

**Report of:** Helen Gee on behalf of the Autism Partnership Board.

**Report to:** Leeds Health and Wellbeing Board

**Date:** 20 November 2013

**Subject:** 2013 Autism Self Assessment

Are there implications for equality and diversity and cohesion and integration?	<input checked="" type="checkbox"/> Yes	<input type="checkbox"/> No
Is the decision eligible for Call-In?	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
Does the report contain confidential or exempt information? If relevant, Access to Information Procedure Rule number: Appendix number:	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No

## Summary of main issues.

1. Leeds has entered a submission for the 2013 autism self assessment. The Department of Health has asked The Health and Wellbeing Board to approve this submission prior to the national analysis of the work.
2. The report gives some background on the national and local work to inform the discussion of the self assessment. Leeds has done a considerable amount of work since the passing of the Autism act (2009) and the SAF reflects this progress.
3. There remains more work to be done to meet our obligations and to ensure that people on the autistic spectrum can be fully part of the Health and Wellbeing vision that Leeds will be a healthy and caring city for all ages.
4. Key areas from the Autism self assessment are highlighted together with some priorities for future development

## Recommendations

The Health and Wellbeing Board is asked to:

- Note the partnership work which is already happening to bring about the goals of the Leeds autism strategy.
- Review the 2013 Self assessment form submission and approve the contents.

- Continue to support the remaining joint work necessary to meet our statutory obligations and to achieve the possible cost benefit savings.
- Consider how better meeting the needs of people on the autistic spectrum (and other vulnerable groups) can contribute to achieving the outcomes of the Health and wellbeing strategy.
- Receive a further report following the writing of the autism joint strategic needs assessment (JSNA) in 2014.

## **1 Purpose of this report**

- 1.1 All local authorities have been asked by the Department of Health (DH) to complete an Autism Self-Assessment form (SAF) – completing this will be an annual requirement to enable the measurement of progress against the national strategy objectives. This year's submission will have a particular significance as the results will also contribute the review of the national autism strategy. The DH requires the Health and Wellbeing board to comment on and approve the Leeds submission.
- 1.2 This report begins with some background information on autism, gives an outline of current national and local work and briefly discusses autism's relevance for the joint health and wellbeing strategy.
- 1.3 This background informs a discussion of the key points from the SAF in order that the health and wellbeing board can comment on the submission.

## **2 Background information**

### **2.1 What is autism**

- 2.1.1 Autism is a communication and sensory condition that affects approximately one per cent of the population. It is independent of IQ but people with learning disabilities have a higher probability of having autism - up to 30%.
- 2.1.2 In line with the national autism strategy we use the word autism as an umbrella term to include a number of terms that are currently used to cover a range of needs. These include autistic spectrum disorder, autistic spectrum condition, Asperger's syndrome, high functioning autism.
- 2.1.3 Autism and Asperger's were first recognised (separately) in the 1940s. Since then there has been a gradual increase in recognition in the UK and also a change, and broadening, of diagnostic criteria. Knowledge of autism is new relative, say, to learning disabilities, and understanding of autism is still developing. As a result of this and as processes for diagnosis are still developing, the number of people on the spectrum is not completely well known; knowledge and evidence of how to support people is still developing.
- 2.1.4 Increasing awareness of the condition began for children with the result that there has been a considerable deficit in both awareness and availability of support in

adult services. For these reasons, across the UK, health and social care services, as well as universal services, have not been well designed to meet the needs of people on the autistic spectrum.

## 2.2 National context

2.2.1 As a result of this increasing awareness the following national actions took place:

- The Autism Act was passed in 2009. This is the first single disability specific legislation and places a number of obligations on a range of public bodies to improve opportunities for people across the autism spectrum.
- The national autism Strategy 'Fulfilling and Rewarding Lives' was published in March 2010 and is for a four year period until 2014.
- The Autism statutory guidance was published Dec 2010. This covers a narrower range of areas and applies to both health and social care bodies:
  - training for staff
  - identification and diagnosis of autism in adults
  - the transition from child services to adult services
  - planning of services for people with autism and local leadership

The lead responsibility sits with the director of adult social services even though much of the task sits with various health bodies.

It is worthy of note that the roll out of this guidance was not accompanied by any extra funding for local areas.

2.2.2. The national strategy 'Fulfilling and Rewarding Lives' is currently being reviewed. It will be reissued in early 2014 following a considerable consultation process.

