



Public Health
England

Autism self-assessment exercise 2013

Initial findings

About Public Health England

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What is autism?

Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them.

It is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in different ways. Some people with autism are able to live relatively independent lives but others may have accompanying learning disabilities and need a lifetime of specialist support. People with autism may also experience over- or under-sensitivity to sounds, touch, tastes, smells, light or colours.

Asperger syndrome is a form of autism. People with Asperger syndrome are often of average or above average intelligence. They have fewer problems with speech but may still have difficulties with understanding and processing language.

Source: The National Autistic Society (www.autism.org.uk). For further information about Autism see www.autism.org.uk/about-autism.aspx.

Executive summary

Background

This report presents initial findings from the second self-assessment exercise of the Adult Autism Strategy [1]. The purpose of the exercise was to provide wider context for local authorities and their NHS and other partners in assessing their progress in implementing the Strategy. It also aims to provide evidence of examples of good progress made that can be shared and of remaining challenges. Along with other information gathering commissioned by the Department of Health, these findings are intended to inform the current review of the Strategy. A more detailed report will follow.

Initial findings

Response

All 152 upper tier local authorities responded. This was an improvement on the baseline exercise where responses were received from only 137 (90%).

Local authority area

Local authorities work with a number of partners. In the majority of areas the local authority (71%) works with only a single NHS clinical commissioning group (CCG), but in 29% the situation is more complex. 8% of local authorities work with four or more CCGs. 59% of local authorities reported that they also work with other local authorities in implementing parts of the strategy.

Planning

Almost all authorities (99%) now have a joint commissioner or senior manager responsible for services for adults with autism.

A majority of authorities reported using data about people with autism in their Joint Strategic Needs Assessment (JSNA) (56%) and commissioning plans (87%). 63% reported that they collect data on the number of people with autism eligible for social care.

The involvement of CCGs and people with autism and their carers in planning the implementation of the strategy was mostly rated positively (60%). However, there was minimal widespread implementation of reasonable adjustments to everyday services (12%).

Training

The majority of authorities reported having a multi-agency autism training plan (59%). The majority of authorities also reported that CCGs and primary care practitioners (60%) and local criminal justices services were involved in the training agenda (61%).

Most authorities reported that there was a good range of local autism training that meets NICE guidelines (53%). Half of authorities reported that at least 50% of staff that carry out statutory assessments have attended specialist autism training (50%).

Diagnosis led by the local NHS Commissioner

Just under half the respondents stated that they had asatisfactory local diagnostic pathway (49%). Most reported that the local CCG had taken the lead in developing a pathway (72%), and just over half reported it as a specialist autism specific service (51%). In 58% of cases the pathway was integrated with local authority adult social care services, with diagnosis triggering an automatic offer of a Community Care Assessment.

Care and support

There were positive results in the ways people with autism can access care and support. However, the proportion of amber ratings indicated that training for advocates (47%) and the level of information about local support are areas that could be improved (74%).

Housing and accommodation

The question asked referred to the local housing strategy, but the top (green) response option required both consideration in the local housing strategy and the availability of a range of accommodation options. 18% of local authorities indicated that they reached this level. A further 63% reported that the needs of disabled people were addressed in the local housing strategy, although not necessarily specifically those of people with autism.

Employment

The majority of authorities reported that autism awareness is delivered to employers on an individual basis, local employment support services include autism and there some contact with local jobs centres in most areas (65%). Most areas had detailed reference to employment in their transition processes to adult services (49%).

Criminal justice system

In most areas, discussions were underway to improve criminal justice system involvement in planning for adults with autism (60%).

Further publications

This report provides only an initial outline view of the responses to coded questions. More detailed reports covering commentary as well as rated questions will follow. A separate collection of 258 personal stories included by 91 local authority areas will be published at the same time as this report.

Introduction

The Adult Autism Strategy

Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them (see description on page four). In 2009, the Autism Act was passed by the UK Parliament [2]. This commits the Department of Health in England to producing, and periodically revising, an Autism Strategy for England and Guidance for local health and social care services about its implementation. "Fulfilling and rewarding lives: the strategy for adults with autism in England" [1] was published in 2010. It focusses on five areas:

1. Increasing awareness and understanding of autism
2. Developing clear, consistent pathways for diagnosis of autism
3. Improving access for adults with autism to services and support
4. Helping adults with autism into work
5. Enabling local partners to develop relevant services

The Strategy is not just about providing special services for people with autism, but also about enabling equal access to mainstream services, support and opportunities through reasonable adjustments, training and awareness raising.

Review of the strategy

The Autism Act requires the government to review the Strategy and the associated Statutory Guidance [3] from time to time. In doing this the government is required to work with a wide range of other government departments and agencies, local health and social service providers, self-advocates and family carers. In revising the associated Guidance it is also required to take into progress made towards implementing the strategy.

The Department of Health is now undertaking a formal review of the Strategy. This review has two main phases. The first investigative phase comprised a range of information gathering exercises including a survey of people with autism, a small number of in-depth local area reviews and the self-assessment exercise for all local authorities described in this document. Other government departments are also reviewing their progress in this area at the same time. The second phase, anticipated to run through December 2013 and January 2014, will comprise a focussed engagement with stakeholders to develop a refreshed Strategy. The full outcome is expected to be published in March 2014.

