

HEALTH AND WELLBEING BOARD: 29 NOVEMBER 2018

REPORT OF THE DIRECTOR OF THE ADULTS AND COMMUNITIES

DEPARTMENT OF HEALTH AND SOCIAL CARE
2018 ADULT AUTISM SELF-ASSESSMENT

Purpose of report

1. The purpose of this report is to inform the Health and Wellbeing Board on the findings from the 2018 Leicestershire Autism Self-Assessment, which will be submitted to the Department of Health and Social Care by 10 December 2018.

Link to the local Health and Care System

2. The purpose of the Autism Self-Assessment Framework (SAF) is to assist local authorities and their partners in assessing progress on the implementation of the 2014 Think Autism: Adult Autism Strategy. The Health and Wellbeing Board received a report in November 2016 on the completed 2016 Autism Self-Assessment.
3. The Health and Wellbeing Board is required by the Department of Health and Social Care to endorse the findings of the 2018 Leicestershire Autism Self-Assessment.

Recommendation

4. It is recommended that the Health and Wellbeing Board endorses the findings of the 2018 Leicestershire Autism Self-Assessment noting that they will be submitted to the Department of Health and Social Care by the 10 December 2018 deadline.

Policy Framework and Previous Decisions

5. The purpose of the Autism Self-Assessment is to evaluate Leicestershire's progress on the Autism Act 2009 and the National Strategy, Think Autism, which was published in 2014.
6. This includes a set of mandatory recommendations regarding what actions Clinical Commissioning Group's and local authorities should take to develop services for people with Autistic Spectrum Disorder.
7. Statutory guidance for local authorities and NHS organisations to support the implementation of the Adult Autism Strategy was published in March 2015. The guidance refers to the legal duties imposed upon local authorities and NHS bodies by the Autism Act 2009. It includes the Care Act 2014 and the Children and Families Act 2014. The guidance not only refers to what "must" be done to comply with legislation, but also says what local authorities and NHS bodies "should" do with regard to the way in which they exercise their functions with a view to securing the

implementation of the Adult Autism Strategy. The National Autism Strategy, along with the guidance, is due to be revised in 2019.

Background

8. Directors of Adult Social Services were notified of the fifth self-assessment on 19 September 2018 for completion and submission to the Department of Health and Social Care by 10 December 2018.
9. The 2018 Self-Assessment is comprised of 129 questions across seven sections: planning, training, diagnosis, care and support, accommodation, employment and the criminal justice system, with additional sections to highlight local good practice.
10. Data collection continues to be challenging across a range of sources. Both the quality and quantity of data collected affects the ability to accurately assess progress in certain areas explored within the self-assessment.
11. There are 33 questions which are red, amber and green (RAG) rated indicating green in areas where the requirements are being met, amber where the requirements are progressing and red where the requirements are not met and highlight future priorities. A summary of findings is provided in Appendix A.
12. The last Autism SAF was completed in 2016. The table in Appendix B outlines the key RAG rating findings from 2018 and the previous self-assessments for comparison. Details from Health and one from Criminal Justice are still to be confirmed. There were three new RAG rated questions for 2018 where comparisons cannot be made.
13. The results show some good progress, but also highlight other areas that need to be developed: 10 ratings remain green, six ratings remain amber and one rating remains amber/green. Four questions remain red (Q64, Q75, Q77 and Q79) with respect to the post diagnostic support for people with autism without a learning disability. Changes from 2016 include good progress with one rating moving from amber to green and two ratings moving from red to amber. However, three ratings moved from green to amber and three from amber to red (Q32, Q54 and Q82). Of the new RAG ratings, one was red (Q99), one was amber and one green.
14. Work is already being undertaken to ensure autism is recorded where appropriate for the current cohort of service users to ensure effective planning and additional specialist training sessions are provided for social care staff who have undertaken social care assessments.
15. The Leicester, Leicestershire and Rutland Transforming Care Programme has agreed to fund an Autism Development Worker. The proposal is a 25 hour per week funded post for three years so that a number of sustainable developments will be in place for the next Autism Self-Assessment, including greater engagement with Autistic people and improved information, advice and support for autistic people without a learning disability. The role will also work in the community to raise awareness of autism amongst employers.
16. There is also a proposal to pilot and develop an Autism Friendly Community in both the Kibworths (Kibworth Beauchamp and Kibworth Harcourt) in partnership with the

