



Autism Self Evaluation

Local authority area

1. How many Clinical Commissioning Groups do you need to work with to implement the Adult Autism Strategy in your local authority area?

1

Comment

2. Are you working with other local authorities to implement part or all of the priorities of the strategy?

- Yes
 No

If yes, how are you doing this?

We have an overview of strategies in other geographical areas in the wider locality and work with others where it is effective.

Planning

3. Do you have a named joint commissioner/senior manager of responsible for services for adults with autism?

- Yes
 No

If yes, what are their responsibilities and who do they report to? Please provide their name and contact details.

Michelle Hill. Group Manager. Vulnerable Adults and Workforce Planning. Reporting to Katherine Marks, Head of Adult Services. Civic Centre. Victoria Avenue. Southend-on-Sea, Essex. SS2 6ER.

4. Is Autism included in the local JSNA?

- Red
 Amber
 Green

Comment

Autism is included in the JSNA. Estimates of the numbers of those with ASD for Southend-on-Sea are given and are based on national and localised studies. This includes those who do not have a learning disability i.e. 'Higher level' ASD. There is a description of complex conditions and co-morbidity in relation to autism and learning disability.

5. Have you started to collect data on people with a diagnosis of autism?

- Red
 Amber
 Green

Comment

Data on people with a diagnosis of autism is collected as part of their social care assessment. We have changed our Care First System to break down the diagnosis of autism further into categories which include: High functioning autism; Aspergers Syndrome only; Aspergers Syndrome and Learning Disability; Autism. This gives us an up-to-date view of the numbers. We have a data sharing protocol with health services to support and jointly use CareTrak.

6. Do you collect data on the number of people with a diagnosis of autism meeting eligibility criteria for social care (irrespective of whether they receive any)?

- Yes
 No

If yes, what is

the total number of people?

48

the number who are also identified as having a learning disability?

47

the number who are identified as also having mental health problems?

0

Comment

The above is taken from the Care First System which is Southend-on-Sea Borough Council's system. The Community Mental Health System (owned by the South Essex Partnership Trust, SEPT) is a different system which includes those with a co-morbid mental health condition and under 65 years of age, and also those with Autism/Aspergers only. This means that the figures above reflect those with a Learning Disability and autism. At present, CareTrak, which brings up data for both systems does not do so effectively. The local CCG is seeking consent to share data but there is not date for the completion of this yet. We think that systems need to be improved to capture all those with autism.

7. Does your commissioning plan reflect local data and needs of people with autism?

- Yes
 No

If yes, how is this demonstrated?

The Commissioning plan includes local data on autism and indicates prevalence of aspects of ASD including higher functioning ASD. This is based on national and local studies. This helps us to commission services effectively.

8. What data collection sources do you use?

- Red
 Red/Amber
 Amber
 Amber/Green
 Green

Comment

Data is collected from a number of sources. The Commissioning Strategy contains data from PANSI and also from primary sources listed in the JSNA. We collect data from internal systems to assist commissioning decisions. This includes data on children and young people within the transition age range. (14-25). We also use information provided from local organisations and have collected information from autism consultation events. We have therefore made a good start in collecting data and plan to progress.

9. Is your local Clinical Commissioning Group or Clinical Commissioning Groups (including the Support Service) engaged in the planning and implementation of the strategy in your local area?

- Red
 Amber
 Green

Comment

The local CCG and previously the PCT have been involved in our consultations around Autism and additionally transitions. They have inputted into the process and we have included health aspects which have come from their Autism Strategy. An autism partnership board was discussed at the autism consultation event and it was viewed that an autism partnership board was not necessarily needed due to our local authority area being quite small.

We have also been working with the CCG and wider health and social care providers around the actions that have come out of Winterbourne View. Over previous years we have set up a preferred providers list. This means we have appropriate services locally that support people that display behaviour that challenges (often autism related). This offers support to the service user and also allows better links to the families of individuals who often live locally too. We have shared this good practice with other local authorities regionally when we undertook the work. We have also re-shared this with the CSU\CCG when they have been reviewing their placements. We currently have no service users in long term health settings.

We would welcome further practice engagement with our local health services particularly around diagnostic and support pathways.

10. How have you and your partners engaged people with autism and their carers in planning?

- Red
 Amber
 Green

Please give an example to demonstrate your score.