About self-assessment exercise 2013

Local authorities play a key role in implementing the recommendations of the Strategy and the statutory Guidance that supports it. An initial self-assessment exercise was conducted to establish the extent of the task in achieving the Strategy aims. This reflected the position as at March 2011, soon after the publication of the initial Guidance [4-5]. This second self-assessment followed the basic format of the first exercise. Its purpose was to:

- help local authorities and their partners assess their progress implementing the Strategy
- establish how much progress has been made since the baseline survey, reflecting the position as at March 2011
- provide examples of good progress and identify remaining challenges

To help address all these aspects, the structure of the survey was developed in a number of ways. Most questions were reworded for clarification. More detailed guidance was given about how each of the questions inviting ratings of "Green" (good), "Amber" (working on it) or "Red" (little or no progress) should be rated. In some cases additional, more specific questions were added. In addition to documenting progress, the exercise also aimed to understand the nature of the challenges impeding progress and the local solutions people have found for them. To achieve this, respondents were invited to contribute commentary in relation to most questions. A section for illustrative personal stories was also added. All the findings of the exercise will feed into the review of the Strategy. Full details of the self-assessment exercise can be found at:

<http://www.improvinghealthandlives.org.uk/projects/autism2013>

Structure and arrangements

The 2013 exercise ran between August and October 2013. Local authorities reported responses directly onto the Improving Health and Lives (IHaL) Learning Disabilities Observatory website. Local authorities were asked to co-ordinate their local responses, but instructions emphasised the importance of obtaining a multi-agency perspective, reflecting the task of implementing the strategy. They were specifically asked to include liaison with the new NHS Clinical Commissioning Groups.

Questions covered broadly the same areas as in the previous exercise:

1. Local authority area
2. Planning
3. Training
4. Diagnosis led by the NHS Commissioner
5. Care and support
6. Housing and accommodation
7. Employment
8. Criminal Justice System
9. Optional Self-advocate stories

Initial findings structure

For some questions numbers were required, for some it was yes or no answers. For some questions local authorities were asked to rate their area Red, Amber or Green (RAG) using a set of defined criteria for each related question. Finally, accompanying most of these questions, respondents were asked for further comments or explanations of the answers. In the final section, respondents had the opportunity to provide up to five self-advocate stories to illustrate the answers they had given to some of the questions.

The returns were analysed by Public Health England and Improving Health and Lives (IHaL) Learning Disabilities Observatory.

Presentation in this report

This report provides the initial findings from the Autism Self-Assessment Exercise 2013. Firstly, the response rate by local authorities is reported. Then for each section, background information to the questions is provided. This includes a summary of the results from the previous exercise where appropriate. Next, a narrative summary of findings from the questions in that section is given followed by the results.

For questions seeking yes/no answers or RAG ratings, responses are shown as a single horizontal bar coloured to represent the numbers of each type of answer. Numbers and percentages are shown below the bars. For RAG rated questions, the rating criteria is reproduced below each question. Number questions were analysed in several different ways; these are described in the sections.

Further publications

This report provides only an initial outline view of the responses to coded questions. A fuller report providing regional breakdowns, maps and thematic analysis of comments will follow in March. Alongside the full report we will publish all local authority responses, including comment text, both as reports for individual local authority areas and as a spreadsheet to facilitate comparative analysis.

Many areas provided illustrative personal accounts and/or stories of people with autism, providing a perspective of using local services often in their own words. These stories, anonymised, will be published in a separate volume alongside this report. They are intended not as critique of specific local services, but to provide an insight into the experience of living with autism in England today.

Findings

Response rate

All 152 local authorities in England completed the self-assessment exercise on the IHaL website. This was a substantial improvement on the baseline exercise when only 137 responded. Respondents were asked to confirm that they had completed two requirements before finishing the data collection process:

1. Inspected the PDF output available online to ensure that the answers recorded on the system match what they intended to enter
2. Agreed the response for their local authority area with their local Autism Partnership Board or equivalent group, and had the ratings validated by people who have autism, as requested in the ministerial letter [6] of 5th August 2013

Table 1 shows the numbers and proportion of authorities confirming completion of these requirements. 148 (97.4%) authorities reported they had checked the output for accuracy, 123 (80.9%) authorities confirmed they had completed both.

Table 1. The proportion and number of local authorities confirming they had met the two requirements and finished the data collection process

	Yes N (%)	
Submitted data	152	(100.0%)
Data checked	148	(97.4%)
Data validated	123	(80.9%)
Checked and validated	123	(80.9%)

Local authority area

Background

The majority of the responsibility of implementing the Strategy lies with local authorities, NHS bodies and other partnership organisations working together to plan and deliver services in their local authority area. The findings of the first self-assessment exercise [4] indicated that some local authorities had been working together. This was because a number of answers were repeated from different authorities.

Since the first self-assessment exercise there have also been a number of changes in the way health and social services are delivered and commissioned. These were introduced via the Health and Social Care Act 2012 [7] which came into being on 1st April 2013. One of the aims of the Act was to have more joint commissioning of services between local government and health services. This could impact on how the Strategy was implemented in each area.

