



# 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?

4

### Comment

*South West Lincolnshire Clinical Commissioning Group has the lead function under a federative arrangement with the three other 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?

*Working with the Autism Leads Network for the East Midlands which provides peer support for local authority commissioning managers and lead officers with responsibility for autism.*

*The regional clinical leads network is in the process of being refreshed.*

## 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.

*Justin Hackney, Joint Assistant Director MH & LD Commissioner & Category Manager*

*Senior Commissioner for MH & LD Services, including autism. Reports to Director of Adult Social Services. The existing Joint Commissioning Board for Learning Disabilities will be recreated to include autism and mental health.*

*Tel: 01522 554259*

*Mobile: 07774 661042*

*Email: justin.hackney@lincolnshire.gov.uk*

*Address: Room 114a, County Offices, Newland, Lincoln, LN1 1YQ*

#### 4. Is Autism included in the local JSNA?

- Red  
 Amber  
 Green

##### Comment

*Autism will be included in next JSNA due for publication in 2014. An autism commentary will be included in Mental Health narrative. An application for a separate autism chapter in the JSNA has been lodged.*

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

- Red  
 Amber  
 Green

##### Comment

*Lincolnshire Partnership Foundation NHS Trust collect some data relating to referrals specifically for ASD assessments.*

*These figures will establish some baseline information on service users understood to have autism and development plans will address the need to ensure comprehensive data capture in the future.*

*Primary care also collects some data on the incidence of autism but this is not currently available. Further discussions with CCGs will aim to agree guidance on read codes, and a data sharing protocol.*

*The national prevalence database PANSI (Projecting Adult Needs and Service Information System) projects the number of adults 18-64 with autism spectrum disorders. The figures for Lincolnshire show : 4,237 (2014), 4,288 ( 2016), 4,343 ( 2018), 4,381 (2020).*

#### 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?

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

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

##### Comment

*Data on autism is not currently collected by Lincolnshire County Council using the social care database AIS. However, an internal audit of 1,978 sample cases currently open to Learning Disability Services has shown the following results :*

*\* How many cases in total are currently open to your team?      1,978*

*\* Of this total, how many service users have a confirmed diagnosis of Autism? 459*

*\* Of the total, how many additionally do you regard as having Autism?      299*

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

- Yes  
 No

#### If yes, how is this demonstrated?

*If yes, how is this demonstrated?*

*Local data is acknowledged in the Adult Care current commissioning intentions plan for 2013/14 although this document is not yet published.*

### 8. What data collection sources do you use?

- Red  
 Red/Amber  
 Amber  
 Amber/Green  
 Green

#### Comment

*PANSI and social care data referred to in Q5 and Q6 above.*

### 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 CCG representative is a permanent member of the Autism Partnership Group and is in regular liaison with Lincolnshire County Council.*

### 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.

*People with autism, and carers of people with autism are involved in the Autism Partnership Group, and included in co-production of the Adults with Autism Strategy and other documents.*

*A consultation process leading to the drafting of a Joint Commissioning Strategy for Lincolnshire was held earlier in 2013. A consultation questionnaire was developed and made available on-line, in hard copy and in an easy read format. In addition to the questionnaire, a facilitated consultation workshop was conducted to discuss key themes in respect of autism with a wider audience consisting of service users, carers and providers.*

*The finale of the consultation period also coincided with the 10th Lincolnshire Autism Conference, organised by the Lincolnshire Autistic Society and STAPS (Specialist Teaching and Applied Psychology Service). Each delegate (approximately 225) was provided with a hard copy of the consultation questionnaire in their delegate pack, which they were able to complete and return to staff on the day for submission.*

*A total of 214 questionnaires were received during the consultation period, with 160 of these submitted online. A further 54 hard copy paper versions of the questionnaire were returned, five of which were completed in the Easy Read format.*

*21 people stated that they were a person with autism, which amounts to 9.8% of the total responses. Almost 50% of respondents (106) confirmed that they were a carer of someone with autism.*

*A significantly larger proportion of females (73.8%) completed the questionnaire, with the number of male respondents being 44, which amounts to 20.6% of the total participants. 12 people (5.6%) preferred not to provide details of their gender.*

*All future planning work incorporates the need for involving people with autism and carers. This will include work to review current autism pathways and to develop autism training plans.*

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.

