



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?

3

Comment

There are three CCGs in the Leeds area. The North CCG hosts the mental health, learning disabilities and autism clinical commissioning function on behalf of all three CCGs.

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 are fully engaged with the Yorks and Humber regional autism planning group.

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.

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Head of service
Adult Social Care Commissioning.
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Reports to Dennis Holmes. Deputy director strategic commissioning. Adult Social Care. Leeds city council.*

4. Is Autism included in the local JSNA?

- Red
 Amber
 Green

Comment

Our Joint Strategic Needs Assessment is an iterative process. The 2012 JSNA identified a number of areas where we need more detail, greater clarity and deeper understanding- adults with autism was one of these areas. As such, our autism lead is compiling both quantitative and qualitative data (including the HNA which informed the Leeds Adult Autism Strategy) and working with public health staff through the Joint Information Group to develop a set of information which will be included in the next version of our JSNA, due to be published next year.

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

- Red
 Amber
 Green

Comment

We do collect some data on people with a diagnosis of autism from a number of sources. This is not complete and is unlikely to be complete until recording systems in health and social care are fully required to collect information on diagnosis. Question 8 lists sources.

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?

71

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

57

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

4

Comment

We have entered figures which we have extracted from our system. These will be a considerable underestimate as there is currently no requirement to formally enter autistic spectrum conditions as a health need- however some workers have chosen to do this giving us these limited figures.

We will comply with the guidance from the Health and Social Care Information Centre on recording autism and Asperger's as an additional health need. This will come into use in 2014/15.

Over a period of time this will give us the information we need to be able to answer this question more fully.

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

- Yes
 No

If yes, how is this demonstrated?

We are in the process of developing a joint health and social care autism commissioning plan. This will be informed by the quantitative and qualitative needs data which we currently hold.

The Leeds market position statement (to inform local providers of market needs) includes a section on autism which uses the data we currently have.

8. What data collection sources do you use?

- Red
 Red/Amber
 Amber
 Amber/Green
 Green

Comment

We have, and use, information from children's services, further education and higher education, provider services, social care (Mental health, learning disabilities and generic) and health (diagnostic service and GP audit) in order to broaden our understanding of demand. This information is compared against the local demographic prevalence rate. We will continue to collect and refine this data. As yet it is incomplete and will remain incomplete until diagnosis and recording rates have improved.

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

A representative of the CCGs sits on the autism partnership board and is in regular liaison with the autism lead about planning and implementation.

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.

There are reference groups for carers and people with autism. The meetings are timed to fit in with the quarterly autism partnership boards (APB) -the APB agenda is discussed at the meetings and feedback is taken. Each reference group selects three delegates for the partnership board. Input from the reference groups heads the agenda for the APB - the groups raise the three issues which they think are currently of most importance. The advocacy service provides support to the reference group for people on the spectrum in order to make it more accessible.

In addition to this the autism lead visits groups of people on the spectrum and carers to update on progress and take feedback - either on invitation or approximately annually. Providers of services for people with autism are encouraged to speak to their service user and to invite the autism lead to speak to them.

Although systems are in place we would have preferred to score this amber/green as engaging people well on the autistic spectrum will continue to need attention.

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.

Some reasonable adjustments have been made to some services and others are exploring options.

We have rated this as red but feel that there are areas of progress and increasing awareness by public bodies of their obligations under the equalities act.

Examples include:

LCC Equality monitoring form references autism.

Museum services including the accessibility needs of people with autism in their project to increase access.

LCC are in the process of adding autism to their HR toolkit

The partnership board were unclear why the RAG ratings only referred to council services when there are many others which could be included.

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.

The transitions service is targeted at children with complex needs in receipt of children's social care who are likely to be eligible for adult social care. Referral should be automatic following a year nine review.

Most children on the autistic spectrum do not fit these criteria in that they are not in receipt of children's social care.

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

- Red
 Amber
 Green

Comment

As yet, the information we have does not allow us to be specific about the needs of older people. There are relatively few known diagnoses of older adults who do not have an additional diagnosis of learning disabilities. Those older adults should ideally receive a person centred service which will cater for their autistic needs as well as their other needs. Another group of older adults is those who may be living at home with older parent carers not yet in receipt of services.

We work on the assumption that there will be a hidden population of older adults on the autistic spectrum and we will be making our awareness training available to provider services for older people who will, it is probable, be supporting people on the spectrum.

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.

We have a range of awareness training on offer from various organisations. Adult social care has a regular programme of awareness training available to its own staff and provider organisations. In addition there is a shorter session incorporated in induction and E&D training. Health agencies are in general less far forward in this process.