Children and Families and Chief Executive's Departments, Harborough District Council, local communities and the Leicestershire Autistic Society. The vision of the project aims to support both, individual and families that experience autism; considering how access to local facilities can be improved, facilitating safe environments and giving them the opportunity to participate in their community. As part of the development, engagement with local Elected Members has taken place and this is now being rolled out to the wider community in both the Kibworths.

Consultation/Patient and Public Involvement

17. A joint vision, along with a set of joint principles, will be agreed by local partners in 2019 and the Council will work with individuals, carers and partners to get the approach right in Leicestershire. Local consultation with adults with autism and their carers is planned for the revised Leicestershire Autism Implementation Plan which will be developed in 2019, based on the results of the Autism SAF and our statutory duties.
18. The 2018 Leicestershire Autism Self-Assessment will also be taken to the Leicestershire Learning Disability Partnership Board for information.

Resource Implications

19. There are no implications in relation to the completion of the self-assessment. Actions arising from the assessment and revised Autism Strategy may have resource implications for relevant agencies, but these will be assessed on a case by case basis.

Timetable for Decisions

20. The 2018 Autism Self-Assessment will be submitted by 10 December 2018 as directed by the Department of Health and Social Care.

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List of Appendices

Appendix A: Summary of 2018 Autism Self-Assessment RAG Ratings
 Appendix B: 2018 and Previous Autism Self-Assessment RAG Ratings

Relevant Impact Assessments

Equality and Human Rights Implications

21. The self-assessment is a means for local areas to assess their progress against statutory requirements. The self-assessment will highlight areas for further work in relation to equalities to ensure people with autism can access services.

Appendix A: Summary of 2018 Autism Self-Assessment RAG Ratings

Areas where we are doing particularly well and some listed local innovations in the Self-Assessment (Green rated):

- Working in partnership to ensure better data for planning and commissioning e.g. The Deveron Way innovation concerns the remodelling of two existing buildings at a council residential home in Hinckley, Leicestershire, into Supported Living provision for people on the Transforming Care Programme. The innovation involved the reconfiguration of the current buildings into four, self-contained single, long term accommodation units, designed for individuals seeking Support Living, targeted at those who are currently in hospital or part of the transforming care cohort including Autistic people
- Involvement of LLR partnership in planning and implementation of the Autism Strategy
- Encouragement of autistic people in physical fitness, cultural and leisure activities e.g. All Leicestershire County Council Museum & Heritage sites have autism audits and the feedback gathered is influencing site and programme developments. Heritage, Libraries and Adult Learning have successfully tailored opportunities and projects to meet community motivations and needs and at engaging 'non-traditional volunteers', including young people and adults with learning difficulties and autism.
- Transitions taking into account the needs of young Autistic people
- There is an established local autism diagnosis pathway
- People with autism and a learning disability are able to access post diagnosis support in psychology, speech and language and occupational therapy
- Awareness training is available to all staff working in health and social care
- Advocates working with autistic people have access to specific training
- Carers of autistic people are offered assessments through the care pathway
- Autistic people have access to an Appropriate Adult who has an understanding of autism

Areas of general progress but could be improved (Amber rated):

- Including autism explicitly in the local Joint Strategic Needs Assessment (JSNA)
- Improved collection and reporting of data on autism (health and social care) for purposes of planning and commissioning
- Greater involvement of autistic people and their families in planning and commissioning
- Reasonable adjustments to services such as universities, libraries and public transport
- Reasonable adjustments to promote access for autistic people to health and social care information, support and advice
- Planning that specifically includes the needs of autistic people aged 65 and over
- Accessible information about local support for autistic people
- A higher profile for autism in partner housing strategies
- Greater employment focus for autistic people going through transitions

