



**Report of:** Leeds Autism Partnership Board

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

**Date:** 25 April 2019

**Subject:** Leeds Autism Strategy Update

Are specific geographical areas affected? If relevant, name(s) of area(s):	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
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

The health and wellbeing system in Leeds has been working to improve the life of adults with autism since 2010. This report updates the Health and Wellbeing Board on our progress so far against our local strategy, current national developments and the emerging evidence base for the real issues for autistic people. It also summarises briefly Leeds submission to the autistic national return (SAF) and broadly references the imaginative improvements that agencies and individuals are taking.

The needs of the autistic population fit neatly within the Leeds Health and Wellbeing Strategy, and indeed, meeting autistic needs will make a contribution to achieving most of our priorities. For the autistic person or family carer meeting individual needs will enable them to contribute fully to society and maintain or improve their wellbeing. From a service perspective, meeting these individual needs in a timely way will have a positive impact on the demands on the whole Leeds system and hence on the Leeds £.

The Board will also be discussing the Leeds Mental Health Strategy on 25 April 2019. The prevalence and demand figures below indicate that the need for mental health support is substantially higher proportionally for autistic people than it is for the mainstream population. The way in which the mental health needs of those with additional needs are met has the potential to substantially improve the well-being of those with autism, and also, once embedded, could reduce the pressures on the mental health system.

The report concludes by recommending that, once we are clearer about national intentions, the Board approves an intention to explore an integrated city wide system for facilitating improved access. Given the work already underway in existing services and other current moves towards integrated this might be very manageable.

## **Recommendations**

The Health and Wellbeing Board is asked to:

- Recognise the city's progress on meeting the aims of the Leeds Autism Strategy.
- Recognise the contribution of the work underway within health, third sector and social care provider and commissioner services. This is outlined in more detail at the briefing document at appendix 3.
- Agree to (subject to national guidance) support the development of a whole system approach to communicating autistic needs and encouraging reasonable adjustments. aligned with other citywide approaches to integration and meeting the needs of vulnerable people.

## **1 Purpose of this report**

- 1.1 Leeds has been working to improve the health and wellbeing of people with autism since 2011. We have made substantial improvements, but there is still some way to go. This report will update the board on: progress on the strategy so far; the outcomes of the recent self-assessment framework (SAF); and developing information from national and local research.
- 1.2 The wider autism work covers a number of different agencies, this report focuses on the health and social care elements.
- 1.3 We seek the advice and commitment of the members of the Health and Wellbeing Board to continue the good work done so far and propose some next steps to build on this.

## **2 Background information**

- 2.1 The Board agreed the Leeds Autism Strategy 2017-22 in July 2017 (Appendix 1). This strategy takes a broad brush approach which recognises the breadth of need and ability within autistic individuals and the wide range of areas which may need to make reasonable adjustments to appropriately meet their needs.
- 2.2 Leeds' undertook a range of work since 2010 following the statutory guidance arising from the Autism Act (2009). As part of this work we developed a wide ranging strategy and set up a partnership board and reference groups for the various stakeholder groups of autistic people, carers and providers. Because of the varied needs of autistic people we work with a wide range of partners including the DWP, the criminal justice system, education, health, housing and social care. We have achieved some of those initial goals and improved in a range of areas. This original structure, having proved its worth, is still in place.
- 2.3 Currently, it is estimated that approximately 1% of the population is on the autistic spectrum. This will be equally true across the age range, but as a result of changing access to diagnosis, changing diagnostic criteria and changing patterns of recording we will know more people in the younger age ranges. Autism is a communication and sensory disorder which is independent of IQ. Historically autism was hardly recognised so we are still catching up with diagnosis, recording and awareness.
- 2.4 This means that the needs of autistic people can be met within a wide range of different services and some people do not use 'services' at all. Autistic people in themselves can have a wide range of different needs with areas of strength and of weakness that both they and other people can struggle to articulate.
- 2.5 The national return for autism is known as the self-assessment framework (SAF) and we were asked to complete the 5th version of this at the end of 2018. It consisted of 104 questions in total, 33 of which were RAG rated submitted by the Director of Adults & Health, Leeds City Council and the Chief Officer, NHS Leeds CCG. The Autism Partnership Board agreed all the RAG ratings prior to sign off and stakeholder groups contributed to the submission. Eventually a

national/regional comparison document will be produced by Public Health England. The implications of Leeds submission are discussed below.