We have engaged people with Autism and their carer's in the development of the Autism Commissioning Strategy. We have run a major local event that brought stakeholders and people with autism together. We regularly attend our local Asperger's Group and people with autism have regularly attended the Learning Disability Partnership Board. We have also included carers and family members of those with autism or Asperger's to other events including carers focus groups, day service reviews and transition design pathways.

11. Have reasonable adjustments been made to everyday services to improve access and support for people with autism?

- Red
 Amber
 Green

Please give an example.

Our services will support clients from a wide range of backgrounds and appropriate personalised support is offered where needed to in order to access our services. This might include the development of accessible information and we adapt the ways in which we undertake consultations in order to meet the needs of individuals. Websites are produced in accessible formats.

The Councils main priorities include the requirement to 'Reduce inequalities and increase the life chances of people living in Southend'. This is our main policy umbrella that helps to drive our approach to improving access and support for all people including those with autism.

12. Do you have a Transition process in place from Children's social services to Adult social services?

- Yes
 No

If yes, please give brief details of whether this is automatic or requires a parental request, the mechanism and any restrictions on who it applies to.

We have a multi agency transition protocol that informs our policy and practice and which has been recently updated. The transitions process is successful in ensuring that adult services are aware of young people well before they become the responsibility of adult services. The multi agency protocol is available to parents and practitioners. We also undertook a multi-stakeholder workshop to discuss transitions where people that had ASD were invited along with family members, professionals and providers.

13. Does your planning consider the particular needs of older people with Autism?

- Red
 Amber
 Green

Comment

We ensure all of our planning and services have an equality impact assessment undertaken and that older people are supported appropriately. We use person centred approaches so that services fit the individual not the individual fit the service. Some social workers who work with older people with autism have received training. The needs of older people with Autism will be considered as part of strategic development.

Training

14. Have you got a multi-agency autism training plan?

- Yes
 No

15. Is autism awareness training being/been made available to all staff working in health and social care?

- Red
 Amber
 Green

Comment: Specify whether Self-Advocates with autism are included in the design of training and/or whether they have a role as trainers. If the latter specify whether face-to-face or on video/other recorded media.

Our autism training is open to all social care staff, care providers, shared lives carers, carers and local authority staff. Health care staff can also attend this training. We also have extended invites around challenging behaviour workshops regionally and this has included other local authorities, providers and health services.

16. Is specific training being/been provided to staff that carry out statutory assessments on how to make adjustments in their approach and communication?

- Red
 Amber
 Green

Comments

More than 75% of assessors have attended autism training to help apply their knowledge in undertaking statutory assessments. This includes social care staff across a range of client groups: Learning Disabilities, Older People and People with Sensory Impairments. In addition, training is available, where a specific need is identified. This helps meet challenges in making specific reasonable adjustments and improve approaches to communication.

17. Have Clinical Commissioning Group(s) been involved in the development of workforce planning and are general practitioners and primary care practitioners engaged included in the training agenda?

- Yes
 No

Please comment further on any developments and challenges.

We are yet to understand what training is being offered by the CCG or CSU. Although the local authority training is open to health staff, including those in the CCG etc. We are in the process of developing a tailored training package which we will make available to our CCG and local GPs. The Royal College of General Practitioners has now made this a priority area for GPs and we hope that they will take up our offer of training support.

18. Have local Criminal Justice services engaged in the training agenda?

- Yes
 No

Please comment further on any developments and challenges.

There is some engagement with staff within Criminal Justice services. Staff who are employed by the Local Authority (within Criminal Justice services in health) are able to take part in training on autism. The local police service has a very robust training programme around autism and Asperger's which is compulsory for all officers to undertake. This includes service user experiences and the ways they can be supported. Police officers basic training also includes vulnerable adults including those with learning disabilities and Asperger's. Some officers will also have had placements in learning disability services and would have supported people with autism. Police officers have also been invited to our autism consultations and work has been ongoing around a local card that can help identify those that need support whether in the community or in police stations. Referrals are made to social care teams where there could be safeguarding issues.

Locally police have attended the local Asperger's groups along with Police Community Support Officers to give reassurance to parents, learn from a police perspective and offer advice and information. They have also provided an emergency services day and visit the local learning disability day service hub.

Diagnosis led by the local NHS Commissioner

19. Have you got an established local diagnostic pathway?

- Red
 Amber
 Green

Please provide further comment.

