life care
- 18-65
- 18-65
- 18-65
- 18-65
- We do not currently support people on the spectrum but the age range of our service users is 45-60
- If we did support people on the spectrum, it would be from 18 to 65

- N/A
- N/A
- 19 - 35

7. As a provider, what autism-specific support do you access?

Answered question 12
Skipped question 2

Showing 12 text responses

- Training via NAS, online training via learning pool and internal training for staff
- None
- N/A
- External training previously (private company - specific and in depth) Council offer autism awareness training - if we requested detailed training from the workforce team - I'm sure it could be provided.
- Training Families help us also to keep up to date - communication is vital between all parties
- Training wise - we have training from LDQF
- We have registered with NAS and all our staff are trained on a one day awareness course
- If we needed to access such support in the future we would access directories on the internet and word of mouth
- For the individual who displays autistic traits, we utilised the behavioural specialist - community living team in Basildon, the specialist is named Roger
- NA
- N/A
- LD Nurses for Challenging behaviour

8. Who provides this service for you?

Answered question 12
Skipped question 2

Showing 12 text responses

- NAS, Thurrock Council, ENS
- N/A
- N/A
- See above.
- External trainers
- LDQF

- The course was by Learning Disability Qualification Framework
- N/A
- Community Team in Basildon
- N/A
- N/A
- SEPFT

9. Thank you for taking the time to complete this survey. If you would like to receive information on the results of this survey please provide a contact email address below. For more information on the work of Thurrock Coalition, please visit our website: <http://www.thurrockcoalition.co.uk>

Answered question 7
Skipped question 7

- TLC Care
- jtree@thurrock.gov.uk. Joy Tree - Hathaway Road Respite
- usha.devan@east-living.co.uk Breakaway
- logan@satashcommunitycare.com Satash
- AM Care logan@amcarehome.com
- heather.cairns@familymosaic.co.uk Bellmaine and Long Lane
- Whitehall Lane ade@aksupportedhousing.com
- Hello Ian, just to let you know I have filled out the survey today and we are very interested in anything you have to offer for our staff so we can specialise as much as possible in helping people on the Autism Spectrum.

We have just developed our 1 bedroom Autism Studio at Sunnyside and are developing a team to work with a young man with Aspergers Syndrome who is moving into the unit on 01st December 2012 .

We are undertaking some training with National Autistic society and also some online training but we are keep to support and develop our staff in this regard to the highest possible level so we can assist all of our users as much as possible in their quest to become more independent.

Regards

Andrew Azzopardi – Sunnyside House

Appendix C - Thurrock Council Adults Autism Strategy Consultation Questionnaire

Thank you for completing this survey.
Your views will help to inform Thurrock's Autism Strategy.

Contact Details (optional)

1. Name

2. Age

3. Email address

4. Do you live in Thurrock?

Yes

No

5. Do you consider yourself to be a disabled person?

Yes

No

6. Which of the following best describes you?

Someone with Autism/Asperger's

Someone who carers for a person with Autism/Asperger's

Someone who works with people with Autism/Asperger's

Other (please specify)

7. Would you like to be involved with the work the council is undertaking on a local autism strategy and action plan

Yes

No

8. For you, how easy was it to access health services? This could be around gaining a diagnosis or accessing universal health services.

Please circle appropriately

☺ ☹ ☹

Very easy Quite easy Quite difficult Difficult

9. Did you feel supported following diagnosis?

- Yes
- No

What support do you think would have been helpful following diagnosis?

10. What type of accommodation do you live in?

- At home with parents
- In private rented accommodation
- In a home I own
- In social/council housing

11. Are you living in accommodation that meets your needs?

- Yes
- No

Please give details about what's good and what's bad about the accommodation that you live in

12. If you are experiencing problems with your accommodation, please tell us why.

13. What are your experiences/views of social care, good and/or bad.

14. Have you heard of Direct Payments?

- Yes
- No

Please share your experiences

15. Do any voluntary sector organisations provide support for you?

- Yes
- No

If yes, please tell us the name of the organisation

16. What is your experience of the transition from children to adult services? Good and /or bad. This could be health or social care.

17. What is your experience of accessing employment or benefits? Good and/or bad.

18. What is your experience on accessing further education or training? Good and/or bad

19. Do you feel socially isolated?

- Yes
- No

If yes, please explain why.

20. If you are a carer, would a local support group be helpful?

- Yes
- No

21. Have you ever used an Advocate?

- Yes
- No

If yes which organisation was it?

22. How easy was it for you to access advocacy services?

Please circle appropriately

- | | | | |
|---|---|---|--------------------------|
|  |  |  | |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Very easy | Quite easy | Quite difficult | Difficult |

23. If it was difficult, what made it difficult to access?

23. Do you have anything else to add?

Collated Responses following Thurrock Council's Online Autism Survey 12/8/12 to 16/10/12

Thurrock Council ran the survey as an additional means of consulting on what's available locally for people on the autistic spectrum. Thurrock Council want to know what people have found helpful, where the gaps are and - in an ideal world - what they would like to see. The purpose of this is to inform the Adult Autism Strategy.