2.6 There have been some significant national developments recently, which may impact actions Leeds take in the future:

- The existing statutory guidance was revised in 2018 to add two overarching objectives: 1: Reducing the gap in life expectancy for autistic people and 2: Autistic people are able to play a full role in society. Autistic people and family carers in Leeds would agree that these are priorities and are supportive of this change.
- The NHS Long Term Plan gives the needs of autistic people proper weighting. Some of the proposals in the plan suggest extending some models developed for people with learning disabilities to autistic people. There is a current national consultation on training which relates to this.
- There is another current consultation on a new version of the national statutory guidance, which asks for submissions from adults and children's services. The possible implications of this are addressed in para 3.4.

### **3 Main issues**

#### **3.1 Current evidence for prevalence and service use**

##### **3.1.1 Local figures/ Joint strategic needs assessment (JSNA)**

With Public Health assistance, Leeds has begun the process of re writing the autism JSNA. We have some provisional figures (Appendix 2), which indicate that, relative to 2014 we are now aware of substantially more autistic adults. We have some interesting figures indicating the level of need particularly around mental health services. These figures need to be read with some care as the various registers have a level of intrinsic uncertainty and the age ranges vary. In addition, these are early results and the figures are subject to change as we do more work on them.

The Adult Psychiatric Morbidity Survey (APMS) estimate for autism prevalence is 1%. The Leeds GP held autism register now records 2,003 autistic people over 16 years old (3,489 all age), which is 0.37% of the expected prevalence. Although clearly incomplete this represents a considerable improvement on the earlier figure and reflects both better recording and better diagnosis.

We can see that 40% of people on the autistic register have a common mental health disorder (compared with 26% of the general population) and 5.5% of autistic people have a severe mental illness (compared with 1.1% of the general population.). This is beginning to give us numerical evidence that autism is an important dual diagnosis for mental health services. Autistic people and their family carers have been saying this for a long time, from a service point of view this also implies that great benefits could be achieved by being able to provide in a way that was more accessible to autistic people.

The figures for people with autism and learning disabilities are substantially under what we might expect, as research suggest that learning disabled people have a higher probability of autism than the mainstream population. Estimates of autistic people with learning disabilities range from 15/20% to (in older research) 40-50%. Learning disabled people are thought to have a 30% chance of having autism. The Leeds GP figures is 4.7 % of people on the LD register have autism, and 6% of people on the autism register have LD.

We also have some information about numbers of autistic people using specific local services, this arises from ongoing commissioning work requiring the recording of autism as a diagnosis.

### 3.1.2 National research

Over the past few years there has been a steady stream of credible research indicating the negative impacts of autism on wellbeing and health. The evidence for the substantial impact of autism on life expectancy is widely accepted. Recent more specific (peer reviewed) research indicates the overrepresentation of autistic people (relative to a demographic baseline of 1.1%). For example, 8-12% of service users in a homeless service were or might be autistic and a review of substance misuse indicated a doubled risk of substance misuse problems for individuals with autism diagnoses, higher if they had a comorbidity with ADHD. Evidence of and concern about suicide and suicidality is also growing.

### 3.1.3 Summary of evidence

It can now be safely concluded from both the local and national work that autistic people are over represented (relative to baseline prevalence) in a wide range of different services. This has implications for how those services work with autistic people and potentially could reduce the pressures on them. It is of course likely that if we succeed in improving early responses to autistic needs and post diagnostic options this deficit will reduce, i.e. it is not necessarily intrinsic to being autistic.

## 3.2 Outcome of SAF

3.2.1 As mentioned above the SAF is a complex and uneven document; its questions range from very broad to very narrow, some are numerical and others ask for a collective RAG rating. Leeds Autism Partnership Board (APB) has historically chosen to give what it considers a realistic answer to the value questions. As many of the questions are very broad this inevitably means that our most common response is amber- i.e. we are doing reasonably well but are conscious we can still do better. For instance:

3.2.2 We do particularly well on our planning process and on our target times for adult diagnosis – Our team is one of the few teams in the country to meet NICE targets.

