



**'Think Autism' Strategy –
Update Report**

Report of Jane Robinson, Corporate Director of Adult and Health Services, Durham County Council, and John Pearce, Corporate Director of Children and Young People's Services, Durham County Council

Electoral Division affected

Countywide

Purpose of the report

- 1 This purpose of this report is to update the Health and Wellbeing Board as to progress following the launch of the all age 'Think Autism': Autism Strategy and Action Plan across County Durham (2018/19-2020/21).

Executive Summary

- 2 The 'Think Autism' all age joint strategy was formally launched at an event at County Hall on 5 April 2019, including a presentation event, information stalls and celebration activities. Since approval of the Strategy in April 2019, partners have championed this within their own organisations and an approach of co-production in progressing actions has been strong across partners.
- 3 Priorities from the action plan have been agreed and task and finish groups established to progress the development of solutions. Progress has been made in all six of the priority areas identified within the strategy although some developments are at an early stage of implementation.
- 4 The Autism Self-Assessment Framework (SAF) was completed in December 2018. Feedback was received by Public Health England in June 2019 and can be found at <https://www.gov.uk/government/publications/autism-self-assessment-framework-exercise>
- 5 The SAF has helped to shape the strategy action plan and agree priorities.

Highlights of Progress, in summary

- 6 **People on the autism spectrum and their families contribute to planning** – The autism steering group has parent/ carer representatives and an adult on the autism spectrum who attends the meetings with close links to Investing in Children working to ensure the views of children and young people are captured. There are also regular separate stakeholder engagement groups for people on the autism spectrum and parent/carers that feed into the steering group. Task and finish groups include parent/ carers representation and the Autism Employment Subgroup is led by carers.
- 7 **All staff working with people on the autism spectrum have the right knowledge and skills and staff who need more specialist training access it** - A task and finish group has been established with final workforce development recommendations reported for approval in November 2019 and forecast implementation across workforce from March 2020.
- 8 **There is timely and appropriate access to diagnostic pathways for those who need it** – there have been a number of improvements made in relation to the autism diagnostic pathway for children and young people, which are in line with NICE guidance.
- 9 **The support offer available is clear and appropriate to need** – a revision of the Local Offer is currently underway which will include an Autism ‘landing page’ which will ensure that appropriate information is available from a central point. It is anticipated that this will be completed by the end of March 2020.
- 10 **All support promotes well-being and independence** - Two prototype initiatives to support families of children on the autism spectrum are planned for later this autumn. Additionally, in response to requests Durham County Carers have set up a pilot for a new group in Consett on 18 September 2019. The impact of these groups will be monitored.
- 11 **There are reasonable adjustments enabling access to public services for people on the autism spectrum and people on the autism spectrum are able to participate fully in their local community** - A Strategic Review of short break opportunities within communities has been completed, which included a key line of enquiry in relation to this area of the strategy with recommendations will be made to management teams early in 2020.

- 12 **There is easy and positive access to employment and benefits pathways and there is support to help retain employment or access volunteering or learning** – Durham Works held an Employer Event to promote the benefits of employing young people with Autism in an attempt to increase the opportunities available with County Durham and have employed a Supported Internship Co-ordinator who are supporting the Autism Employment Sub group to develop models of social enterprise(s), Community Interest Companies (CICs) as well as the realistic views of developing a mainstream business model and/or self-employment status. The group hosted a partnership event on 4 October 2019.
- 13 A new strategic group led by DCC looking at Employment Opportunities for People with Disabilities, includes the needs of people with Autism, in line with the autism strategy.

Recommendation(s)

- 14 Members of the Health and Wellbeing Board are recommended to:
- (a) Note the findings of this report.
 - (b) Agree the next steps as outlined in the report
 - (c) Continue to support the implementation of the All Age Autism Strategy

Background

- 15 In September 2018, the Health and Wellbeing Board agreed that there should be a combined all age 'Think Autism in County Durham' Action Plan and an overarching all-age strategy for 2018-20. This has been developed with both the Autism Strategy Implementation Group (ASIG) and Children and Young People Autism Steering groups.
- 16 A new joint strategic approach was developed through partnership working with adult and health services and children and young people's services, which was later endorsed by Durham County Council's Cabinet on Wednesday 3 April 2019. National Autism Awareness Week (2 – 7 April 2019) saw partners across County Durham raising awareness with a focus on:
 - (a) The needs of people on the autism spectrum are known and understood
 - (b) The workforce understands and meets the needs of people on the autism spectrum
 - (c) People on the autism spectrum participate equally within their community
 - (d) The all age joint strategy was formally launched at an event at County Hall on the 5 April 2019, including a presentation event, information stalls and celebration activities.
 - (e) This was received extremely well from a number of partners, individuals on the autism spectrum and their families. The event was co-produced in partnership and feedback confirmed unanimously that this felt like a shared partnership approach, which should be repeated annually.

Current Position

- 17 Since approval of the Strategy in April 2019 partners have championed this within their own organisations and the approach of co-production in progressing actions has been strong across partners.
- 18 Priorities from the action plan have been agreed and task and finish groups established to progress the development of solutions. A clear methodology has been adopted to consider needs, review existing arrangements, identify gaps and co-produce options available to fulfil the action plan priority areas identified.
- 19 The over-all Strategy and progress against the Action Plan has been steered to date through the Autism Steering Group for Children and

Young People and the Autism Strategy Implementation Group for Adults 14+.