This year, the exercise ask how many Clinical Commissioning Groups each area had to work with and if they were working with other local authorities to implement the Adult Autism Strategy in their area.

Initial findings

The results showed that 108 (71%) authorities worked with one Clinical Commissioning Group (CCGs) to implement the Strategy. One local authority reported they had 8 CCGs to work with. Over half of all local authorities in England reported that they work with other local authorities to implement part or all of the priorities of the Strategy.

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

Number of CCGs	N (%)
1	108 (71%)
2	15 (10%)
3	15 (10%)
4	2 (1%)
5 or more	11 (7%)
No answer	1 (1%)

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

Yes: 89 (59%) No: 62 (41%) No answer: 1 (1%)

Planning

Background

The Adult Autism Strategy and the statutory Guidance features a number of recommendations and expectations about the planning of the services for adults with autism locally. These include:

- the appointment of a joint commissioner or senior manager who have a clear commissioning responsibility for adults with autism
- the development of a local commissioning plan for adults with autism based on the Joint Strategic Needs Assessment (JSNA) and other relevant data
- the improvement of transition planning for young people with autism
- the improvement of transition planning and reasonable adjustments to services and support for adults with autism to enable them to live independently

The results from the first self-assessment exercise showed that 75% of authorities indicated they were considering allocating responsibility to a named joint commissioner or senior manager of community care services for adults with autism in their area by rating themselves as green. However, 66% of authorities rated their area as amber when asked if their JSNA mentioned adults with autism and if they had plans to collect and collate relevant data about adults with autism. This indicated that they were working on it. There was an even split between areas who answered the question whether or not they were in a position to answer a series of numerical questions about people with autism and services.

Findings

The results showed that 151 (99%) authorities said they had a named joint commissioner or senior manager responsible for services for adults with autism. 85 (56%) authorities who submitted data rated their area as green indicating that autism is included in the local JSNA. 116 (76%) authorities rated themselves as amber when asked about the collection of data on people with diagnosis of autism. This means that most authorities agree with the statement: "A variety of mechanisms are being used so a cross section of people on the autistic spectrum are meaningfully engaged in the planning and implementation of the Adult Autism Strategy. People with autism are thoroughly involved in the Autism Partnership Group."

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

Yes: 151 (99%) No: 1 (1%) No answer: 0 (0%)

4. Is Autism included in the local JSNA?

Red: 6 (4%) Amber: 60 (39%) Green: 85 (56%) No Answer: 1 (1%)

- No.
- Steps are in place to include in the next JSNA.
- Yes.

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

Red: 18 (12%) Amber: 116 (76%) Green: 18 (12%) No Answer: 0 (0%)

- Data recorded on adults with autism is sparse and collected in an ad hoc way.
- Current data recorded annually but there are gaps identified in statutory health and/or social care services data. Some data sharing exists between services.
- Have you an established data collection sharing policy inclusive of primary care, health provision and adult social care.

The results showed that 96 (63%) of authorities said they collected data on the number of people with a diagnosis of autism meeting the eligibility criteria for social care (irrespective of whether they received any).

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: 96 (63%) No: 55 (36%) No answer: 1 (1%)

Table two shows the total rate and the number of local authorities who provided numbers per client type. 88 authorities were able to provide a figure for the number of people who had a diagnosis of autism and met eligibility criteria for social care. Using the combined figure for these authorities and 2012 mid-year estimates [8] the overall rate was 47.2 people per 100,000 of their population. 78 of these authorities were able to report the numbers of people known to them with autism who also had learning disabilities. The proportion of people with autism and a learning disability for these authorities combined was 69.2%. 67 of these authorities were able to report the numbers of people known to them with autism who also had mental health problems. The proportion of people with autism and a mental health problem for these authorities combined was 16.4%. Table two also shows the profile of how these values varied between local authorities.

Table 2. Rates of people known with autism and meeting eligibility criteria for social care, and proportions of these also identified as having learning disabilities and mental health problems. The bottom row shows the number of local authorities from which data were available in each case.

Rate of diagnosis		Proportion with learning disability		Proportion with mental health problem	
Rate per 100,000	Number of LAs	% with LD	Number of LAs	% with MH problems	Number of LAs
<20	18	<20%	0	<2%	9
20 to 39.9	18	20%-39.9%	8	2%-3.9%	9
40 to 59.9	14	40%-59.9%	18	4%-5.9%	13
60 to 79.9	11	60%-79.9%	14	6%-7.9%	19
80 to 99.9	12	80% or more	38	8% or more	17
100 or more	15				
Number of LAs	88	Number of LAs	78	Number of LAs	67

This year, most authorities indicated they had met two of the expectations outlined in the Strategy. Firstly, 132 (87%) authorities reported that they had a commissioning plan that reflected local data and needs of people with autism. Secondly, 151 (99%) authorities reported that they had a transition process in place.

