

Manchester Health and Wellbeing Board Report for Information

Report to: Health and Wellbeing Board – 14 May 2014

Subject: An overview of developments for childrens and adults on the Autistic Spectrum

Report of: Strategic Director, Families Health and Wellbeing

Summary

This report provides Members of the Health and Wellbeing Board with a detailed overview of developments for childrens and adults on the Autistic Spectrum in the city. It includes the outcomes from the annual statutory return for autism led by Public Health England and sets out how Manchester compares against the national picture of provision.

In addition, there is a progress report on developments for the new Special Educational Needs (SEN) Reforms, a draft diagnostic pathway for autism designed by the Clinical Commissioning Groups and provides some key highlights from emerging work to produce a dedicated JSNA for autism. Finally, the new national strategy for autism entitled: Think Autism, Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update sets out 15 Priority Challenges for Action; accordingly Manchester remains committed to improving the range of provision for people with autism across the life course and has a variety of fora to deliver on these requirements.

Recommendations

Members of the Board are recommended to note the developments on autism and approve this report.

Board Priority Addressed

Strategic Priority 1 – getting the youngest people in our communities off to the best start;

Strategic Priority 2 – educating, informing and involving the community in improving their own health and wellbeing;

Strategic Priority 4 – providing the best treatment we can to people in the right place and at the right time.

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Background Documents

Previous report to Health Scrutiny on Autism Developments

http://www.manchester.gov.uk/meetings/meeting/1949/health_scrutiny_committee

1. Background and Introduction

1.1 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 colours¹.

1.2 Regular progress reports on Autism developments are channelled via the Health Scrutiny Committee; the last progress report on key developments was November 2013. In this prior report, updates were provided on:

- The national reform of Special Educational Needs (SEN) and Disability as outlined in the Children and Families Bill and the development of visible information as part of the Local Offer to families and carers (http://www.manchester.gov.uk/info/500132/special_educational_needs/6181/manchesters_local_offer_for_children_and_young_people_with_sen_and_disabilities)
- The annual statutory self-assessment to Public Health England (PHE) on Autism developments against the national strategy *Fulfilling and Rewarding Lives*
- The Manchester statistics on the Autism cohort; as at May 2013. there were 459 children and young people had a SEN with Autism as a primary need (402 male and 57 female), and 181 adults with Autism; 172 were classed as having a learning disability with 3 people having additional mental health needs
- New arrangements for joint commissioning across health and care as part of the introduction of a single Education, Health and Care Plan (EHC) in order to provide a seamless provision of services from 0 – 25 years of age
- Progress with a new Autism diagnostic pathway via the CCGs
- New work to produce a Joint Strategic Needs Assessment (JSNA) for Autism

1.3 As part of the PHE annual statutory self-assessment on Autism, a key requirement for the submission is to formally set a date for when the Autism submission can be considered by the Health and Wellbeing Board. This report, therefore, focuses in the main on five main areas:

- a) The PHE return national findings
- b) A progress report on the SEN Reforms and progress towards a single EHC plan
- c) An update on the new diagnostic pathway via the CCGs
- d) Key findings from the Autism JSNA
- e) The refreshed Autism national Strategy: Think Autism, Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update

¹ The National Autistic Society (www.autism.org.uk)

2. The PHE Annual Self Assessment – national findings

2.1 The Adult Autism Strategy "*Fulfilling and Rewarding Lives*" *The Strategy for adults with autism in England* was published in 2010. It focused 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

2.2 The Strategy was not only about specialist services for people with autism. It also considers how mainstream services can be made equally accessible to them and the reasonable adjustments and staff training that may be needed to achieve this. More broadly it discusses the need to raise awareness of the different ways people with autism experience the world around them and the wide range of issues this can raise. The PHE annual self assessment was introduced to measure how the strategy was influencing local progress and key developments.