There is a local established diagnostic pathway for adult Asperger's, but there is no locally established diagnostic pathway for other aspects of Autism. There are effective pathways for children with Autism and effective transitional arrangements. The autism diagnostic pathway is being reviewed to ensure they are easily accessible. This is in the light of the CCGs coming into being.

The Asperger's Service (for young people aged 18-30) is based in the Basildon Community Resource Centre but where possible individuals are offered appointments in other settings in their local areas as well as home visits also. As the Service develops further community bases may be utilised so as to provide services across the Trust area. The Service is a two tier service, providing assessment; and where a diagnosis of Aspergers Syndrome, is made, access to a range of support including occupational therapy, family therapy and individual psychology services.

People over the age of 30 will be offered an assessment only, as the service develops this may be reconsidered

20. If you have got an established local diagnostic pathway, when was the pathway put in place?

Month (Numerical, e.g. January 01)

Year (Four figures, e.g. 2013)

Comment

21. How long is the average wait for referral to diagnostic services?

Please report the total number of weeks

Comment

22. How many people have completed the pathway in the last year?

Comment

23. Has the local Clinical Commissioning Group(s)/support services taken the lead in developing the pathway?

- Yes
 No

Comment

24. How would you describe the local diagnostic pathway, ie Integrated with mainstream statutory services with a specialist awareness of autism for diagnosis or a specialist autism specific service?

- a. Integrated with mainstream statutory services with a specialist awareness of autism for diagnosis
 b. Specialist autism specific service

Please comment further

25. In your local diagnostic path does a diagnosis of autism automatically trigger an offer of a Community Care Assessment?

- Yes
 No

Please comment, i.e. if not who receives notification from diagnosticians when someone has received a diagnosis?

26. What post-diagnostic support (in a wider personalisation perspective, not just assuming statutory services), is available to people diagnosed?

For those who are eligible for statutory services a social care assessment and support, including for a person's carer, is available. For those not eligible, then people are signposted to other services including floating support (which helps to support people in their community), local voluntary organisations, and the National Autistic Society. Locally we have a SAFE (Supporting Asperger Families in Essex) group and there is also an Asperger's family counselling service and occupational therapist following Asperger's diagnosis.

[Care and support](#)

27. Of those adults who were assessed as being eligible for adult social care services and are in receipt of a personal care budget, how many people have a diagnosis of Autism both with a co-occurring learning disability and without?

a. Number of adults assessed as being eligible for adult social care services and in receipt of a personal budget

b. Number of those reported in 27a. who have a diagnosis of Autism but not learning disability

c. Number of those reported in 27a. who have both a diagnosis of Autism AND Learning Disability

Comment

Again the above figures are from the Care First System and have learning disabilities. There will be others with a co morbid mental health condition who are not on this system. From the above and in comparison with question 6 it can be seen that most people are in receipt of self directed support/personal budget

28. Do you have a single identifiable contact point where people with autism whether or not in receipt of statutory services can get information signposting autism-friendly entry points for a wide range of local services?

- Yes
 No

If yes, please give details

There are a range of access points. For access to local authority services and for signposting we have an access service. Individuals can also contact Healthwatch for social care and health advice, information and health complaints advocacy. People may also want to contact local voluntary organisations such as SAFE or our regional NAS.

29. Do you have a recognised pathway for people with autism but without a learning disability to access a community care assessment and other support?

- Yes
 No

If yes, please give details

For all people with a diagnosis of autism and learning disability, the transition lead and assessing team will be the Learning Disability Service. For all people on the autistic spectrum including those with Asperger's syndrome without a Learning Disability, the transition lead and assessing team will be the Community Mental Health Team. However, this is dependent on there being a co-morbid condition.

30. Do you have a programme in place to ensure that all advocates working with people with autism have training in their specific requirements?

- Red
 Amber
 Green

Comment

We ensured that when recently procuring our advocacy services that the advocates have training around autism and offer a professional client led advocacy service. Our Healthwatch complaints advocacy service also has professional advocates that sit within Healthwatch and will support clients if they have a complaint around healthcare.

Since April 2013 we now have a special advocacy service specifically for those with Asperger's as this was identified as a gap in our services. There have been close links with regards to the Asperger's advocacy providers (which also had specialist knowledge in Asperger's as well as autism) and the local Asperger's group. Since this service has started we have had very good feedback which has included the appreciation this is a stand-alone service and not incorporated into either learning disabilities or mental health. We will monitor this service to see if it identifies any trends around support needed or service gaps.