Areas for development include (Red rated):

- Reasonable adjustments to general council services to improve access and support for autistic people

- The local autism diagnosis pathway currently not able to meet the NICE recommended waiting times for diagnosis
- People with autism and without a learning disability are not able to access post diagnosis support in psychology, speech and language and occupational therapy
- Mental health services able to offer crisis support for people with autism without a learning disability
- Increased uptake of specialist autism training for staff carrying out statutory assessments
- Tailored programmes to help autistic people into employment

Appendix B: 2018 and Previous Autism Self-Assessment RAG Ratings

Planning					2013	2014	2016	2018
18	Is autism included and explicitly considered in the local JSNA?	Red: No	Amber: Steps are in place to include in the next JSNA.	Green: Yes				
20	Do you collect data on those people referred to and/or accessing social care and/or health care and does your information system report data on people with a diagnosis of autism, including as a secondary condition, in line with the requirements of the social care framework? Comment: Add any further comments you want (optional)	Red: Data recorded on adults with autism is sparse and collected in an ad hoc way	Amber: Current data recorded annually but there are gaps identified in statutory health and/or social care services data. Some data sharing exists between services	Green: An established data collection and sharing policy inclusive of primary care, health provision, adult social care, schools or local education authority and voluntary sector care providers is in place and used regularly	N/A			
27	Taking together any data in the JSNA and any other sources referenced here, how adequately do current collections of data sources service the requirements of planning and commissioning?	Red: No work underway. Red/Amber: Collection of limited data sources.	Amber: Have made a start in collecting data and have plans to progress. Amber/Green: Have started to collect data and whilst not comprehensive, consider this is an accurate reflection.	Green: Information from GPs, Schools or Local Education Authority, voluntary sector, providers, assessments and diagnosis are all collected and compared against the local population prevalence rate.	N/A			
28	Are your Local Authority and local Clinical Commissioning Group(s) (including the support service) both engaged in the planning and implementation of the strategy in your local area?	Red: None or minimal engagement between the LA and CCG(s) in planning and implementation.	Amber: Representative (s) from CCG(s) and / or the support service sits on autism partnership board or alternative and are in regular liaison with the LA about planning and implementation.	Green: 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.				
31	How have you and your partners engaged autistic people and their families and carers in planning? Comment: Specify what you did to demonstrate your score.	Red: Minimal autism engagement work has taken place.	Amber: Some autism specific consultation work has taken place. Autism partnership board is regularly attended by one person with autism and one parent/carer who are	Green: 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.				

			meaningfully involved.	Autistic people are thoroughly involved in the autism partnership board.				
32	Have reasonable adjustments been made to general council services to improve access and support for autistic people? Comment: Please give an example.	Red: Only anecdotal examples.	Amber: There is a clear council policy covering reasonable adjustments to statutory and other wider public services which make specific reference to autism	Green: Clear council policy as in Amber and evidence of widespread implementation in relation to needs of autistic people.	N/A			
33	In your area have reasonable adjustments been promoted to enable autistic people to access NHS services including primary care or GP services, mental health and acute services? Comment: Add any further comments you want (optional)	Red: There is little evidence of reasonable adjustments in NHS services, to improve access for autistic people.	Amber: There are some examples of reasonable adjustments being made to NHS services to improve access for autistic people, across a small range of services.	Green: There is evidence of implementation of reasonable adjustments for autistic people in a wide range of NHS services	N/A	N/A	N/A	
34	In your area have reasonable adjustments been promoted to enable autistic people to access health and social care information, support and advice? Comment: Add any further comments you want (optional)	Red: There is little evidence of reasonable adjustments to health and social care information, support and advice services, to improve access for autistic people.	Amber: There are some examples of reasonable adjustments being made to health and social care information, support and advice services, across a small range of services.	Green: There is evidence of implementation of reasonable adjustments for autistic people in a wide range of health and social care information, support and advice services.	N/A	N/A		
35 p1	In your area have reasonable adjustments been promoted to enable autistic people to access other public services including colleges and universities, libraries and all forms of public transport? Comment: Add any further comments you want (optional)	Red: There is little evidence of reasonable adjustments in other public services, to improve access for autistic people.	Amber: There are some examples of reasonable adjustments being made to public services to improve access for autistic people, across a small range of public services.	Green: There is evidence of implementation of reasonable adjustments for autistic people in a wide range of publicly provided and commercial public services	N/A			
35 P2	Is the local authority or its partners encouraging autistic People to take part in culture and leisure activities, or physical fitness programmes and private sector services such as shopping? Add any further comments you want (optional)	Red: The local authority and/or its partners cannot identify substantial actions to encourage autistic people to take part in culture or leisure activities, or physical fitness programmes and private sector services such as shopping.	Amber: There are a few examples of the local authority and/or its partners encouraging autistic people to take part in culture or leisure activities, or physical fitness programmes. and private sector services such as shopping.	Green: The local authority and/or its partners have a substantial programme of work to encourage autistic people to take part in culture or leisure activities, or physical	N/A	N/A	N/A	