3.2.3 Some of the areas we do less well on are ones we have chosen not to prioritise, for example a citywide autism workforce development plan, or those which country wide are challenging. As yet the Leeds Partnership Board has not chosen to go down the route of seeking a commitment such as Autism Friendly Leeds.

- 3.2.4 There are some new questions which prompt interesting lines of work, we will follow up on the recording of autism specific hate crime for example. In addition we are exploring with the reference group for autistic people the possibility of having an autistic co- chair for the Autism Partnership Board.
- 3.2.5 There are no or very few questions on some of the areas which are of current local (and national) concern particularly around the ability of generic mental health services to make the appropriate reasonable adjustments to meet autistic mental health needs.
- 3.2.6 The SAF is not sufficiently sophisticated to bring out such points but it will be hard to make further major improvements as a city without a change of focus to have a system wide approach in some areas.
- 3.2.7 Leeds APB would welcome a change in shape of the SAF, so that it better reflected current concerns rather than those which were more significant 10 years ago – however we respect the need to allow some comparability over time.

### 3.3 Current developments in improving access to services/supports

- 3.3.1 One of the core pieces of work undertaken where opportunity arises is to influence provider services to record the numbers of autistic people using their services. Ultimately this will allow comparison of outcomes between autistic and neuro typical people and support services in identifying changes to enable them to better support autistic people.
- 3.3.2 In response to the objectives of the Leeds Autism Strategy there are a number of valuable pieces of work underway within health, third sector and social care provider services (see Appendix 3). The Autism Partnership Board wishes to acknowledge the commitments of the individuals and services who have already gone far to make things better than they were.
- 3.3.3 Although the different mental health services are working to improve their offer in different ways the majority of the stakeholder feedback is still on mental health services, and the demographic information above supports this.
- 3.3.4 As individual service areas make adjustments to their offer, questions of how we can facilitate this work by improving communication of individual need between services, ideally using existing mechanisms, come more to the forefront.
- 3.3.5 The CCG has funded a small pilot project to work with self-advocates to support other newly diagnosed autistic people to identify and share their individual needs/abilities. This will be evaluated and the outcome could feed into a future developments.

### 3.4 Children/transitions

The Autism Act (2009) was focused on adult needs as have been the two subsequent statutory guidance documents. This was because, at that stage, adult autism needs were recognised as being poorly served relative to those of children's. Since then the Care Act (2014) and the Children and Families Act (2014) have broadened responsibility for the transitions period and in addition some families of autistic children feel that they would like a more autism specific planning process. The current national consultation to inform new statutory guidance is aimed at both adults and children so this implies an intention to broaden the focus of the next set of statutory guidance. Locally we have had an adult strategy overseen by the adult partnership board; the APB has been very pleased to have constructive involvement from a range of different children's services.

Any developments in children's services clearly have an impact on the lives of those children when they become adult and this in its turn will influence the demand and provision of adult services and resources. There are various developments underway that will have such an impact including changes in eligibility criteria for the transitions team, the development of post 16 teams in children's services and over 18 teams in Sensap. The growth in supported internship schemes and college placements also supports the adult agenda. The waiting times for a children's autism assessment are now very close to delivering the 12 week NICE waiting time standard. This has been despite a significant increase in demand over the last couple of years.

### 3.5 Training

A key and continuing area of concern is that of staff training, as there is a national consultation on this this report does not go into any detail on this but it is suggested that the board notes that a local whole system attention to training needs/take up, once we have more national guidance, would be helpful.

### 3.6 Transforming care

The major transforming care project is managed outside of the mainstream autism work. It is however worthy of note that many of the people included within the transforming care programme have autism as a primary or a secondary diagnosis.

## **4 Health and Wellbeing Board governance**

### **4.1 Consultation, engagement and hearing citizen voice**

4.1.1 The autism planning structure is designed around the need to involve autistic people and family carers. There are reference groups for carers and people with autism. The meetings are timed to fit in with the Autism Partnership Boards (APB) –the APB agenda is discussed at the meetings and feedback is taken. Each reference group selects three delegates for the partnership board. Input from the reference groups heads the agenda for the APB - the groups raise the three issues which they think are currently of most importance. The reference group for people on the spectrum now meets in the Hub and has a higher level of attendance. In addition to this the autism lead will visit groups of people on the spectrum and carers to update on progress and take feedback – either on

invitation or approximately annually. Providers of services for people with autism are encouraged to invite the autism lead to speak to them.