For three out of five of the RAG rated questions in this section amber was the most frequently reported rating by authorities. 82 (54%) authorities agreed that for the data collection sources they use they "Have made a start in collecting data and plan to progress." 96 (63%) authorities agreed that they had "clear council policy covering statutory and other wider public services" regarding reasonable adjustments (Q19). Only 18 (12%) authorities agreed that there was "evidence of widespread implementation". 86 (57%) authorities agreed that "training in some but not all services designed for use by older people, and data collection on people over-65 with autism;" when asked about the planning for the needs of older people.

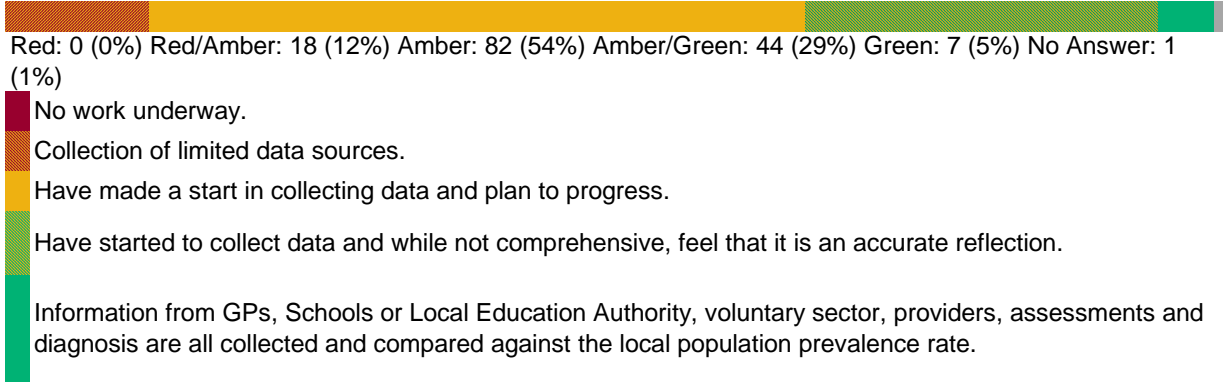
For the other two RAG rated question, green was the most frequent rating. 91 (60%) authorities reported that "CCG are fully engaged and work collaboratively to implement the NHS responsibilities of the strategy and are equal partners in the implementation of the strategy at a local level." 83 (55%) authorities reported that "a variety of mechanisms are being used so a cross section of people on the autistic spectrum are meaningfully engaged in the planning and implementation of the Adult Autism Strategy. People with autism are thoroughly involved in the Autism Partnership Group."

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

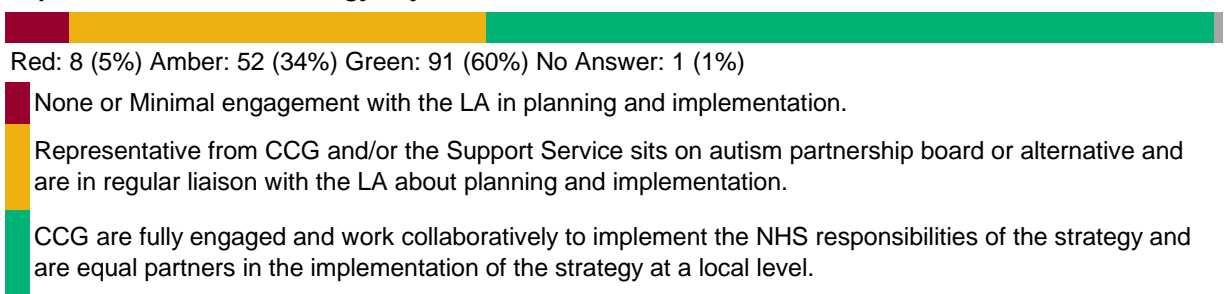


Yes: 132 (87%) No: 20 (13%) No answer: 0 (0%)

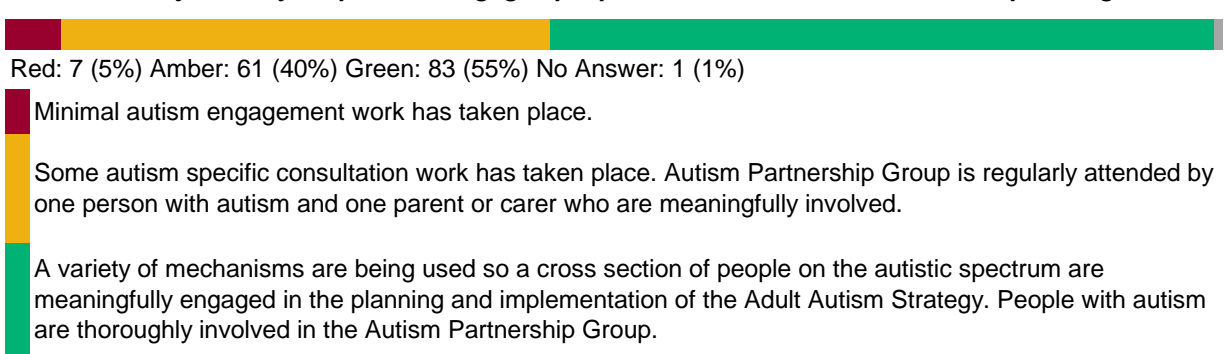
8. What data collection sources do you use?



