

REPORT TO THE HEALTH AND WELLBEING BOARD

24 January 2014

PUBLIC HEALTH ENGLAND AUTISM SELF-ASSESSMENT

Report by the Commissioning Specialist

1. PURPOSE OF THE REPORT

- 1.1 The purpose of the report is to inform the Health and Wellbeing Board of the process followed in completing the Public Health England Autism Self-assessment and to share the document for discussion at the January meeting of the Board.
- 1.2 The report will also provide a brief overview of work carried out by the Local Autism Working Group during the last six months and the next steps for the Group moving into 2014.

2. BACKGROUND

- 2.1 *'Fulfilling and rewarding lives: a strategy for adults with autism in England'* was published by the Department of Health in March 2010.
- 2.2 The strategy sets out a number of key actions and recommendations for local authorities and their partners.
- 2.3 In Sunderland, a multi-agency Local Autism Working Group (LAWG) meets on a bi-monthly basis to support the implementation of the strategy recommendations. The membership of the group includes representatives from Sunderland City Council, Sunderland Clinical Commissioning Group, Jobcentre+, Northumbria Probation Service, the voluntary and community sector and a parent carer.
- 2.4 The National Autism Strategy is currently being reviewed and will be revised accordingly by March 2014. As part of the review, local authority areas have been asked by Public Health England to complete a self-assessment exercise which monitors progress made against the strategy.
- 2.5 In August 2013, a letter was sent from Norman Lamb MP, Minister of State for Care and Support, to all Directors of Adult Services introducing the 2013 autism self-assessment and giving a timescale of 30th September 2013 for completion and submission of the document to Public Health England (Appendix 1).
- 2.6 The following is an extract from the letter detailing action needed from Directors of Adult Services:

'The response for your Local Authority area should be agreed by the Autism Partnership Board or equivalent group, and the ratings validated by people who have autism. I am also asking that you are aware of the content of the return when it is submitted and that it is discussed by the local Health and Well Being Board by the end of January 2014 as evidence for local planning and health needs assessment strategy development and supporting local implementation work.'

3. COMPLETION OF THE AUTISM SELF-ASSESSMENT

- 3.1 The Self-assessment had to be completed online and included a series of questions, some of which required a yes/no answer and others where a rating of red, amber or green had to be assigned. Criteria were given to inform the ratings.
- 3.2 The on-line submission could only be accessed by a maximum of two people and as a consequence the commissioning support officer had to create a template of the self assessment questions to enable the Local Autism Working Group (LAWG) to respond to the request made by Norman Lamb, MP.
- 3.3 Each question within the self-assessment was sent to key representatives from the Local Autism Working Group for an initial response. Responses were collated by the LA Strategic Commissioning Team and the completed document was sent to the LAWG for comments.
- 3.4 A LAWG workshop was held on Thursday 12th September where a discussion took place to formally agree the ratings and evidence included in the self-assessment.
- 3.5 Following the workshop, amendments were made to the document and it was circulated to the LAWG for sign off. The completed self-assessment is attached at Appendix 1.

4. AUTISM WORKSHOP – 12TH SEPTEMBER 2013

- 4.1 The main aim of the workshop was to formally agree the ratings and evidence in the self assessment and to develop new priorities for the LAWG for the next phase of implementation of the autism strategy.
- 4.2 A number of exercises were undertaken, designed to identify gaps in services for people with autism and areas of the strategy that had not been fully implemented.
- 4.3 The group agreed that smaller working groups should be formed that would take forward discreet pieces of work to meet the identified priorities. The groups would co-opt representatives as necessary to carry out their work.

Leads from each of the groups would report back to the bi-monthly meetings of the LAWG and progress would be monitored by the LAWG.

- 4.4 It became apparent during the discussions that many of the groups already existed as sub-groups of the LD Partnership Board and the group felt that the best course of action would be for the LD Partnership Board sub-groups to broaden their remit to include autism and representatives from the LAWG would join the sub-groups to take forward the work to meet the LAWG priorities. This approach has been discussed by the LAWG and agreed to be a more efficient way of working.

5. SUMMARY OF THE AUTISM SELF-ASSESSMENT FOR SUNDERLAND

- 5.1 A number of clear priorities for the LAWG emerged from the completion of the self assessment:

- 5.1.1 Collection of data on the number of people with a diagnosis of autism and information sharing between health and social care organisations - All statutory agencies have begun to collect data on the number of people with autism and some data sharing exists between health partners. Further work needs to be taken forward by the LAWG to investigate current data collection methods and how data can be shared between health and social care agencies. Accurate data is needed to feed into the JSNA which currently does not contain any data on the number of people with autism in the city.
- 5.1.2 Engagement of people with autism and their carers in the work of the LAWG - As part of the needs assessment exercise, people with autism and their carers were consulted via online questionnaires and focus groups, however, the response was relatively poor. One parent carer is currently part of the LAWG and this person works with a number of families across the city. The engagement and involvement of people with autism and their carers is a priority for the LAWG moving into 2014. The group will consider the best way to involve and consult with people with autism and their carers including through the inclusion of an adult with autism in the LAWG membership.
- 5.1.3 Autism training for health and social care staff – All staff who work with people with autism have received specialist training appropriate to their role. E-learning autism awareness training is also available to all Council staff. Within Sunderland CCG, training is also available to all sectors. Other training has been accessed by agencies across the city, e.g. awareness training for GPs, but a citywide training plan is not in place. A priority for the LAWG will be to map existing training and training needs and develop a training plan across health and social care agencies, where possible.
- 5.1.4 Improving the support available after diagnosis – A diagnostic service was established in April 2014 and was accessed by 37 people from Sunderland in its first year of operation. Following diagnosis, people receive a range of support from the diagnostic service and are also signposted to other services as necessary. Two post-diagnostic workshops have been held on a pilot