*No clear policy has been published yet. Some anecdotal examples suggest improvements are being made as a result of autism awareness and professional training.*

*Future work will ensure that the needs of people with autism are specified in the procurement of everyday services.*

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 transition process is intended to be comprehensive and to account for all young people from age 14 (Year 9) who are identified as having autism. Children with autism identified in the Special Educational Needs system have statements of Special Educational Needs (SEN) and are entitled to transition planning from Year 9. This process is intended to include anticipated social care need which can initiate a request for a social care assessment by the local authority. Parents and carers can also request a social care assessment independently by contacting the Customer Services team. Access to services following a social care assessment is subject to meeting access criteria. Children and carers not meeting access criteria for social care may be signposted to alternative sources of support.*

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

- Red  
 Amber  
 Green

**Comment**

*Members of the autism partnership are aware of this issue and the need for further work in this area. Older people with autism are mostly supported in generic older peoples services; Learning Difficulty services can cater for older people with autism if they also have a learning difficulty. Older People's Mental Health services can offer a similar specialist function. Future planning will incorporate recommendations from the National Autistic Society report "Getting On ?" (2013) which summarises the work of the Autism and Ageing Commission.*

**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.

*Lincolnshire Partnership Foundation NHS Trust provides autism awareness training to all its staff as part of the mandatory training programme.*

*A similar training programme is being extended to social care staff; to date 48 have attended, including 24 assessment and care management staff, the majority in learning disability services.*

*Training plans are being developed to ensure that all adult care staff receive an appropriate level of autism awareness or training. Members of the autism partnership have had input into training design and will be represented on the autism training working group.*

*There is limited self-advocate involvement in training delivery. Training plans will ensure self-advocate involvement in future delivery.*

**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**

*Some specialist training has been provided for assessment staff but this has been on a voluntary basis and does not cover 50% of those eligible. A revised training plan will address this requirement to ensure all assessment staff are able to make necessary adjustments.*

*Lincolnshire Partnership Foundation NHS Trust provides training to staff under an existing programme.*

**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.

*Some training has been promoted to GPs but no comprehensive plan has been developed yet. CCGs will be included in developing training plans.*

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

- Yes  
 No

Please comment further on any developments and challenges.

*Lincolnshire Police provide some autism awareness training to their staff delivered by a self-advocate. Lincolnshire County Council has appointed a dedicated social worker (Associate Lead Professional) to develop advice and in-reach support to local prison inmates. The opportunity will also be taken to raise awareness of autism and address the needs of inmates with autism.*

## Diagnosis led by the local NHS Commissioner

19. Have you got an established local diagnostic pathway?

- Red  
 Amber  
 Green

Please provide further comment.

*The pathway enables individuals with presenting needs to receive a spot purchased DISCO (Diagnostic Interview for Social and Communication Disorders ) assessment, Those requesting a diagnosis who have no presenting needs do not have access to a diagnostic assessment. Waiting times are within 6 months and NICE guidelines are considered within the model.*

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

Month (Numerical, e.g. January 01)

10

Year (Four figures, e.g. 2013)

2012

Comment

*Pathway to be reviewed October 2013*

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

Please report the total number of weeks

4

Comment

*Average wait 4 weeks, longest wait 11 weeks.*

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

25

**Comment**

*25 individuals excluding learning disabilities (data for secondary diagnosis ASD for people with a primary LD diagnosis is not collected)  
Around 50% of referrals have had funding for an assessment agreed*

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

- Yes  
 No

**Comment**

*Through a federated function agreement with South West Lincolnshire CCG*

**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**

*Specialist diagnostic pathway via main stream mental health practitioners who have undergone DISCO training. The diagnostic pathway is compatible with pathways for community health services and for social care although it is acknowledged that improvements need to be made. The diagnostic pathway review due to be launched in October 2013 will give opportunities to develop a more integrated autism pathway.*

**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?**

*A referral may be made but diagnosis is not in itself accepted as a prima facie need for assessment. Where a carer has been identified an automatic referral for a Carer's Assessment is made. Referrals can also be made to universal support services such as First Contact. The First Contact scheme, is a partnership operating across Lincolnshire which encourages older people to fill in the First Contact checklist. The checklist helps people to access free information and advice from a range of relevant organisations offering help to stay safe and independent.*

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

*Local information and advice website [www.mychoicemycare.org.uk](http://www.mychoicemycare.org.uk)  
National and local voluntary organisations such as the National Autistic Society  
Continuing healthcare NHS funding ( subject to eligibility)  
Signposting to housing support, advocacy, short breaks  
Telephone advice lines : National Autistic Society  
Statutory social care services (subject to eligibility)*

**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

*Of the total of 5,232 for all adults, 1,080 are people with a Learning Disability receiving a Personal Budget. Of this number 283 have a Direct Payment. It is not currently possible to confirm numbers of people with autism within these figures. A new IT system is currently being designed and will incorporate the necessary functionality to capture autism data.*

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

*The local website [www.mychoicemycare.org.uk](http://www.mychoicemycare.org.uk) which lists sources of health and social care support.*

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

*The general community care assessment pathway is available but is not autism specific and is subject to eligibility criteria. Access is through the Customer Service team who carry out an initial screening process and refer for full assessment or sign post to alternative courses of advice or support. The local website MyChoiceMyCare is widely advertised as a source of information for those either wishing or needing to access services independently.*

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

*Staff with the contracted advocacy service provided by Voiceability receive some autism awareness training. Not all advocates have received autism training but those that have are matched with clients with autism.*



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

*Lincolnshire County Council commissions a generic advocacy service from Voiceability.*

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.