9. Is your local CCG or CCGs (including the Support Service) engaged in the planning and implementation of the strategy in your local area?



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



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



Red: 38 (25%) Amber: 96 (63%) Green: 18 (12%) No Answer: 0 (0%)

- Only anecdotal examples.
- Clear council policy covering statutory and other wider public services.
- Clear council policy and evidence of widespread implementation.

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



Yes: 151 (99%) No: 1 (1%) No answer: 0 (0%)

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



Red: 48 (32%) Amber: 86 (57%) Green: 17 (11%) No Answer: 1 (1%)

- No consideration of the needs of older people with autism: no data collection; no analysis of need; no training in older people's services.
- Training in some but not all services designed for use by older people, and data collection on people over-65 with autism.
- Training inclusive of older people's services. Analysis of the needs of population of older people inclusive of autism and specialist commissioning where necessary and the appropriate reasonable adjustments made.

Training

Background

The training of staff who provide relevant services to adults with autism is one of the six areas of the Autism Act that required guidance to cover. The Strategy states that it is important for autism training to be available for everyone working in health or social care. This training should aim to change staff behaviour and attitudes as well as improve knowledge and understanding of autism. The Guidance for implementing the strategy is aimed at both general autism awareness training and specialised training for staff in key roles.

In the first self-assessment exercise, most authorities rated themselves as amber when asked about issues in relation to training. 57% of authorities rated themselves as amber when asked are staff who carry out assessments receiving training on how to make adjustment in their behaviour and communication. This indicates that they were working on it. 66% rated their area as amber when asked if they have considered what autism awareness training is made available to all staff working in health and social and how training can be prioritised. In addition, when asked about adults autism no longer managed inappropriately in the criminal justice system, thirty authorities had highlighted autism awareness training as a positive area. Twenty authorities identified this as a gap.

Initial findings

The results outlined on the following page show that just over half of the authorities answered positively to the three yes or no questions about training. Firstly, 89 (59%) authorities reported that they have got a multi-agency autism training plan. Secondly, 91 (60%) said that CCGs have involved in the development of workforce planning and are GPs and primary care practitioners engaged included in the training agenda. Finally, 93 (61%) said their local Criminal Justice services have engaged in the training agenda.

Authorities most frequently rated their areas as amber for the RAG questions relating to training. 80 (53%) authorities agreed that there was a "good range of local autism training that meets NICE guidelines - and some data on take up. Workforce training data available from statutory organisations on request. Autism training plan or strategy near completion." 76 (50%) authorities agreed that for staff that carry out statutory assessments "at least 50% of assessors have attended specialist autism training."

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



Yes: 89 (59%) No: 63 (41%) No answer: 0 (0%)

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



Red: 14 (9%) Amber: 80 (53%) Green: 58 (38%) No Answer: 0 (0%)

Historical workforce training data available from statutory organisations on request. Not yet devised an autism training plan or strategy.

Good range of local autism training that meets NICE guidelines - and some data on take up. Workforce training data available from statutory organisations on request. Autism training plan or strategy near completion.

Comprehensive range of local autism training that meets NICE guidelines and data on take up. Workforce training data collected from all statutory organisations and collated annually, gaps identified and plans developed to address. Autism training plan/strategy published.

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: 30 (20%) Amber: 76 (50%) Green: 46 (30%) No Answer: 0 (0%)

No specific training is being offered

At least 50% of assessors have attended specialist autism training.

More than 75% of assessors have attended specialist autism training specifically aimed at applying the knowledge in their undertaking of a statutory assessment, ie applying FACs, NHS Community Care Act.

17. Have CCGs been involved in the development of workforce planning and are GPs and primary care practitioners engaged included in the training agenda?



Yes: 91 (60%) No: 60 (39%) No answer: 1 (1%)

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



Yes: 93 (61%) No: 57 (38%) No answer: 2 (1%)

Diagnosis led by the local NHS Commissioner

Background

For people with autism and their families and carers, having a clear clinical diagnosis of autism is an important step in leading fulfilling and rewarding lives. A diagnosis can help people understand their behaviour and responses and access services and support [1].

However, the Strategy emphasised that a diagnosis is not the end goal and should be part of an integrated process. The Strategy and required Guidance made several recommendations about what this process should entail. These include:

- appointing a lead professional to develop diagnostic and assessment services for adults with autism working closely with the specialised commissioning group
- a clear pathway to diagnosis by 2013
- recognition of an autism diagnosis as a reason for assessment under the NHS and Community Care Act 1990 and for a carer's assessment
- local authorities and health services commissioners develop relevant, clear and accessible information for adults with autism and their families and carers

A clear and trusted diagnostic pathway available locally was one of the identified service ambitions in the first self-assessment exercise. The previous results showed that when asked "Have you a clear pathway developed locally?", the most common rating was amber (62%) by authorities who responded. Amber again was the most common answer (46%) when asked "Following diagnosis does the pathway include the healthcare professional informing the adult diagnosed under the NHS Community Care Act 1990 LAs have a duty to carry out an assessment?". These amber ratings indicated that areas were working on it. Of the 48 local authorities who answered this question, there was a overall rate of 0.4 people per 1,000 population who had been assessed in the past 12 months using the diagnostic pathway. An issue which was identified in the thematic analyses was that diagnostic pathways were only available for adults with learning disabilities and/or a mental health problem.