basis, provided by ESPA and funded by the SHA, which aimed to provide people who had recently been diagnosed with information about their condition and how it may affect their lives. Initial feedback from the workshops has been very positive and ESPA is currently exploring how the programme of workshops can be extended. A priority for the LAWG in 2014 is to consider how low-level support can be improved for people with autism, in particular, those with needs at the higher functioning end of the spectrum. The LAWG has identified low level support and advocacy as a gap in the city.

- 5.1.5 Helping adults with autism into work – There are a number of projects in place across the city which aim to increase the skills and work experience of people with autism. An awareness raising event for employers was planned but had to be cancelled due to lack of interest from employers. Moving into the New Year, a sub-group will consider how the employment of people with autism can be promoted amongst employers and will consider the employment support available to people with autism in the city.

6. VALIDATION OF THE RATINGS BY PEOPLE WITH AUTISM

- 6.1 The letter from Norman Lamb MP required the self-assessment RAG ratings to be validated by people with autism.
- 6.2 A parent carer, Carole Rutherford, who sits on the LAWG runs a support group for people with autism and their families, Autism in Mind, and works with a large number of families affected by autism in Sunderland. The Strategic Commissioning Team initially approached Carole with a view to establishing a small focus group of people with autism who would like to take part in the exercise. 11 individuals were identified and were keen to take part.
- 6.3 At the workshop on 12th September, Carole and other members of the group expressed concerns that the format and language of the self-assessment document would not be easily understood by the general public who would be unlikely to be able to relate to any of the answers given. The self-assessment is a high level strategic document that considers issues such as data collection, inclusion of autism in strategies and the JSNA, policies and procedures, training of health and social care staff, etc, and the group felt that the people attending the focus group would not be able to validate ratings against questions they did not understand or had little knowledge of, and any validation exercise risked becoming tokenistic.
- 6.4 Following similar concerns from a large number of local authorities, Public Health England extended the deadline for submission of the self-assessment to allow more time for the validation exercise to be carried out.
- 6.5 On 7th November 2013, an event was held at Fulwell Day Centre. Invitations were sent to the parents and carers of people with autism who attended the LA day centres across the city and also to people with autism receiving residential care in the city. Parents and carers were encouraged to bring the person who they were caring for if they wanted to attend. The event was

attended by six carers and was facilitated by members of the Strategic Commissioning Team with support from Fulwell Day Centre staff.

- 6.6 The Commissioning Specialist gave a short presentation on the National Autism Strategy and the work that had been done in Sunderland to meet the strategy recommendations. This was then followed by an interactive exercise where attendees were able to rate the evidence given in support of some of the outcomes in the self-assessment as red, amber or green based on the criteria supplied by Public Health England. One person disagreed with the rating given for one of the outcomes and her comments were noted for discussion by the LAWG.
- 6.7 Before leaving the event, attendees were asked to complete a questionnaire asking them if they would be interested in attending similar events in the future and if they would like to be kept informed of the work of the LAWG. The majority of people expressed an interest in becoming involved in the future work of the group.
- 6.8 A similar event was planned to take place with the group of adults that attend the Autism in Mind support group, but due to unforeseen circumstances, Carole Rutherford was not able to support this work within the timescales set by Public Health England.
- 6.9 The validation exercise has highlighted the need to improve engagement and consultation with people with autism and their carers which has been identified as a priority for the LAWG in 2014.

7. NEXT STEPS FOR THE LAWG

- 7.1 The LAWG members have agreed that a priority for the group is to develop mechanisms to meaningfully engage people with autism and their carers in the work of the group. The group is exploring possibilities to work with Sunderland People First to explore how networks can be established to allow involvement of local people with autism and their carers. Alongside this, the group will consider how individuals with autism can be approached to join the membership of the LAWG and sub-groups.
- 7.2 Additional priorities outlined in 5.1 will also be taken forward as part of a revised action plan.
- 7.3 It was agreed at the autism workshop, held in September 2013, that the potential to broaden the remit of the LD Partnership Board sub-groups to include autism would be explored as this would lead to a more efficient way of working. Appropriate members of the LAWG would be required to join the sub-groups to take forward actions identified by the LAWG. Key LAWG members have been identified to join each of the sub-groups and discussions are ongoing to begin this work. Each of the sub-groups, in conjunction with the LAWG, will identify the actions they will be taking forward in relation to the

autism strategy and the LAWG will continue to monitor progress against the action plan.

8. RECOMMENDATIONS

- 8.1 HWBB is requested to receive this report for discussion as requested in the letter from Norman Lamb MP.

9. APPENDIX

1. Public Health England Autism Self-assessment for Sunderland

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