As none of the local training providers actively engaged people on the spectrum or carers in their training we have invested some one off training money in developing a local autism training social enterprise. We had a competitive process and have selected a provider who will provide training at a very reasonable cost and work to engage self advocates and carers in the process in a variety of ways appropriate to their needs and wishes. The implementation phase of this service is due to begin in October 2013.

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

Adult social care has trialled a day's training from a specialist agency for social care assessors. This was well received. The details of roll out are being finalised in parallel with the work on the diagnostic and assessment pathway. In addition some care managers have received training from the diagnostic team.

We would have preferred to score at red/amber as specific training has been offered (and will be extended) but as yet we are not at 50% of all community care assessors.

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.

This remains a challenging process due to the size of the city and- as much as anything- the massive amount of health service reorganisation. Moving the process on to be able to score green on question 15 will now necessitate engaging a different set of people.

The PCT was involved in the initial development of the workforce plan. The involvement of the various health trusts has been variable.

We are aware of the issues around GPs and primary care practitioners and intend to offer some targeted training for them to coincide with the development of a diagnostic and assessment pathway.

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

- Yes
 No

Please comment further on any developments and challenges.

We are aware that some training has been accessed by elements of the criminal justice service. For example the in prison health service has had some awareness training as have some probation staff. The police are exploring how to increase take up of their existing e learning package by front line staff. This is not however systematic.

[Diagnosis led by the local NHS Commissioner](#)

19. Have you got an established local diagnostic pathway?

- Red
 Amber
 Green

Please provide further comment.

We have a local diagnostic service which has been awarded additional funding to enable it to expand to meet existing demand. There is a recognised pathway in that the referral route is clear but not all GPs are aware of this. NICE guidelines are considered within the pathway.

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

Month (Numerical, e.g. January 01)

9

Year (Four figures, e.g. 2013)

2011

Comment

We have a local diagnostic service which has been awarded additional funding to enable it to expand to meet existing demand. There is a recognised pathway in that the referral route is clear but not all GPs are aware of this. NICE guidelines are considered within the pathway. This diagnostic service started on this date.

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

Please report the total number of weeks

36

Comment

The diagnostic service has now (September 2013) recruited new staff so this waiting time is likely to reduce.

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

34

Comment

For comparison.

2011-12 92 assessments, 63 completed pathway

2012-13 67 assessments 34 completed pathway

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

Yes

No

Comment

Yes they are working together with the local authority autism lead to develop the pathway to include assessment and post diagnostic support.

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?

People who have received a diagnosis are informed of their right to ask for a community care assessment. Current joint work on the assessment diagnostic pathway will build this step in.

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

Currently only 1 follow up post diagnostic appointment with the diagnostic team.

Post diagnostic health support is currently being planned for. The need for non- statutory post diagnostic support will be flagged up in the diagnostic and assessment pathway planning process and in the commissioning plan. Currently there is a small amount of social group and also advocacy support available.

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

30

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

29

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

1

Comment

13 of these people are receiving their personal budget as a direct payment (i.e. getting a cash payment) 17 are receiving a local authority managed budget.

See the answer to q 6 for the limitations of these figures.

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

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

People with autism but without a learning disability can access a community care assessment and support in the same way as people with autism and with a learning disability ie by requesting an assessment via the contact centre. The assessment and support planning (if found to be eligible) will however be carried out by a different care management team. We are currently working on a diagnostic and assessment pathway which will firm up the referral from the diagnostic service to the social care assessment. This process will apply equally to both groups. (see q. 25)

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

Local advocacy organisations are part of a consortium tasked with working together to meet all the advocacy needs in the city. We have an autism specific advocacy service - this however is on short term funding so its continued existence is not secure. All volunteers/workers in this autism advocacy service have received specific training. Other advocacy services in the city know that they can refer to the specialist service if necessary and they do do this. Some other advocacy groups have accessed autism awareness training for some of their staff.

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

Specialist volunteer advocates have access to more in depth training and information around autism. In addition they have access to a wide range of autism specific information and resources, short advocacy and autism awareness training and a full day in autism, advocacy and communication. Some professional advocates have also attended more specialist training and most have had some autism awareness. The autism volunteer co-ordinator has attended further training, picks up some autism cases and can offer information and advice to the wider team and other advocacy services when needed.

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.

We have answered this question as no on the assumption it referred to a generic support service for non FACS eligible people but there are some more specific resources. People can access universal services such as employment support or education some of which are beginning to make reasonable adjustments to the things they offer. In addition there is a some specialist support within different services.

There are a few voluntary social support groups.