2.3 The 2013 exercise ran between August and October 2013. Questions covered broadly the same areas as in the previous exercise:

- Planning
- Training
- Diagnosis (led by local NHS Commissioner)
- Care and Support
- Housing and Accommodation
- Employment
- Criminal Justice System

2.4 Key findings

- Planning – 99% of authorities have a named senior manager or commissioning lead for Autism, 56% include autism in their JSNAs and 63% collect data on people with autism in receipt of a service
- Training - 59% have a multi-agency training plan in place
- Diagnosis led by the local NHS Commissioner – less than half (49%) of authorities stated that they had an established local diagnostic pathway. Of those who did have a diagnostic pathway, 58% reported that the pathway was integrated with adult social care and leads to a community care assessment where necessary
- Care and Support – This was one of the lower achievement areas with only 47% of authorities providing training for advocates
- Housing and Accommodation – Another low achievement area with only 18% meeting the level of including autism in their housing strategy and the range of accommodation options
- Employment – Most authorities detailed reference to employment in their transition processes to adult services (49%)

- Criminal Justice System – 60% of authorities reported progress to improve the criminal justice system involvement in planning for adults with autism
- 2.5 Manchester's results compare favourably against the national picture. *Appendix A* (table) sets out the top Green rated areas and the top Red rated areas and is a useful picture of progress. There remain some key areas for development – such as the housing strategy and training for advocates – and these are being actively progressed via the Learning Disability Joint Commissioning Board.
- 3. A progress report on the SEN Reforms and progress towards a single Education, Health and Care Plan**
- 3.1 The Children and Families Act 2014 received Royal Assent on 13th March 2014. This will reform systems for adoption, looked after children, family justice and special educational needs. The timescales for implementing the SEND reforms are:
- April 2014 - September 2015: Local Authorities work with partner agencies and parents to plan for implementation and delivery of the new system
 - From September 2014: Local Authorities publish Local Offer, following consultation with parents and young people
 - September 2014: new joint commissioning duty commences
 - September 2014: new entrants to be offered Education, Health and Care plans, personal budgets to be offered as part of EHC plans, new arrangements for mediation in place
 - By September 2016: young people with Learning Difficulty Assessments (LDAs) transfer to the new system
 - By April 2018: children and young people with Statements of SEN transfer to the new system
 - April 2015: new duties for young offenders with SEN commence
- 3.2 The Special Educational Needs and Disability reforms are linked to wider health and social care reform, including the Health and Social Care Act 2012, the Care Bill and the NHS Mandate. From September 2014 Local Authorities and CCGs must work together to jointly commission services for children and young people 0-25 with SEND, including securing provision to meet a child/young person's reasonable health needs. There is a duty on health practitioners to bring 0-5 year old children who may have SEN or a disability to the attention of the Local Authority, so they can consider whether an assessment is necessary.
- 3.3 Manchester has been testing the reforms as part of the government SEND pathfinder programme since 2011. The SEN Reform Board is overseeing the implementation of the reforms. In April 2014 all Local Authorities received a grant (as part of the Early Intervention Grant) to assist with implementation of the reforms. Manchester is using this grant to assist with converting from Statements and LDAs to EHC plans, set up new procedures and systems, and workforce development.

3.4 Manchester is supporting other local areas with the reforms as a regional and national SEND champion.

4. An update on the new diagnostic pathway via the Clinical Commissioning Groups (CCGs)

4.1 Appendix B provides an overview of the new draft Autism Spectrum Disorder (ASD) Diagnostic Pathway. This work is almost completed and a GM provider will be commissioned to provide diagnostic support. Autism diagnostics has also been added as a pathway in the Manchester Mental Health Improvement Programme.