In addition we also have SHIELDS which is a service user led self-advocacy service whom will have an understanding of issues from a service user perspective.

31. Do adults with autism who could not otherwise meaningfully participate in needs assessments, care and support planning, appeals, reviews, or safeguarding processes have access to an advocate?

- Red
 Amber
 Green

Comment

People, whatever their level of communication are entitled, and are helped to use advocacy services either contracted by us or they can use another voluntary advocacy service. Families\Carers are also entitled to use our advocacy service if in relation to a vulnerable adult.

32. Can people with autism access support if they are non Fair Access Criteria eligible or not eligible for statutory services?

- Yes
 No

Provide an example of the type of support that is available in your area.

They can access support in the community including from voluntary organisations or floating support. In addition to this support would be based on the particular need of the individual.

33. How would you assess the level of information about local support in your area being accessible to people with autism?

- Red
 Amber
 Green

Comment

We have a learning disability partnership board website for those with learning disabilities and their families\carers. We also create client specific literature which is made, on an as- needed basis, by experienced team members. For instance, when we consulted on day services we produced information in an accessible format, and delivered message content through people with knowledge of people's ability to communicate. There could be improvements around centralised information.

Housing & Accommodation

34. Does your local housing strategy specifically identify Autism?

- Red
 Amber
 Green

Comment

The present housing strategy mentions disability, including learning disability, and seeks to develop a range of offers. Accommodation is tailored to meet the needs of individuals. Where there is a specific need for accommodation this will be either sourced or developed locally taking into account the specific needs of individuals including high level needs and needs around people that may display behaviour that challenges, and which may need specially reinforced furniture or accommodation. All clients are treated on an individual basis.

Employment

35. How have you promoted in your area the employment of people on the Autistic Spectrum?

- Red
 Amber
 Green

Comment

The employment of people with ASD has been promoted on an individual basis by Local Authority employment co-ordinators. For instance, one individual with high functioning autism was placed in a voluntary position working in a stockroom in a charity shop. The manager did not have much experience with Autism so the Learning Disabilities employment co-ordinator discussed the nature of the disability and helped the manager to understand it. The individual volunteered for 3 years in the charity shop and due to his confidence levels increasing, he was able to work on the shop floor when required. This intervention is against a general approach of matching the right people to opportunities and offering tailored support. We also promote employment by stressing the competences that individuals can bring.

The local Job Centre has also been supported to understand the needs of those with autism in order to understand how they could make their services more accessible. The local authority facilitated staff from the job centre to attend the local SAFE group. Follow changes to the location of day services, service users now access the town centre more frequently. This means more travel and interaction which helps people gain independence and take on voluntary and paid work. This benefit was planned for as part of our review into day services.

Our local authority also employs people with a learning disability and people with Asperger's.

36. Do transition processes to adult services have an employment focus?

- Red
 Amber
 Green

Comment

Transition social workers discuss employment with young people, which is a part of their transition plan. They then make referrals to the employment team within the Local Authority who then further discuss the individual's future aspirations, choice and opportunities available. Appropriate placements are then made.

Criminal Justice System (CJS)

37. Are the CJS engaging with you as a key partner in your planning for adults with autism?

- Red
 Amber
 Green

Comment

There has been lots of individual pieces of work undertaken such as training around learning disabilities with the witness care team and links to safeguarding with the local police but this work needs to be developed further.

Optional Self-advocate stories

Self-advocate stories.

Up to 5 stories may be added. These need to be less than 2000 characters. In the first box, indicate the Question Number(s) of the points they illustrate (may be more than one). In the comment box provide the story.

Self-advocate story one

Question number

34

Comment

One Shared Lives Carer has told us about her experience in being a Shared Lives Carer for someone with Autism in helping someone achieve independence in accommodation through supported living. The development of shared living relates closely to our accommodation and support strategies and this example shows the practical approach to this.

She says that:

** The young man that she cared for has severe autism and behaviour that challenges is being helped over an 18 month period to be enabled to take up a supported living tenancy. The Shared Lives Carer has helped that person to:*

o Improve their travelling skills, giving them the independence to go where they want to. Previously they had got lost.

o Develop cooking-skills and personal hygiene skills. This has been to a simple level but the person is now likely to be able to support themselves.

o Understand that person and the environments that are not conducive. This enables activity and environments to be adapted, reducing the risk of frustration and behaviour that challenges. This adaptation also takes place at home, with the Shared Lives Carer telling us that an understanding and knowledge has been developed that enables transition.