				fitness programmes and private sector services, such as shopping.				
36	How do your transition processes from children's services to your local adult services take into account the particular needs of young autistic people? Comment: Add any further comments you want (optional)	Red: No consideration of the needs of young autistic people: no data collection; no analysis of need; no training in young people's services.	Amber: Transition process triggered by parental request. Training in some but not all services designed for use by young people, and data collection on young autistic people and/education health and care (EHC) plans with autism as a primary or secondary need.	Green: Transition process automatic. Training inclusive of young people's services. Analysis of the needs of population of young people, including those without education health and care (EHC) plans with autism as a primary or secondary need and specialist commissioning where necessary and the appropriate reasonable adjustments made.	N/A			
42	How does your planning take into account the particular needs of adults age 65 and older. Comment: Add any further comments you want (optional)	Red: No consideration of the needs of people aged 65 and older with autism: no data collection.	Amber: There is some work in needs assessment, data collection and/or service planning for autistic people aged 65 and older.	Green: Analysis of the needs of the population of people aged 65 and older inclusive of autism and specialist commissioning where necessary and the appropriate reasonable adjustments made.				
Training								
48	Is autism awareness training being/been made available to all staff working in health and social care as directed in Chapter 1 of the Statutory Guidance?	Red: Historical workforce training data available from statutory organisations on request. Not yet devised an autism training plan/strategy.	Amber: Client facing staff identified as a priority. 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/strategy near completion.	Green: Focus on all staff. 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 them. Autism training plan/strategy published.				
54	Is specific training provided to staff that carry out statutory assessments on how to make	Red: Specific training is either not being offered or uptake by	Amber: At least 50% of assessors have attended	Green: More than 75% of assessors have attended				