See also answers to q 34 and 35

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 small range of low level direct access services, in order to fully meet the needs of people on the autistic spectrum these would need to be broadened. The current commissioning process is addressing the range of paid for support. The information on what we have so far is up to date but there is still an issue of some people knowing where to access the information.

Housing & Accommodation

34. Does your local housing strategy specifically identify Autism?

- Red
 Amber
 Green

Comment

The existing Housing Strategy has Independent Living as a theme with the expectation of promoting independence, dignity and respect for vulnerable groups. In the updated Housing Strategy we will include something about the needs and requirements of people with autism.

There is some autism specific supported living accommodation in the city. The mental health floating support housing service (delivered by a consortium of third sector organisations) specifically includes people on the autistic spectrum as an eligible group. The consortium are able to identify their autistic clients and are accessing training.

Employment

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

- Red
 Amber
 Green

Comment

We have done a lot of work in partnership with the DWP locally. The outcomes of this are awareness training of all job centre staff, the beginnings of engaging employers, two new grant aided employment support services, one for people with a range of disabilities but the staff have autism specific training and another one for people with autism diagnoses. In addition we have worked on collating and distributing information about employment advice services which are accessible to people on the autistic spectrum.

A local trainer is able to work with employers around individual needs.

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

- Red
 Amber
 Green

Comment

The transitions service for children with complex needs address children's needs for employment, education or meaningful occupation in adult life.

There is some employment support work undertaken by other transitions services eg the CAMHS transitions service. However as yet there is not a consistent employment focus across all the transitions supports for young people on the autistic spectrum.

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

We have regular CJS involvement in our autism partnership board and we know that sections of the CJS have accessed autism awareness training. We have had initial discussions with the police and are considering autism alert cards.

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

192830

Comment

I am a 42 year old man. The first time anyone mentioned Asperger's to me was when I was at the university on an access course. That started me on a path to getting social care support which still isn't quite finished. My story shows how complicated it is to get what you need in a reasonable amount of time. People have been helpful and the different bits of services are beginning to be in place but they are still disjointed and a bit hit and miss.

This was my pathway to getting support:

*Nov 2011 - referred for 'non clinical assessment'.
Because I had this my psychiatrist referred me to the Leeds diagnostic service.*

April 2012 - I was diagnosed and had one follow up interview.

May 2012 - I requested a community care assessment (I did this myself following the advice on the NAS website)

October 2012 - Adult social care say I can have some support. I have been allocated funding (in the form of a direct payment) for 2 hours support a week. This took two different social workers, one to do the assessment and one for long term support.

My social worker and me talked to the two local specialist providers. Neither of them could help me because they had a long waiting list.

Jan 2013- I found out about Leeds advocacy by accident and referred myself. They did an assessment and have been getting to know me. There is a built in delay in their systems but they are always professional, empathic and understanding.

August 2013 - The advocacy service suggested another local provider - who came to visit me at home. They think they may be able to find someone to help me but they say it would be better if I had three hours support because that is how long their workers normally work.

Sept 2013. I am asking my social worker if I can have three hours rather than two.

So you can see that it has taken nearly 2 years and I still don't actually have anyone in place to help me. People have been helpful but it is the way systems fit together that is difficult. I have done quite a lot of this work myself - and I can do this so that is OK.

Self-advocate story two

Question number

19

Comment

Regardless of how often everyone parrots the latest directive, that a diagnosis is a label, isn't important, etc, the truth is, this is a ploy to save money that should be spent on diagnosis, statements, help and support, etc. A diagnosis is essential to all concerned; the person involved, parents and teachers. It provides an explanation that can be reassuring and should mean the person gets the help, understanding and support they need.

The diagnostics service in Leeds seems to be a resounding success and is something to be proud of.

I am certain that I have Dyslexia, Dyspraxia, Aspergers and Irlen Syndrome, however GP's don't want to invest resources on ordinary women like me. I haven't had a penny or a second invested, in any help or support. These problems have ruined my life and made my life horrendous. I struggle coping, can't get full time work, and suffer from severe depression and numerous problems that I don't know how to deal with. Every so often my life reaches crisis and everything falls apart. I have had virtually nothing but abuse, accusations, threats and blame from parents, GP's, officials and therapists.

As a girl I was beaten, punished and threatened at school and at home, often for my phobias, fears, baffling behaviour and for not talking. I regularly shook from head to foot with terror at the prospect of another beating, or another onslaught. If I wet my pants in terror I got another beating. I had an extreme phobia of school, if someone had burned it down, I would have celebrated.