Initial findings

The results showed that 74 (49%) authorities rated their area as green, agreeing with the statement "A local diagnostic pathway is in place and accessible, GPs are aware and involved in the process. Wait for referral to diagnostic service is within 6 months. NICE guidelines are considered within the model". 102 authorities reported the date when the pathway was put in place and 116 authorities reported the average wait for referral to diagnostic services. Below the tables for questions 20 and 21 show the profile of how these reported figures varied between local authorities.

110 (72%) authorities reported that the local CCG or support services had taken the lead in developing the pathway. 78 (51%) authorities described the local pathway as a specialist autism specific services compared to the 64 (42%) authorities who described it as integrated with mainstream statutory services. However, 10 authorities did not answer the question. 88 (58%) authorities reported that in their local diagnostic path a diagnosis of autism automatically triggers an offer of a community care assessment.

19. Have you got an established local diagnostic pathway?

Red: 13 (9%) Amber: 64 (42%) Green: 74 (49%) No Answer: 1 (1%)

No local diagnosis service planned or established. No clear transparent pathway to obtaining a diagnosis for adults identified and only ad-hoc spot purchasing of out of area services. NICE guidelines are not being followed.

Local diagnosis pathway established or in process of implementation / sign off but unclear referral route. A transparent but out of locality diagnostic pathway is in place. Some NICE guidelines are being applied.

A local diagnostic pathway is in place and accessible, GPs are aware and involved in the process. Wait for referral to diagnostic service is within 6 months. NICE guidelines are considered within the model

20. When was the pathway put in place?

	Number of LAs
Date specified	102
<6 months	21
6 to <12 months	19
12 to <18 months	16
18 to <24 months	10
24 to <30 months	11
30 to <36 months	4
3 or more years	16
Future start date	5

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

	Number of LAs
Wait specified	116
1 to 5 weeks	19
6 to 10 weeks	31
11 to 15 weeks	25
16 to 20 weeks	12
20 or more weeks	29

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

	Number of LAs
Total specified	110
1 to 9	24
10 to 19	29
20 to 29	6
30 to 39	21
40 to 49	6
50 or more	24

23. Has the local CCG or support services taken the lead in developing the pathway?



Yes: 110 (72%) No: 40 (26%) No answer: 2 (1%)

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?



Integrated with mainstream statutory services with a specialist awareness of autism for diagnosis: 64 (42%)
Specialist autism specific service: 78 (51%)
No answer: 10 (7%)

The final question in this section explored the wider aspects of how the whole diagnostic pathway brought together health and social care components.

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



Yes: 88 (58%) No: 59 (39%) No answer: 5 (3%)

Care and support

Background

Personalisation of social care is an integral part of the Strategy. Both the Strategy and the Guidance have a number of recommendations about the care and support an adult with autism should receive to live independently and access mainstream services. This includes achieving the same improvement to public services for people with autism that has occurred for people with learning disabilities and mental health problems through existing programmes. There has been feedback to suggest that people with autism are missing out due not fitting into either of these categories.

In the first self-assessment exercise, most authorities rated themselves as amber when "Do you know how many adults are in receipt of a personal budget?" (48%) and "Are you able to provide advocates to work with adults with autism?" (52%). These answers indicated where areas were working on it.

Initial findings

89 authorities were able to provide a figures for the number of adults with autism who were assessed as being eligible for adult social care services and were in receipt of a personal budget. Altogether these authorities were providing this type of help for 6845 people, a rate of 29 per 100,000 adult population. In giving these numbers, authorities were asked to distinguish between those with autism but not learning disability, and those with both. The overall proportion with autism but not learning disability was 29.47% although this varied widely between authorities. In 13 authorities, amongst people with autism receiving personal budgets, those without learning disabilities outnumbered those with. Table three shows the profile of how these two figures varied between local authorities.

Table 3. Profile of rates of people assessed as eligible for adult social care services and in receipt of a personal budgets per 100,000 adult population (left hand table). Profile of proportions of those diagnosed with autism and receiving a personal budget who do not have learning disabilities. The bottom row shows the number of local authorities from which data were available in each case.

Numbers with autism, eligible for social care, and receiving personal budgets		Proportion of those receiving personal budgets with autism who do not have learning disabilities	
Rate per 100,000 receiving personal budgets for autism	Number of LAs	% with autism but not learning disabilities	Number of LAs
Less than 10	20	Less than 1%	20
10 but less than 20	16	1% but less than 5%	13
20 but less than 30	18	5% but less than 10%	14
30 but less than 50	22	10% but less than 50%	26
50 or more	13	50% or more	16
Total	89	Total	89

Authorities were asked about entry points for services. 104 (68%) said they had a single identifiable contact point where people with autism can get information signposting a wide range of local services. 119 (78%) reported they had a recognised pathway for people with autism but without a learning disability to access a community care assessment and other support. 140 (92%) reported that people with autism can access support if they are non-Fair Access Criteria eligible or not eligible for statutory services.