5. Key Findings from the Autism JSNA

5.1 As part of the wider council approach to develop more specific JSNAs, work has commenced to produce an Autism JSNA – focused on the methodology:

- National and Local Context
- Epidemiology
- Current Services
- Gaps in Services
- What more do we need to know
- Recommendations

5.2 Understanding the local population trends

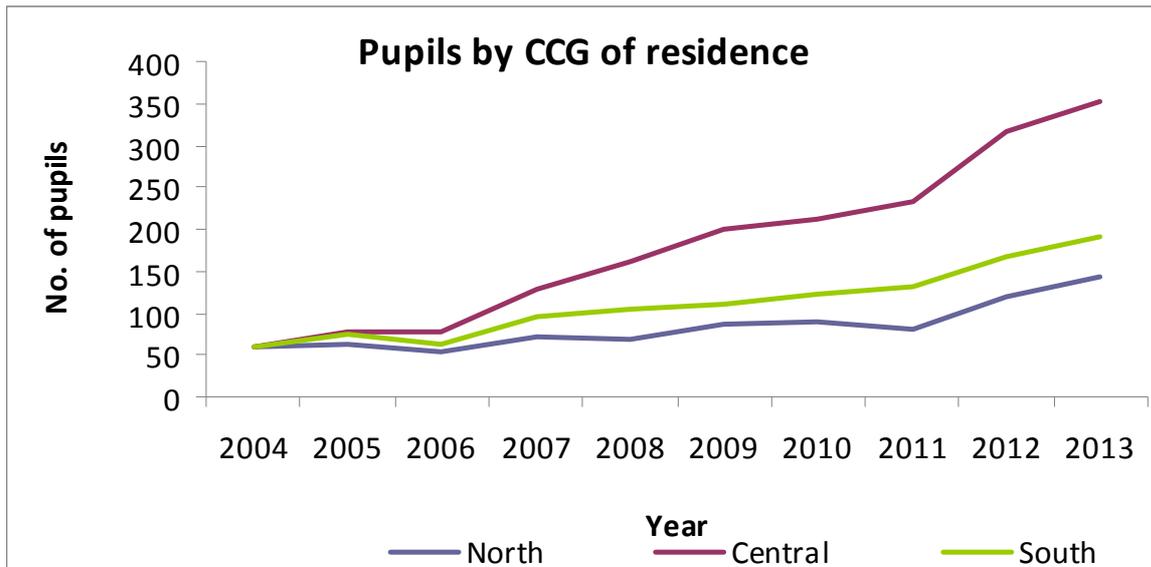
5.2.1 The following table shows the demographic Trends for Manchester (Data from PANSI)

People aged 18–64 predicted to have autistic spectrum disorders, by age, projected to 2020 (Manchester)					
Age	2012	2014	2016	2018	2020
18-24	878	873	860	842	816
25-34	1,059	1,083	1,099	1,113	1,113
35-44	678	671	682	695	722
45-54	540	558	565	561	550
55-64	388	392	401	415	434
18-64	3,544	3,576	3,607	3,627	3,636

The table above shows the projected numbers of people with autistic spectrum disorders resident in Manchester up to 2020. The data shows an overall projected increase of 2.6% from 3,544 in 2012 to 3,636 in 2020. However, the use of PANSI (Predicting Adult Needs and Service Information) is limited to adults age 18 to 64 years. As can be seen later in this section, the autism

trends based on the numbers of children via the school census, is predicted to increase the overall population in Manchester significantly; this will have implications for commissioning of services for the adult population.

5.2.2 There are noticeable differences in the increase of children with autism by CCG areas. In 2004 all three CCG areas had the same number of resident children in schools with autism however as the chart below illustrates the increase has been more significant in Central and South than in North CCG. More work needs to be undertaken to understand the variance.



5.3.1 The production of the JSNA is near completion and some of the early needs analysis shows:

- The latest prevalence studies of autism indicate that 1.1% of the population in the UK may have autism. This means that over 695,000 people in the UK may have autism
- Five times as many males as females are diagnosed with autism. The proportion of males as opposed to females diagnosed with autism varies across studies, but always shows a greater proportion of males
- The National Autistic Society is the UK's leading charity for people affected by autism. They provide a wide range of personalised support services for people on the autism spectrum and their families and carers in Manchester. They report anecdotally that the numbers of people with an autism diagnosis accessing their services is increasing, people are presenting with more complex needs, they often find it hard to get a diagnosis and even when they do medical and social care services and support can be limited. The National Autistic Society in Manchester currently has 188 people over the age of 18yrs with a diagnosis accessing their services
- Currently the most reliable data on children with autism in Manchester is the school census which identifies all children with a special educational need (SEN). This data includes all children in school who are receiving

support through school action plus or a statement it does not include children with autism who have lower support needs.