- 4.1.2 Children's services are represented on the APB, parents of autistic children are involved with children's services through the youth forum and parent and carer forum.

## **4.2 Equality and diversity / cohesion and integration**

- 4.2.1 The broad purpose of this task is to improve access and integration for a group of disabled people and their families. As yet we do not have sufficient information to be able to assure ourselves that the people from the other protected characteristic groups are equally represented. The JSNA work we are undertaking will allow us to improve our data on BAME, gender and age characteristics but because of the historic under recording and diagnosis it will probably be some time until the diversity within autism is as well understood as other areas.

## **4.3 Resources and value for money**

- 4.3.1 Spend on specialist services is relatively modest. Some of the emerging information about the overrepresentation of autistic people in some health/service areas suggest that there would be substantial benefits in terms of the Leeds pound in improving the delivery of those services for autistic people.

## **4.4 Legal Implications, access to information and call In**

- 4.4.1 There are no access to information and call-in implications arising from this report.

## **4.5 Risk management**

- 4.5.1 There are no direct risks arising from this report. Where appropriate risk is managed through the APB and within individual organisations.

## **5 Conclusions**

- 5.1 Improving the options for adults with autism is a complex task which involves a range of different agencies and individuals. We have been working on this for some years now with some achievements.
- 5.2 Autistic needs make a difference to the majority of the priorities within the Leeds Health and Wellbeing Strategy. The health and care partnership and individuals have been working hard to improve their accessibility to autistic people.
- 5.3 The increasing amount of national and local data which indicates the overrepresentation of autistic people in some service areas emphasises the need for continuing this work both to achieve savings for the Leeds pound and importantly to improve individual well-being.
- 5.4 The emerging data around autism suggests a significant impact on mental health services.



- 5.5 The next most useful step is probably to explore ways of integrating mechanisms between different organisations as appropriate ideally in line with existing processes.
- 5.6 There are some complexities around knowing what is likely to be national guidance which might constrain/guide our local initiatives.
- 5.7 Advice and feedback from the board on how best to take existing successes forward would be very welcome

## **6 Recommendations**

The Health and Wellbeing Board is asked to:

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- Recognise the contribution of the work underway within health, third sector and social care provider and commissioner services. This is outlined in more detail at the briefing document at appendix 3.
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## **7 Background documents**

None.

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**How does this help reduce health inequalities in Leeds?**

As stated in the report there is increasingly strong evidence that autistic people are over represented in some areas of the health and care system. As individuals they are likely to have worse health and other outcomes. We are working towards improving access but need to continue to improve our offer to autistic people in the context of other service developments and increasing evidence of need.

**How does this help create a high quality health and care system?**

A system where autistic people (and other neuro diverse people) have their needs met effectively in a timely way would be a more effective system better able to meet the needs of the whole population.

**How does this help to have a financially sustainable health and care system?**

Meeting autistic health and care needs in a timely and effective way would, in the long term, reduce demand for services as well as improving individual well-being.

**Future challenges or opportunities**

There are major challenges in improving access to and outcomes from health and care systems for autistic people. Current service level developments show interesting ways to approach this and there is national developments which are likely to be helpful in this area. If as the board accepts the recommendation to support the development of a city wider approach to autistic health and care needs in line with future national guidance then there are strong opportunities for development. Any systems may be transferrable to, or sharable with other groups of people with additional needs.

<b>Priorities of the Leeds Health and Wellbeing Strategy 2016-21</b>	
A Child Friendly City and the best start in life	x
An Age Friendly City where people age well	x
Strong, engaged and well-connected communities	
Housing and the environment enable all people of Leeds to be healthy	x
A strong economy with quality, local jobs	x
Get more people, more physically active, more often	x
Maximise the benefits of information and technology	x
A stronger focus on prevention	x
Support self-care, with more people managing their own conditions	x
Promote mental and physical health equally	
A valued, well trained and supported workforce	x
The best care, in the right place, at the right time	