	adjustments in their approach and communication? Comment: Add any further comments you want (optional)	staff has not yet reached 50% of those for whom it is intended.	specialist autism training.	specialist autism training specifically aimed at applying the knowledge in their undertaking of a statutory assessment, e.g. applying the Care Act.				
Diagnosis								
60	Have you got an established local autism diagnostic pathway? Comment: Does the pathway meet autistic people's needs regardless of whether or not the person meets learning disability criteria?	Red: 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.	Amber: 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.	Green: A local diagnostic pathway is in place and accessible, GPs are aware and involved in the process. Wait from referral for a diagnosis and initial assessment is less than three months NICE guidelines are implemented within the model				
64	When will your area be able to meet NICE recommended [QS51] waiting time and expect to be able to keep within them? Comment: briefly note any contingency arrangements you have in place to manage short term increases in rate of referral to diagnostic services. 1000 Characters	Red: We do not anticipate being able to reach NICE recommended waiting times sustainably by March 2017	Amber: We anticipate meeting NICE recommended waiting times by March 2017 and to be able to sustain this thereafter	Green: Our area already meets NICE recommended waiting times	N/A	N/A		
74	Can people diagnosed with autism and a learning disability access post diagnostic specific or reasonably adjusted psychology assessments? Comment: Add any further comments you want (optional)	Red: Availability patchy or mainly generic services, with a small number of reasonably adjusted services.	Amber: Available everywhere. Mainly reasonably adjusted services, with some access to autism specific services (when necessary) and some generic services.	Green: All services are reasonably adjusted (in accordance with NICE Guidance) to provide access to post diagnostic specialist assessments. Access to autism specific services is also available when necessary.	N/A			
75	Can people diagnosed with autism and without a learning disability access post diagnostic specific or reasonably adjusted psychology assessments? Comment: Add any further comments you want (optional)	Red: Availability patchy or mainly generic services, with a small number of reasonably adjusted services.	Amber: Available everywhere. Mainly reasonably adjusted services, with some access to autism specific services (when necessary) and some generic services.	Green: All services are reasonably adjusted to provide access to post diagnostic specialist assessments. Access to autism specific services is also available when necessary.	N/A			
76	Can people diagnosed with autism and a learning	Red: Availability patchy or	Amber: Available	Green: All services are	N/A			

	disability access post diagnostic specific or reasonably adjusted speech and language therapy assessments? Comment: Add any further comments you want (optional)	mainly generic services, with a small number of reasonably adjusted services.	everywhere. Mainly reasonably adjusted services, with some access to autism specific services (when necessary) and some generic services.	reasonably adjusted to provide access to post diagnostic specialist assessments. Access to autism specific services is also available when necessary.				
77	Can people diagnosed with autism and without a learning disability access post diagnostic specific or reasonably adjusted speech and language therapy assessments? Comment: Add any further comments you want (optional)	Red: Availability patchy or mainly generic services, with a small number of reasonably adjusted services.	Amber: Available everywhere. Mainly reasonably adjusted services, with some access to autism specific services (when necessary) and some generic services.	Green: All services are reasonably adjusted to provide access to post diagnostic specialist assessments. Access to autism specific services is also available when necessary.	N/A			
78	Can people diagnosed with autism and a learning disability access post diagnostic specific or reasonably adjusted occupational therapy assessments? Comment: Add any further comments you want (optional)	Red: Availability patchy or mainly generic services, with a small number of reasonably adjusted services.	Amber: Available everywhere. Mainly reasonably adjusted services, with some access to autism specific services (when necessary) and some generic services.	Green: All services are reasonably adjusted to provide access to post diagnostic specialist assessments. Access to autism specific services is also available when necessary.	N/A			
79	Can people diagnosed with autism and without a learning disability access post diagnostic specific or reasonably adjusted occupational therapy assessments? Comment: Add any further comments you want (optional)	Red: Availability patchy or mainly generic services, with a small number of reasonably adjusted services	Amber: Available everywhere. Mainly reasonably adjusted services, with some access to autism specific services (when necessary) and some generic services	Green: All services are reasonably adjusted to provide access to post diagnostic specialist assessments. Access to autism specific services is also available when necessary.	N/A			

82	Do mental health crisis services in your area routinely anticipate and provide for the crisis needs of people with autism but without a learning disability?	Red: Mental health crisis services do not provide for people with crises that relate to autism in the absence of acute mental illness	Amber: Mental health crisis services will and do respond to mental health crises in autistic people whether or not these involve an acute mental illness.	Green: Mental health crisis services will and do respond to mental health crises in autistic people whether or not these involve an acute mental illness. In addition staff have specific training about the needs of autistic people and specialised mental health support has been commissioned for this group and is easily available within timescales relevant for crisis work.	N/A	N/A		
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Care and Support