The Supported Living Tenancy will start in April 2014. The Shared Lives Carer will work with support workers in the new supported living environment to enable the transition to the new environment to run smoothly. The objectives of this Shared Care relationship have been clear throughout and the Carer tells us that the Shared Lives manager is always on hand to speak to and resolve any possible problems to achieve those objectives.

Self-advocate story two

Question number

35

Comment

Comment JBS made no attempt to recognise A.S. condition. (they said they did not have a dissability adviser, job centre sent my daughter to Ingeus (who the government pay) to help people into work had no idea about AS, and did not recognise high performing (my daughter was sent on a course for alcoholics and drug addicts)!!!! My daughter felt so humiliated with the lack of understanding by Ingeus and their failure she see her potential that she could endure them no longer, so now she is not claiming benefit.

Self-advocate story three

Question number

12

Comment

The transition from children's to adult services has been particularly difficult for me. I have had huge problems with schools not understanding the difficulties I had being in a classroom with lots of other people due to my Aspergers Syndrome. I am clever and got a place at Southend High for Boys but they didn't want me and didn't understand Aspergers syndrome or how to help me and as a result of this I became very mentally ill and had to be home schooled from the age of 11. Thanks to the help from the social workers and weekly counselling with the children with disabilities team I had managed to go back into education at the age of 17. All the help stopped when I reached 18. There was no social work support (apparently I am too clever but I have had a social worker since 7yrs old) and the counselling stopped. Apparently there is no counselling available to adults, who have training in Aspergers syndrome and normal counsellors don't understand that I didn't know how I was feeling, I couldn't work out my own emotions, whether I was happy or sad and they talk about emotions and social things that I find difficult to understand. Many of the adult psychiatrists also don't seem to understand autism. They tried to diagnose me with things like bipolar when I first began to understand the difference between feeling happy and sad (at the age of 19), they didn't understand and wanted me to take stronger tablets. My parents had to find me private counselling when I left the child and family service as I really needed someone to help me who understood ASC. I also rely on them to defend me when I see the psychiatric services I don't feel safe as they don't understand.

Self-advocate story four

Question number

10

Comment

I, along with a few other Asperger adults and parents, contributed to a consultation on the local autism strategy in autumn of last year. I received positive feedback on my presentation and I believe that our views were taken into account. One of our number was initially hesitant about speaking from the front of the meeting, but having seen the supportive way in which I was received, she felt able to add her input too.

The local SAFE (support group) committee are continuing to be kept informed of developments. We remain concerned about the timescale for implementing the strategy.

One of the concerns I expressed was about the availability of an autism diagnosis, particularly for adults. I was fortunate in that I was able to obtain a private diagnosis some years ago. I hear that progress is being made on this front, but there is still a long waiting list. It worries me that we are basing our ideas about what is needed on a small subset of the total number of autistic people around: those who have had the good fortune to be diagnosed already. Also there are people in need of help, often labelled schizophrenic in the days before autism was widely understood, who aren't aware that they are eligible under the autism strategy.

Self-advocate story five

Question number

19

Comment

My son was referred to the Maudsley Hospital in London for a diagnosis at the age of 23 after years of me trying to get help since he was around 1 year old. He now suffers from depression, anger issues, he is socially isolated and he left school at 15 with only one GCSE as he didn't receive any extra support or understanding.

This marks the end of principal data collection.

Can you confirm that the two requirements for the process to be complete have been met?

a. Have you inspected the pdf output to ensure that the answers recorded on the system match what you intended to enter?

Yes

b. Has the response for your Local Authority area been agreed by the Autism Partnership Board or equivalent group, and the ratings validated by people who have autism, as requested in the [ministerial letter](#) of 5th August 2013?

Yes

The data set used for report-writing purposes will be taken from the system on 30th September 2013.

The data fill will remain open after that for two reasons:

1. to allow entry of the dates on which Health and Well Being Boards discuss the submission and
2. to allow modifications arising from this discussion to be made to RAG rated or yes/no questions.

Please note modifications to comment text or additional stories entered after this point will not be used in the final report.

What was the date of the meeting of the Health and Well Being Board that this was discussed?

Please enter in the following format: 01/01/2014 for the 1st January 2014.

Day

Month

Year