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?

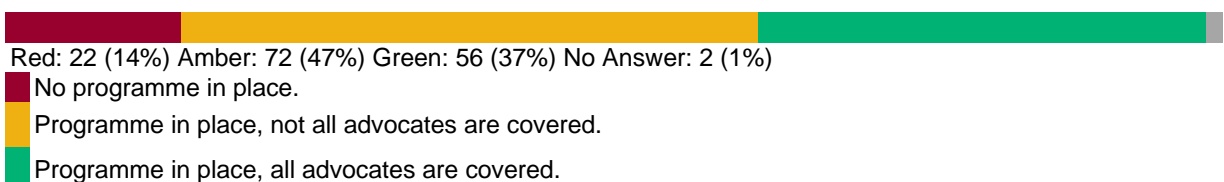


29. Do you have a recognised pathway for people with autism but without a learning disability to access a community care assessment and other support?

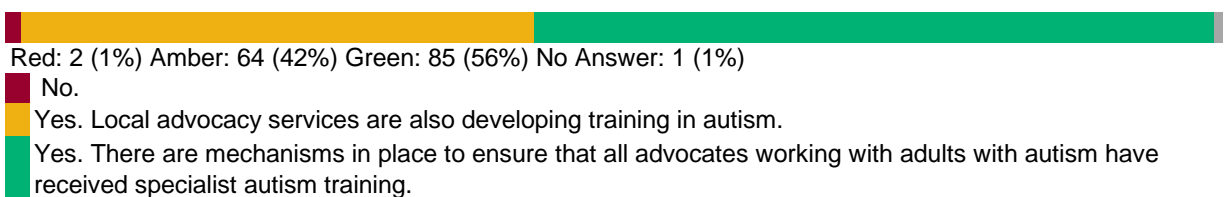


For two out the three RAG rated questions in this section the most common rating was amber. 72 (47%) authorities when asked about training programmes for advocates reported that "Programme in place, not all advocates are covered." 95 (63%) authorities gave this rating agreeing with the statement "Some existence of low level, preventative services such as befriending or mentoring, advocacy, social groups, outreach, activity groups, and access to therapies and counselling (ie IAPT primary care mental health services). Database of universal and autism specific services has known gaps." This was the amber rating asked how would you assess the level of information about local support in your area being accessible to people with autism. Most authorities 85 (56%) rated themselves green when asked do adults with autism have access to an advocate where appropriate. The rating was defined as "Yes. There are mechanisms in place to ensure that all advocates working with adults with autism have received specialist autism training."

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



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?



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



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

Red: 17 (11%) Amber: 112 (74%) Green: 22 (14%) No Answer: 1 (1%)

Minimal choice of appropriate local provision and where required local care and support services. Database of universal and autism specific services is out of date.

Some existence of low level, preventative services such as befriending or mentoring, advocacy, social groups, outreach, activity groups, and access to therapies and counselling (ie IAPT primary care mental health services). Database of universal and autism specific services has known gaps.

Accessible information available on the range of autism accessible support services such as befriending or mentoring, advocacy, social groups, outreach, activity groups, and carer support. There is a progressive level of support dependant of the needs of the individual who happens to have autism. More specialist services accessible to meet their needs with autism for those who needs it from advocacy to high level services.

Housing and accommodation

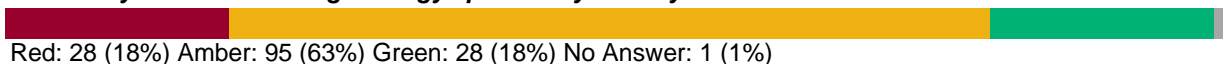
Background

The government aims to enable adults with autism and their families to have greater choice and control over where and how they live. This means that planning of local housing should take into account the needs of adults with autism.

In the previous self-assessment exercise, authorities most commonly (66%) rated their local housing strategy as amber when asked if it is addressing the short and long-term requirement of adults with autism. This indicated that authorities were working on it.

This year, 95 (63%) authorities reported that their local housing strategy specifically included details of the needs of people with disabilities though not necessarily of people with autism. The top (green) rating which 28 (18%) authorities said described their position required not only full consideration in their housing strategy, but also the availability of an appropriate range and amount of accommodation provision to meet the needs of people with autism.

34. Does your local housing strategy specifically identify Autism?



- No mention of Autism within the local housing strategy. No range of options available to meet the broad needs of someone with a diagnosis of Autism. No data available on individual housing needs and usage of different housing services.
- Universal housing strategy details needs of people with disabilities, autism not specifically referenced. Minimal current and historic data availability on individual housing needs and usage of different housing services.
- Autism accessible housing detailed in universal housing strategy. A range of housing and accommodation options available to meet the broad needs of people with autism including universal housing supported living, residential care, etc. Using data to inform future planning, of accommodation and housing needs.