- This data shows a steady increase in the number of children with an SEN whose primary or secondary need is Autism. Between 2004 and 2013 the January 2013 school census shows an increase in both the overall school population and the SEN population. The rate of increase in the Autistic population of Manchester schools is 32 times greater than that of the general school population and 15 times greater than the school SEN population
 - The January 2013 school census shows an increase in total school population from 66067 in 2004 to 71396 in 2013 this is a total increase of 5329 or 8.1%
 - The number of children with school action plus or a statement for an SEN in the same period has increased from 5415 in 2004 to 6379 in 2013 this is an increase of 964 or 18%
 - The increase in number of pupils in Manchester with School Action Plus or a Statement of SEN and a primary or secondary SEN need of Autism is more significant from 195 in 2004 to 714 in 2013. This is an increase of 519 or 266%
- 5.4 With regard to Post-16 provision, in 2013 of the 61 Manchester 16-24 year olds attending Independent Specialist Colleges, 15 had a primary need of ASD.
- 5.5 In 2013, the responsibility for funding 16-25 year olds with high needs in all types of post 16 educational provision moved from the Education Funding Agency to Local Authorities. We do not currently have complete data on achievement and progression for high needs post 16 students, but have set up systems to track students from school to college and beyond. We need to establish a baseline of how many young people with ASD are progressing into college and then into work. The SEND reforms, including the new Education, Health and Care plans, with the focus on outcomes and preparing young people for adulthood will assist us in improving progression. The new high needs funding system also allows us to fund Supported Internships - programmes that are run jointly by employers, colleges and supported employment providers. This type of programme is proving to be a very successful route into work for a number of young people with Autistic Spectrum Conditions.
- 5.6 Once completed, the JSNA will complement the suite of JSNAs and placed on the City Council website: www.manchester.gov.uk/jsna and will inform future commissioning intentions.
- 6. The refreshed Autism National Strategy: Think Autism, Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update**

- 6.1 This strategy, first issued in 2010, has been refreshed and launched in April 2014, for the following three reasons:
1. In line with the requirement in the Autism Act, the strategy has been reviewed in 2013/14, and now incorporates the views of what people with autism, their families and providers have told the government
 2. Recognition that significant progress has been made on the original strategy and this refresh acknowledges what has been achieved and what work there remains to do
 3. Acknowledgement that there has been widespread transformation across public services and new organisations which has improved the lives of people with autism and takes account of these reforms
- 6.2 The annual self-assessment (see section 2 of this report) is inextricably linked to the Strategy and re-states the importance of addressing a wider set of issues to improve key issues that affect people with this disability. Despite Manchester's good performance against a suite of cross-cutting objectives, there remains much work to be done, particularly in terms of embedding the diagnostic pathway work, ensuring that the single EHC plan delivers real and tangible outcomes for people (particularly in that transition phase from 16 – 19) and joint working across both the health and social care economy and with wider partners in the Police and Criminal Justice System.
- 6.3 The refreshed strategy reinforces **15 Priority Challenges for Action**. These can be summarised in three themes:
- An equal part of my local community
 - The right support at the right time during my lifetime
 - Developing my skills and independence and working to the best of my ability
- 6.4 These priority actions will be progressed through a variety of governance processes such as:
- **The Autism Strategy Group** – led by the CCGs in order to own and oversee the resultant action plan, assign leads and develop proposals that address the individual areas
 - **The Learning Disability Joint Commissioning Board** – chaired by the Head of Strategic Commissioning and includes key players from health, Greater Manchester LD lead, housing, finance, education etc
 - **The SEN Reform Board** – chaired by the Director of Education and Skills and overseeing the implementation of the single Education, Health and Care Plan and ensuring that demonstrable improvements are made to improve the co-ordination of care and support to people 0 – 25.