*Support is available from a number of Third Sector groups. Support is likely to be information, guidance and emotional support such as that provided by First Contact : [www.firstcontact.org.uk](http://www.firstcontact.org.uk)*

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

*Comment: some lower level, preventative services provide befriending, advocacy and social activity. A database of services relevant to autism has been compiled and is available on-line. It is being revised to ensure it is as comprehensive as possible. In a large county such as Lincolnshire not all services are available in all districts.*

## Housing & Accommodation

34. Does your local housing strategy specifically identify Autism?

- Red  
 Amber  
 Green

#### Comment

*The seven district local authorities with housing responsibility have separate housing strategies. Lincolnshire County Council is proposing to develop a countywide Housing and Support Strategy which will include Extra Care Housing. The tasks involved would include:*

*Reviewing existing Extra Care Housing, and general housing, strategies*

*Develop new strategy (complete review and analysis)*

*Link into Capital and Infrastructure Plan*

*Map existing provision*

*Develop with assessment and care management and performance clients groups and postcodes*

*Develop the relationship with health commissioners*

*Agree whether we go out to tender for a care/support contract*

*This project is included in the current work programme but timescales or resources have yet to be confirmed.*

## Employment

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

- Red  
 Amber  
 Green

### Comment

*A number of Third Sector agencies such as Linkage and The Shaw Trust provide employment related support for people with special needs including autism. Usually this forms part of the transition process for young people but services can be extended to age 25 in some instances. The Welfare to Work programme fulfils a similar role for the statutory sector.*

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

- Red  
 Amber  
 Green

### Comment

*Linkage, an independent trust provides employment related support as part of the transitions pathway. Other groups such as the Shaw Trust, Pelican Trust and Lincoln College play a role in employment related support. The Welfare to Work programme fulfils a similar role for the statutory sector : for the financial year 2012 - 2013 the number of people aged 17 - 26 receiving employment placement support through this programme was 44. During the same period the number of children and young people with special needs receiving Welfare to Work related training was 169. Data for the Welfare to Work programme does not currently identify how many people accounted for in this data are 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

*The police are members of the Autism Partnership Group. A regional conference on autism and CJC will take place in October 2013. It is intended that this event will initiate further work among the elements of the CJC in Lincolnshire.*

*A dedicated social worker (Associate Lead Professional) has been appointed to develop advice and in-reach support to local prison inmates. The opportunity will also be taken to raise awareness of autism and address the needs of inmates with autism.*

## 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

35

## Comment

*In the few months Peter has been a student at Linkage College, he has amassed a collection of first-time experiences. He has attended his own review, ridden a horse, performed in public for the first time and, most significantly, had a blood test for the first time.*

*Peter is severely autistic and his new experiences, all challenging in their own way, are all reasons to celebrate.*

*'He has made remarkable progress in such a short space of time,' says the manager of Linkage's specialist autism provision.*

*The manager explained that Peter was also accessing more courses in a shorter space of time than had ever been envisaged. The process has been speeded up dramatically, with Peter now accessing College provision on three days each week in addition to work experience at an animal rescue centre.*

*The scale of Peter's achievements is all the more significant because of the challenging journey he has travelled, which included a 'disastrous' experience in specialist further education previously. His parents are over the moon.*

*Peter's father explains that his son's most significant progress has been through his confidence and trust in the staff who work with him. This has enabled him to feel safe and supported in becoming more independent and also in controlling his emotions and handling situations differently.*

*Being able to deal with challenging situations more positively, has also enabled Peter to take on lots of new situations with much greater confidence. He is studying stable management and enjoying riding for the first time. He also enjoys a course in performing arts, part of which involved him singing in a recent College show. He attends a leisure, health and fitness course, works in the College bistro and has started work experience at a local animal rescue centre.*

*He proudly carries his folder of certificates with him whenever he goes home, one of which - the Helpful Horse Award - refers to his skills ensuring a horse does not escape from his paddock.*

## Self-advocate story two

Question number

Comment

## Self-advocate story three

Question number

Comment

## Self-advocate story four

Question number

Comment

## Self-advocate story five

Question number

Comment

## 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