Employment

Background

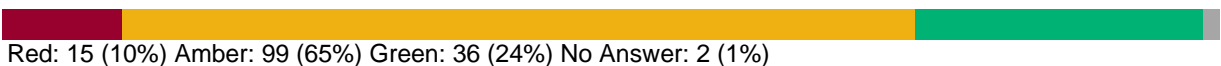
Helping adults with autism into work is one of the key areas in the Strategy. The Guidance emphasises plans for employment as an aspect of effective transition planning.

In the previous self-assessment exercise, most authorities rated themselves as amber in relation two questions about employment. 69% when asked about engaging with local employers to examine and increase employment levels for adults with autism and 66% when asked do transition processes to adult services have an employment focus. This indicated authorities were working on it.

Initial findings

This year, 99 (65%) authorities rated themselves as amber, agreeing with the statement "Autism awareness is delivered to employers on an individual basis. Local employment support services include Autism. Some contact made with local Job Centres." Green was the most common rating 75 (49%) authorities reporting this answer when asked do transition processes have an employment focus. This was defined as "Transition plans include detailed reference to employment, accesses to further development in relation to individual's future aspirations, choice and opportunities available."

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



No work in this area has been provided or minimal information not applied to the local area specific to Autism. Local employment support services are not trained in autism or consider the support needs of the individual taking into account their autism. Local Job Centres are not engaged.

Autism awareness is delivered to employers on an individual basis. Local employment support services include Autism. Some contact made with local Job Centres.

Autism is included within the Employment or worklessness Strategy for the Council or included In a disability employment strategy. Focused Autism trained Employment support. Proactive engagement with local employers specifically about employment people with autism including retaining work. Engagement of the local Job Centre in supporting reasonable adjustments in the workplace via Access to work.

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



Transition plans do not include specific reference to employment or continued learning.

Transition plans include reference to employment or activity opportunities.

Transition plans include detailed reference to employment, accesses to further development in relation to individual's future aspirations, choice and opportunities available.

Criminal justice system

Background

The Strategy recommends that all staff within the criminal justice sector should have training and access to expertise to enable them to support people with autism. In addition, pathways through the system should be developed to identify others who they may need to work with.

In the previous self-assessment exercise, sixteen authorities identified improving links with organisations in the criminal justice system as a priority.

Initial findings

This question was asked in the same way as the previous self-assessment exercise. Amber was the most common response from both exercises, with 91 (60%) authorities rate CJS engagement as this. However, these are not directly comparable due to the way the percentages have been calculated. This year, the rating was defined as "Discussions with the CJS are underway, including training of the police and wider CJS and inclusive of the use of alert cards. Representative from CJS sits on autism partnership board or alternative."

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



Red: 34 (22%) Amber: 91 (60%) Green: 23 (15%) No Answer: 4 (3%)

Minimal or no engagement with the CJS.

Discussions with the CJS are underway, including training of the police and wider CJS and inclusive of the use of alert cards. Representative from CJS sits on autism partnership board or alternative.

People with Autism are included in the local work of local diversion team's from CJS. Representative from CJS regularly attends meetings of autism partnership board or alternative. Alert card or similar scheme in operation. Police training in place.

Optional self-advocate stories

Respondents had the opportunity to leave up to five self-advocate stories. These were to illustrate one or more of the questions in the self-assessment exercise.

92 (61%) authorities provide at least one story. A total of 258 stories about personal experiences of individuals with autism were sent in. Some were told by supporters, advocates or carers, but many were in the voice of the person themselves. These are published in an accompanying report.

References

1. Department of Health. Fulfilling and Rewarding Lives: The Strategy for Adults with Autism, 2010; Department of Health, London
[webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_113405.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_113405.pdf)
. Accessed 10th October 2013.
2. Autism Act 2009; London: Stationery Office ,
www.legislation.gov.uk/ukpga/2009/15, accessed 10th October 2013
3. Department of Health. Implementing "Fulfilling and Rewarding Lives" Statutory guidance for local authorities and NHS organisations to support implementation of the Autism Strategy, 2010; Department of Health, London
www.gov.uk/government/uploads/system/uploads/attachment_data/file/216129/dh_122908.pdf. Accessed 10th October 2013.
4. Roberts H, Baines S, Glover G and Hatton C Autism Self Assessment 2011: Issues from local authorities, IHAL - 2012-10, Durham.
www.improvinghealthandlives.org.uk/gsf.php5?f=16323. Accessed 10th October 2013.
5. Copeland A, McLean J, and Glover G Local Authority self-assessment of services for people with autism 2010/11 - Ratings atlas, IHAL - 2012-06, Durham.
www.improvinghealthandlives.org.uk/gsf.php5?f=14857. Accessed 10th October 2013.
6. Lamb, N. Ministerial Letter, 2013 ; Department of Health, London
7. Health and Social Care Act 2012; London: Stationery Office ,
www.legislation.gov.uk/ukpga/2012/7/contents. Accessed 10th October 2013
8. Office for National Statistics. Population Estimates for UK, England and Wales, Scotland and Northern Ireland - Mid 2012, 2013;
<http://www.ons.gov.uk/ons/datasets-and-tables/index.html?pageSize=50&sortBy=none&sortDirection=none&newquery=Population+Estimates+for+England+and+Wales&content-type=Reference+table&content-type=Dataset>. Accessed 10th October 2013.