2.2.3 In June 2012 the NICE guidance: "Diagnosing, supporting and caring for adults with autism" clinical guideline 142 was released.

## 2.3 Local Context

2.3.1 Leeds City Council has lead responsibility for implementing the strategy arising from the 2009 Autism Act. The council is working in partnership with a range of local statutory and non statutory organisations and service user/carer representatives to drive this forward.

2.3.2 The local adult autism strategy was developed in 2011 (available to download from [www.leeds.gov.uk/residents/Pages/Autism.aspx](http://www.leeds.gov.uk/residents/Pages/Autism.aspx)); this takes a broad view of the needs of people on the autistic spectrum. People on the autistic spectrum have a wide range of needs and, on the whole, wish to engage in the same activities as people who are not on the autistic spectrum. The implication of this is that, in the spirit of the equalities act, a wide range of public and private agencies may need to make reasonable adjustments to the services they provide in order to support individual people on the autistic spectrum to achieve their goals. There is also a smaller range of autism specific statutory obligations for health and social care. The strategy covers all these areas.

- 2.3.3 The objectives of the local strategy are in line with the Better Lives themes of adult social care.
- 2.3.4 In order to support the implementation of the Leeds Adult Autism Strategy, the Autism Partnership Board was established, it is made up of partners from a range of organisations and sectors, including service user and carer representatives. It meets quarterly and is supported by reference groups for both people on the autistic spectrum and their carers. The Partnership Board and its member agencies are responsible for delivering an action plan which includes the main current areas of work. This includes diagnosis and assessment, transitions, training, employment and commissioning. Other significant issues are welfare benefits, housing and the criminal justice system.
- 2.3.5 Children's services are now working to develop a children's autism strategy, there is good communication between the children's strategy working group and the adult autism partnership board.
- 2.3.6 Based on the best accepted 1% prevalence figure Leeds would expect to have about 7,500 people (all age) on the spectrum. - or about 100 people in each year of age. This works out at around 5,700 adults and 1,800 children and young people. The best current estimate is that around 900 people on the autistic spectrum have adult social care support; approximately 600 of these will have a dual diagnosis of learning disabilities. Looked at the other way on – there are about 4,800 adults for whom there is no record of a diagnosis and/or are not known to be receiving a service.
- 2.3.7 The key question here is the level of need of those people who are currently not in receipt of services. As yet this can't be answered in detail, either on the basis of local knowledge or national research. It is however known that there is a steady increase in demand for both diagnosis and social care support.
- 2.3.8 It is important to recognise that the majority of people on the autistic spectrum use mainstream services as well as or instead of health and social care. The main issues here become reasonable adjustments to mainstream services and signposting/navigating between these supports.
- 2.4 Implications for the implementation of the Joint Health and Wellbeing strategy
- 2.4.1 The majority of people on the autistic spectrum are not likely to be eligible for social care support. Thus they will be supported through the same mainstream health and other services as the majority population. They may well have communication needs which will challenge services and result in poorer outcomes for both for individuals and for services.
- 2.4.2 There is little current evidence for any association between autism and life expectancy although people with dual diagnoses of autism with mental health and/or learning disabilities may share the disadvantages associated with those conditions.
- 2.4.3 As local and national knowledge of incidence is limited it is, as yet, challenging to measure if people with autism are equally represented in the indicators on the

Joint Health and Wellbeing strategy. It is however possible to hypothesise that, for many autistic people engaging in, for example, screening and prevention services would be difficult and that an awareness of their needs would facilitate their knowledge of the services and their ability to tolerate the processes.

- 2.4.4 All of the outcomes and priorities in the Strategy are of course relevant to people with autism, increased awareness of autistic needs will lead to mere knowledge of where specific issues lie and how services need to adapt their offer to become equally accessible to people on the autistic spectrum.

### **3. Main issues**

#### **3.1 Leeds submission of the Self-Assessment form.**

3.1.1 All local authorities have been asked by the DH to complete the Autism self-assessment form. This will serve two purposes, to benchmark progress for future years and to contribute to the current review of progress under the national strategy. The Leeds submission is attached as appendix 1.

3.1.2 The final stage of the process is to report to the Health and Wellbeing Board to allow board members to modify the existing ratings if they wish.

3.1.3 The reference groups for people with autism and carers have had an opportunity to contribute to the SAF as it was being written. The NHS, Housing, Department of work and Pensions were asked for figures or comments. The Autism partnership board on Sept 18<sup>th</sup> reviewed the whole document and agreed the RAG ratings.