Whilst I went through absolute hell, in comparison my male counterparts were nurtured, supported and often indulged. This is why a diagnosis is so important and why it is essential to up date diagnostic criteria so that girls/women are included and no longer discriminated against and how Autism affects girls/women will be better understood. Then maybe some girls/women will get the help and support they need to succeed at school and in life and not have disastrous lives.

Self-advocate story three

Question number

26

Comment

I had always had feelings of not fitting in, high anxiety and a chronic fear of failure. I struggled with maintaining employment, despite a high level of education and training. I did not understand the office politics and banter and could not cope well with changes so left many jobs after my anxiety became unmanageable. I was finally officially diagnosed with Asperger Syndrome late in life at 40 years old. I was told there was no support available to me because I was too able and felt in limbo with my life. What helped me enormously was the support of my long term mentor. He opened up opportunities to me and gave me the confidence to achieve my goals in a non judgemental, empathetic way. He believed in me and my abilities despite my lack of awareness and low self esteem. I felt valued despite my oddities! I am now in a much better place emotionally and I am going from strength to strength academically and in my career.

Self-advocate story four

Question number

35

Comment

My work was difficult for these reasons:

Taking on too much responsibility, in any job role if I see a task that needs completing I will be pro-active and do this, then it becomes expected and I am given a lot of responsibility I will do this even though it is not my role.

This and the inability to say no as I do not like to disappoint and I take pride in performing to the best of my ability means I do twice the amount of work than others, without any recognition or a reflection in my pay so I am taken advantage of.

As I suffer from time paranoia I turn up to work approximately 30 minutes to an hour early and then asked to work

I am unable to switch off once I have left work as I am thinking about all the things I need to be doing next shift and any of the problems which need addressing. Also I would analyse the procedures and think of time effective ways to work to ensure efficiency.

As I am a bright individual I am overlooked on training so I am given a lot less training than all other members of staff and I do not have the same benefits as everyone else. For me autism specific training would have been good as I need a logical reason for change. Also the majority of the time the procedures were changed to the correct way when upper management were visiting which also made this very confusing.

I found it extremely difficult to understand why some people were in the positions they had. In the end I realised people were wanting the salary but not willing to put the work in to earn this. Also how people can work in a place where they obviously did not enjoy their role and weren't interested in it.

It was difficult dealing with people who are reactive rather than logical and let their emotions rule their judgement and their work ethic. I am extremely approachable and friendly so if I do identify someone is having problems by their emotions I will let them confide in me and take on their emotional problems as if I was experiencing them myself.

The clear divide between staff and managers then managers and upper management is a hard concept to accept as everyone has a different role supposedly to ensure the smooth running of the business. It means staff are unable to approach managers and managers are isolated and creates a hard to work in environment.

Due to the repetitive process of work I developed an ocd where things had to be done in a particular order at work and this impacted on my home life. Any forward planning would be a massive ordeal and I had to know the exact route, train/bus number time I was setting off, time I was returning and turned any plans into stressful rather than enjoyable ones. I also did a lot of repetitive things without realising I was doing them.

Self-advocate story five

Question number

161930

Comment

My son struggled with life and was not able to manage since leaving high school. He would have liked to have a job and complete further education but did not manage this and had no support. He "didn't fit" but we struggled to get a diagnosis of what was wrong. We couldn't help him to manage his benefits and get social services support as he had no formal diagnosis but he couldn't organise help himself due to his anxiety and communication difficulties.

After several years becoming increasingly isolated, he managed to get a diagnosis of Asperger syndrome (2008) but had to go out of area and found this process very traumatic. He had no support post diagnosis and struggled to understand and accept the diagnosis. Although the out of area service identified many areas of continued need, particularly around speech and language and psychology we were told there was no route in Leeds to help him get this support.

We spent a long time trying different ways to get effective support from social services and health but no one seemed to want to take any responsibility for his needs being met. He was passed between different services and we seemed to be going round in circles. He continued to deteriorate, lose skills and became increasingly "shut down" and isolated.

Finally, he has moved into his own supported living tenancy with staff who have specialist training and this has been positive. He also has a social worker that is more proactive in trying to get the right services for him but accessing support from health is still very difficult. We have been told there is no service locally and he cannot cope with returning to the service out of area due to the distance and negative connotations. We are still trying to get him the speech and language, psychiatric assessments and psychology support that he has been identified as needing.

The greatest help he has received has been from autism advocacy. Their support in trying to get him access to the support he needs has been invaluable. As a family, we found the lack of information about services and lack of a clear route into them very frustrating and we have experienced years of going round in circles on his behalf to try to help him to get the support he needs to enjoy his life.

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