The consultation page can be found here: http://www.thurrock.gov.uk/i-know/consultation/content.php?page=consultation_proforma&ID=180

Below is a verbatim record of the responses received via the above link:

ID	Question 1 - Do you live in Thurrock?
1	Yes
2	Yes
3	Yes
4	Yes
5	Yes

Question 1a - Please tell us below which area you live in:

Question 2 - Which of the following best describes you?
Someone with Autism/Asperger's
Someone who carers for a person with Autism/Asperger's
Someone who works with people with Autism/Asperger's
Other
Someone who works with people with Autism/Asperger's

Question 2 carer - If you are a carer, would a local support group be helpful?
Yes

Question 2 other - If you choose other please specify below:

My sister is Autistic

Question 3 - For you, how easy was it to access health services? This could be around gaining a diagnosis or accessing universal health services
Quite easy
Very difficult
Quite easy
Very difficult
Quite difficult

Question 4 - Did you feel supported following diagnosis?
Yes
No
Yes
No
No

Question 4a - What support do you think would have been helpful following diagnosis?
As a professional working with children with Autism, Tree Tops outreach support team have been very helpful training and supporting staff.
My sister was not fully diagnosed until she was about 8/9 unfortunately. she is now 27 years old.
Support planning for all aspects of daily living; housing, benefits, healthcare, education, 3rd sector support, exercise, diet and nutrition.

Question 5 - What are your experiences/views of social care, good and/or bad, if your experience was bad what could have made it better?
Extremely BAD To many chiefs making bad decisions. Dont listen to gossip and not to abuse data protection and human rights (right to family life)
Mixed vies on Social Care, some Social Workers very pro active others need to communicate with professionals more.
I think that my sister received a great deal of support from Social Care once she was diagnosed including accessing play schemes and respite care.
The support of social care needs to broaden to include all aspects of daily living to provide a firmbase and daily living. My clientele with Autism do not feel they are healthy and this can be corrected by eduction and support with exercise, diet and nutrition. When reliant on a carer the focus of education must shift to the carer to ensure the client has every opportunity for a good diet and regular

exercise. This long term will reduce the healthcare cost and make the client feel good about themselves.

Question 6 - What is your experience of the transition from children to adult services? Good and/or bad, if your experience was bad what could have made it better? This could be health or social care:

No previous experience.

This was a bit more confusing as the level of support changes dramatically.

No experience only work with 18+.

Question 7 - What is your experience of accessing employment or benefits? Good and/or bad, if your experience was bad what could have made it better?

Bad under this evil government the vulnerable have no chance we are being persecuted?

N/A

N/A - my sister accesses relevant benefits.

Linked employment is good but can often let the client down with poor communication and unsuitable offers. There needs to be a wider programme of supported volunteering to ensure correct workplace experience and training in preparation for employment. I have a client I would employ but feel there is insufficient support for me as a small business to develop his true potential. For me to employ him I would need financial support that would allow me to commit time to his development.

Question 8 - What is your experience on accessing further education or training? Good and/or bad, if your experience was bad what could have made it better?

GEARED UP FOR MUMS AND NOT DADS? NEVER GIVEN OPPORTUNITY. NOT WHAT YOU NO WHO YOU NO.

N/A

N/A

Poor if the client does not have good communication skills either written or verbal. I tried to get 2 autistic client on to some ACE training and failed.

Question 9 - Do any voluntary sector organisations provide support for you?

No

No

No

Yes

Question 9a - If yes, please tell us the name of the organisation
Ngage

Question 10 - Have you ever used an Advocate?
No
No
No
Yes

Question 10a - If yes which organisation was it?
BATIAS

Question 10b - How easy was it for you to access advocacy services?
Quite difficult

Question 10c - If it was difficult, what made it difficult to access?
Lack of advocates available

Question 10d - Did you find the service useful?
Yes

Question 10e - If yes, could you please tell us below what you found useful?

1-2-1 advocacy really supports the service user to independent living but only to a point. When the funding runs out often does the support. Those with autism need confidence that those who work with them will be there and not just disappear when there is no money available.

Question 11 - Have you heard of Direct Payments?

No

Yes

Yes

Yes

Question 11a - If yes, please share your experiences below:

I have heard will shortly try to access so I of yet have no experience?

Only seen clients use this service mostly to good effect if they understand what is happening to their money.

Question 12 - What type of accommodation do you live in?

At home with parents

In social/council housing

In social/council housing

In a home I own

Question 13 - Are you living in accommodation that meets your needs?

No

No

Yes

Yes

Question 14 - Please give details below about what's good and what's bad about the accommodation that you live in:

Have no where for dining table and chair, for disabled child to eat from?

My sister lives in a residential setting for Autistic adults - no option for this above. I do not have autism but work with some clients who do. All live with parents or in residential care.

Question 15 - If you are experiencing problems with your accommodation, please tell us why:

Having to be made to pay bedroom tax and also council tax from benefits. Have no were for table and chairs. bathroom and front door need replacing?

NA

Question 16 - Do you feel socially isolated?

No

Yes

No

Yes

Question 16a - If yes, please tell us below why:

You try bringing up a disabled child on your own! and being persicuted by this evil goverment?

I see my clients socially isolted by local community because they are diffent and often do not communiacate well. There is a general lack of tolerance that meakes my clients regularly feel uncomfortable or excluded. This leads to self social isolation. More clubs for all abilities need to be funded to provide education and exercise opportunities easily.

Question 17 - Please use the box below to tell us anything else you would like:

If help can be given! then stand up and be counted against this goverment that are picking on the poor and vunerable in our society.

I would like funding to be able to usefully emply at least one autistic person who is currently a client.