#### **3.2 Overall comments on the SAF process**

3.2.1 The question areas of the SAF follow the main interest areas of the national strategy. As such they are broad and wide ranging. Leeds is working, to a greater or lesser extent in all the areas in the SAF so the Partnership board feels confident that its work is in line with national objectives. Leeds started from a low baseline in terms of autism provision compared to some areas of the country and, relative to that, has made a reasonable amount of progress.

3.2.2 Two areas which are of concern to autism carers and service users are not referenced in the SAF. These are the impact of welfare benefit changes and the ability of mainstream mental health services (both primary and secondary) to meet the needs of people who have a diagnosis of autism as well as a mental health problem.

3.2.3 Transition for young people without complex needs does not have a high profile in the SAF. The partnership board considers this to be an important issue.

3.2.4 Many of the adult autism issues for Leeds are common to other local authorities. As we are a large city this gives us both opportunities and challenges in working across such a wide area of public services. Leeds is lucky to have engagement in this work from a wide range of organisations.

#### **3.3 Numbers and recording.**

- 3.3.1 Leeds (like other local authorities) has very restricted numerical information on numbers of people with autism and the services they receive. This is because autism has never been a service user group so there has been no incentive or mechanism to record. Monitoring of success in any of the strategy areas is challenged by this limited present and historical recording of autism diagnoses.
- 3.3.2 For example the figures for people diagnosed and receiving social care support are very low (Questions 6 and 27). It is estimated, on the basis of the demographic information that the actual figures are substantially higher than this – most people however will be recorded as having learning disabilities or mental health problems – either because they have a dual diagnosis or because the recording relates to the section which holds the budget. New guidance on recording autism as an additional health need will gradually begin to improve these figures. GP audit figures are also low.
- 3.3.3 Lack of recorded diagnostic information also has an impact on evaluating the impact of universal services such as primary care, employment and housing services.
- 3.3.4 The Partnership Board is currently working on developing information for the next edition of the JSNA. This will incorporate all the existing local information in the context of the research led demographic information to give guidance on the level of unmet or insufficiently met need.

#### 3.4 Overall level of achievement

- 3.4.1 The overall areas included in the SAF are Planning, Training, Diagnosis, Care and Support, Housing and Accommodation, Employment and the Criminal Justice System. There are a total of 37 questions, 17 of which require a RAG rating. The SAF gives guidance for the RAG ratings (Appendix 2). In addition there are 5 self-advocate stories which show the experience of autistic people in Leeds trying to access services. The discussion below picks out significant issues.
- 3.4.2 In most areas the Partnership board felt that amber was an appropriate rating relative to the guidance given. Most of the topic areas are complex and involve multiple inputs to bring about the desired overall change so this would appear to be reasonable.
- 3.4.3 Two questions were scored at green – both around partnership work.
  - 3.4.4 Q 9 - CCG involvement. Although statutory guidance applies to health as well as social care some areas are struggling to engage health partners in this work. In Leeds the CCGs are actively engaged and there has been recent funding for a larger scale diagnosis service.
  - 3.4.5. Q 10 – involving carers and people with autism in planning. As the submission indicates there is a system in place to support this process.

### 3.5 Areas which scored red or were answered no.

- 3.5.1 Q 11: Have reasonable adjustments been made to everyday services? This is a very broad question which appears to address all the areas not otherwise included in the Strategy. Although there are some examples of developments which we listed we didn't consider it was possible to rate at higher than red. The rating criteria only referred to council services although the question appeared to be broader.
- 3.5.2 Q13: Planning for older people's needs. This is a particularly challenging area as there is a lower rate of diagnosis for older people, this taken together with the limitations of knowledge of need for all ages means that there is little known about this. The initial approach will be to make awareness raising training and further information available to services targeted towards older people.
- 3.5.3 Q16: Specific training for staff carrying out statutory assessments: This was rated at red as we did not meet the amber RAG rating criteria (of 50%) for the proportion of staff already trained. This however will be a temporary problem as plans are already being put in place to roll out training.
- 3.5.4 Q28 and 32 Information and support for non FACS eligible people. These two questions are closely linked. In order to fully achieve the goals of the local autism strategy it will be essential to have these two areas in place. An information and sign posting resource is necessary for the proper functioning of the diagnostic and assessment pathway and to enable health and social care services to achieve their goals. It would also be helpful in providing the tailored resource to enable the achievement of the Joint Health and Wellbeing strategy outcomes and priorities for the 1% of the population which is on the autistic spectrum.
- 3.5.5 Such a service would require new funding which is a challenge at the moment. It would however be relatively economical to fund, There is an outline plan available which would meet local needs, benefit multiple agencies and have a potential cost benefit saving.