88	Do you have a programme in place to ensure that all advocates working with autistic people have training in their specific requirements? Comment: Add any further comments you want (optional)	Red: No programme in place.	Amber: Programme in place, not all advocates are covered.	Green: Programme in place, all advocates are covered.				
89	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 appropriately trained advocate? Add any further comments you want (optional)	Red: No autism specific advocacy service available	Amber: Yes. Local advocacy services are working at becoming autism-aware.	Green: Yes. There are mechanisms in place to ensure that all advocates working with adults with autism have received specialist autism training.				
92	How would you assess the level of information about local support across the area being accessible to autistic people? Comment: Add any further comments you want (optional)	Red: Information about support services for autistic people is either seriously incomplete or not easily accessible.	Amber: There is a moderate level of information available about support services for autistic people which is either incomplete or not readily accessible to autistic people.	Green: There is readily accessible information (as required in the statutory guidance and the Accessible Information Standard) available on all relevant support services available for autistic people.				
93	Where appropriate are carers of people assessed	Red: Carers assessments are not	Amber: Where carers are	Green: Upon assessment of	N/A			

	as having autism and eligible for social care support offered assessments? Comment:	consistently routinely offered	identified in the course of assessments of autistic people, they are routinely offered carers assessments	autistic people carers are routinely identified and offered a carers assessment. Carers can also self-identify and request a carers assessment. Information about how to obtain a carers assessment is clearly available.				
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Housing and Accommodation

95	Does the local housing strategy and/or market position statement specifically identify autism? Comment: Please provide a web link and page references to support your answer.	Red: Needs of autistic people (as distinct from needs of people with other disabilities) not specifically mentioned in housing strategy and/or market position statement (for two tier authorities in any district council areas)	Amber: Housing requirements of autistic people are specifically mentioned but not to level described in Green rating (for two tier authorities not in all district council areas)	Green: Comprehensive range of types of housing need for autistic people considered including estimates of numbers of placements required in each category (for two tier authorities and in all district council areas)				
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Employment

97	How have you promoted in your area the employment of people on the Autistic Spectrum? Add any further comments you want (optional)	Red: 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 do not routinely consider the support needs of the individual taking into account their autism. Local job centres are not engaged.	Amber: Autism awareness is delivered to employers on an individual basis. Local employment support services include autism. Some contact made with local job centres.	Green: 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 of autistic people including retaining work. Engagement of the local job centre in supporting reasonable adjustments in the workplace via Access to work.				
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98	Do autism transition processes to adult services have an employment focus? Add any further comments you want (optional)	Red: Transition plans do not include specific reference to employment or continued learning.	Amber: Transition plans include reference to employment/activity opportunities.	Green: Transition plans include detailed reference to employment, access to further development in relation to individual's future aspirations,				
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				choice and opportunities available.				
99	Does the local authority offer tailored support or programmes to help autistic people enter employment or self-employment, including those with SEND and those with EHC plans?	Red: No tailored support programmes currently provide support specifically for young autistic people.	Amber: Local commissioning of these schemes specifies for at least some they should specifically address the needs of young autistic people.	Green: Local commissioning of these schemes specifies for at least some they should specifically address the needs of young autistic people.	N/A	N/A	N/A	
Criminal Justice								
101	Are the Criminal Justice Services (police, probation and, if relevant, court services) engaged with you as key partners in planning for adults with autism? Comment: Add any further comments you want (optional)	Red: Minimal or no engagement with the criminal justice services.	Amber: * discussions between local authority adult social care services and criminal justice service agencies are continuing; * representatives from criminal justice service agencies sit on autism partnership board or alternative	Green: As amber, but in addition: * autistic people are included in the development of local criminal justice diversion schemes * representative from criminal justice services agencies regularly attend meetings of the autism partnership board or alternative * there is evidence of joint working such as alert cards or similar schemes in operation. * there is evidence of joint/shared training	N/A			
102	Is access to an appropriate adult service available for people on the Autistic Spectrum in custody suites and nominated 'places of safety'? Comment: Add any further comments you want (optional)	Red: There is not reliable access to an appropriate Adult service	Amber: Yes, but appropriate adults do not necessarily have autism awareness training	Green: Yes and these have all had autism awareness training	N/A			