7. Recommendations and Next Steps

- 7.1 Autism work in Manchester is well-developed and, based on the national findings of the autism annual return; we have made more progress than our comparators. However, there remain some key actions to progress over the next twelve months, as follows:

- Incorporate the JSNA actions and align to the new autism national strategy – the 15 priority challenges for Action – to produce a comprehensive autism action plan for Manchester
- Ensure the Autism Strategy Group, reporting into the Learning Disability Joint Commissioning Board, effectively oversees progress and reports any challenges to the Board
- Work with the National Autistic Society (NAS) at Greater Manchester level to ensure that the GM training plan addresses the need to train advocates on Autism
- Ensure that the developing housing strategy includes people with a disability and also those with autism/learning disability and sets out the accommodation offer for adults
- Implement the SEND reforms to ensure that the single Education, Health and Plan meets the needs of young people with needs, particularly those with autism to support the strategic priorities of the Health and Wellbeing Board
- Further investigate the recommendations from the National Autistic Society on “Growing Older with Autism” and take account of best practice via older people’s commissioning practice
- Report ongoing annual progress to the Health Scrutiny Committee as necessary

Appendix A

The PHE Annual Self Assessment – national findings

Analysis of national findings and how Manchester compares

Question	RAG rating	Manchester status
Questions that scored the highest GREEN RAG rating		
3. Do you have a named joint commissioner/senior manager of responsible for services for adults with autism?	Manchester = Green	Manchester confirmed it had 3 named leads for Autism covering health/CCG commissioning, assessment and care management and social care commissioning
7. Does your commissioning plan reflect local data and needs of people with autism?	Manchester = Green	There is reference to autism in the Market Position Statement - (http://www.manchester.gov.uk/downloads/download/5544/market_position_statement) And the JSNA (www.manchester.gov.uk/jsna)
23. Has the local Clinical Commissioning Group(s)/support services taken the lead in developing the pathway?	Manchester = Green	Yes, the development of the autism diagnostic pathway had been led by the Citywide Commissioning Team, working on behalf of the 3 CCGs. This work is nearly completed and a GM provider will be used to provide diagnostic support. Autism diagnostics has been added as a pathway in the Manchester Mental Health Improvement Programme.
32. Can people with autism access support if they are non Fair Access Criteria eligible or not eligible for statutory services?	Manchester = Green	Yes, via the National Autistic Society Helpline. We also have local service directories available to ensure that non-FACS customers can access a wide range of non-statutory and universal services.
Questions that scored the highest Red RAG rating		
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)?	Manchester = Green	Manchester captures autism at the core community care assessment and can therefore produce meaningful statistical data on the Manchester cohort
14. Have you got a multi-agency autism training plan?	Manchester = Green	Manchester, alongside the other Greater Manchester authorities, commissions the National Autistic Society to provide multi-agency training across the region.
17. Have Clinical Commissioning Group(s) been involved in the development of workforce planning and are general practitioners and primary care practitioners engaged	Manchester = Green	Dr Ruth Thompson (Salaried GP and MH Commissioner) has promoted the following level 1 ASC awareness courses. http://www.mhsc.nhs.uk/gp-web-zone/general-news/useful-links.aspx

included in the training agenda?		
18. Have local Criminal Justice services engaged in the training agenda?	Manchester =Green	Yes, Greater Manchester Police have commissioned their own ASD awareness training. The training is based on a 'train the trainers' model. It has been delivered to custody Sergeants and new police recruits.

As it can be seen, Manchester compares very favourably when compared to the national picture, with matching the highest Green RAG rated responses and, in contrast, does not have any Red RAG rated responses. The detailed results of the national autism self assessment can be found via:

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

Appendix B

Draft Manchester Autism Diagnostic Pathway (NON LD)

Garry Parvin	2/3/2014	V0.2
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