## 4. **Health and Wellbeing Board Governance**

### 4.1 Consultation and Engagement

- 4.1.2 The reference groups for people with autism and carers have had an opportunity to contribute to the SAF as it was being written. The partner bodies on the autism partnership board were asked to contribute answers to particular questions these included the NHS (CCG and diagnostic team), Housing, and the DWP. The autism partnership board reviewed the whole document on Sept 18<sup>th</sup> and agreed the RAG ratings.

### 4.2 Equality and Diversity / Cohesion and Integration

- 4.2.1 People with autism are a disability group and as such are entitled to reasonable adjustments to enable them to access public services. The numerical information is insufficient to allow us to know if there is any difference in incidence or access to services based on ethnic or cultural background other than a small indication that there may be a relative under diagnosis in children from south Asian communities.

4.2.2 It is known that there are few known older people with a diagnosis and that women are underdiagnosed relative to men. There is current concern that part of the latter is due to an under recognition.

4.2.3 People with autism have communication needs so it is possible that they may need additional support to benefit from the work designed to achieve the outcomes of the health and wellbeing strategy.

#### 4.3 Resources and value for money

4.3.1 The breadth of this agenda makes establishing cost benefits from any changes a challenge. We know that lifetime costs for someone on the autistic spectrum are high A tentative “lifetime cost for someone with autism and intellectual disability is £1.5 million. For someone with autism but without ID it is about £900,000”. [<http://blogs.lse.ac.uk/healthandsocialcare/2012/04/09/professor-martin-knapp-autism-costs/>].

4.3.2 The NAO [2009] estimated that there is a strong possibility that an effective support system for people with Asperger’s will, in the long term, save money. [Supporting people with autism through adulthood: Model to assess the financial impacts of providing multi-disciplinary support services for adults with high-functioning autism/Asperger syndrome. National Audit Office. (2009)]

4.3.3 It is also known that the costs to services from individuals who enter into crisis can be substantial. Locally there is evidence of people moving between health and social care services frequently in early adulthood in a way that is both distressing to them and their families and costly to service providers.

#### 4.4 Legal Implications, Access to Information and Call In

4.4.1 The legal background to the autism delivery work is firstly the statutory guidance arising from the Autism Act. This applies to health and social care bodies and the lead sits with the Director of Adult Social Services. Access to wider universal services falls under the Equality Act and much of the work here is around training and to enable services and individual workers to make the reasonable adjustments which will enable people with autism to access their services.

#### 4.5 Risk Management

4.5.1 The risks from failing to achieve the goals of the Leeds strategy are initially to individuals who will not receive the supports they need and also to organisations who will not achieve their statutory obligations.

### **5. Conclusions**

5.1 Leeds is working towards achieving the objectives of its autism strategy. This involves input from a wide range of partner organisations. This is reflected in the submission for the autism SAF which indicates that progress has been made in most areas.

5.2 There are some outstanding goals, which will require input from a wide range of agencies to achieve.



5.3 The achievement of the objectives of the Leeds adult autism strategy will contribute to the achievement of the outcomes of the joint Health and wellbeing strategy.

## **6. Recommendations**

6.1 The Health and Wellbeing Board is asked to:

- Note the partnership work which is already happening to bring about the goals of the Leeds autism strategy.
- Review the 2013 Self assessment form submission and approve the contents.
- Continue to support the remaining joint work necessary to meet our statutory obligations and to achieve the possible cost benefit savings.
- Consider how better meeting the needs of people on the autistic spectrum (and other vulnerable groups) can contribute to achieving the outcomes of the Health and well-being strategy.
- Receive a further report following the writing of the autism joint strategic needs assessment (JSNA) in 2014.

## **References**

The Leeds autism strategy: [www.leeds.gov.uk/residents/Pages/Autism.aspx](http://www.leeds.gov.uk/residents/Pages/Autism.aspx)

Epidemiology of Autism Spectrum Disorders in Adults in the Community in England  
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