- 20 Appendix 2 highlights some of the progress against the six main aims outlined in the strategy. More detailed information is contained within the autism action plan which is available if required. An update on the 2018 Autism Self-Assessment Framework (SAF) including how Durham compared with other authorities is provided at appendix 3.

Next Steps

- 21 It has been agreed by members of the Steering Group for children and young people and the Autism Strategy Implementation Group for adults to merge both groups as a pilot exercise from November 2019. This will ensure a more streamlined approach and that cross-cutting areas are tackled in co-production.
- 22 Priorities for the next six months will be:-
- (a) Development of an over-arching communication plan across all partners to ensure this continues to be implemented and embedded across all Organisations.
 - (b) Develop a clear framework to enable the impact of the strategy actions to be captured.
 - (c) Recommend and approve a workforce development programme.
 - (d) Approve model for family resilience across County Durham.
 - (e) Develop a service specification for Autism champions in County Durham.
 - (f) Ensure autism pathway timescales are in line with NICE guidelines and continue to monitor this.
 - (g) To complete a strategic review of post diagnosis support and make recommendations to the all age Steering Group.
 - (h) Plan how World Autism Awareness week will be promoted across County Durham in April 2020.
 - (i) Identify wider communities and continue to grow partners sign up to the strategy

Conclusion

- 23 Progress is being made in several key areas of the autism strategy, with further work required to meet the full aims and objectives. The all age-approach will help facilitate further improvements as the scope of partnership working is widened. Information from the self-assessment and ongoing feedback from stakeholders, including during Autism

Awareness week in April, will help to shape and drive forward the strategy implementation plan and track progress.

Background papers

- None

Other useful documents

- None

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Appendix 1: Implications

Finance – No implications.

Staffing – No implications.

Risk – There is a risk that an opportunity is missed to improve the service by working more collaboratively

Equality and Diversity/Public Sector Equality Duty –Accommodation – None highlighted

Climate Change – No implications

Crime and disorder – It is hoped that by improving the service available to prisoners and ex-offenders that re-offending will reduce

Human rights – No implications

Consultation – No implications

Procurement – Approval will be required for a variation to Contract Procedure Rules to enter into a contract with the new healthcare provider in prisons to also provide social care in prisons.

Disability issues – No implications

Legal implications – No implications

Appendix 2:

1. The needs of people on the autism spectrum are known and understood

1.3 People on the autism spectrum and their families contribute to planning – The autism steering group has parent/ carer representatives and an adult on the autism spectrum who attends the meetings with close links to Investing in Children working to ensure the views of children and young people are captured. There are also regular separate stakeholder engagement groups for people on the autism spectrum and parent/carers that feed into the steering group. Task and finish groups which are created to complete actions always have parent/ carers invited to be part of these. The Autism Employment Subgroup is led by carers.

2. The workforce understands and meets the needs of people on the autism spectrum

2.1 All staff working with people on the autism spectrum have the right knowledge and skills & 2.2 Staff who need more specialist training access it - A task and finish group has been established to develop an appropriate workforce development programme. The initial recommendations of this group are to develop a graduated tailored programme of training appropriate to the level of involvement. Final workforce development recommendations will be reported for approval by November 2019 and forecast implementation across workforce from January 2020.

3. People on the autism spectrum have good physical and mental health

3.2 There is timely and appropriate access to diagnostic pathways for those who need it – there have been a number of improvements made in relation to the autism diagnostic pathway for children and young people, in line with NICE guidance.

4. People on the autism spectrum and their families receive the right amount of support at the right time

4.1 The support offer available is clear and appropriate to need – a revision of the Local Offer is currently underway. Part of this revision work will include an Autism 'landing page' which will ensure that appropriate information is available from a central point. It is anticipated that this will be completed by the end of March 2020.

4.2 All support promotes well-being and independence – A task and finish group has been established which is working jointly with parent/ carers and

professionals on a model for County Durham in relation to family resilience which considers what the needs are, what currently exists, identify gaps develop a options to best meet the needs of families and support independence and resilience. Two prototype initiatives to support families are planned for later this autumn.

Carers have requested/suggested more peer support Adult Carers groups across the county. Durham County Carers have set up a pilot for a new group in Consett Sept 18th 2019 The impact of this group will be monitored. The current post diagnostic service is being reviewed in line with the autism strategy.

5. People on the autism spectrum participate equally within their community

5.1 There are reasonable adjustments enabling access to public services for people on the autism spectrum & 5.2 People on the autism spectrum are able to participate fully in their local community – a Strategic Review of short break opportunities within communities has been completed, which included a key line of enquiry in relation to this area of the strategy. A number of key recommendations will be made early in 2020.

6. People on the autism spectrum access aspirational employment, volunteering or learning opportunities

6.3 There is easy and positive access to employment and benefits pathways -

A Supported Employment Service is planned which is specifically designed to offer an easy and positive route into paid employment, using the British Association for supported employment (BASE) model. Durham County Council's Human Resources Service is applying for Disability Confident Leader status, has amended the recruitment pack to identify applicants on the autism spectrum and is improving the process for reasonable adjustments to help applicants gain employment and then retain it. The Ausome Enterprise event on 4th November 2019 was well attended and discussions have started with Smile for Life to expand into Durham to provide jobs and training. Strong links have been established with Disability Employment Advisors and the Autism Passport has been promoted to enable benefit claimants to convey their difficulties to work coaches more easily.

6.4 There is support to help retain employment or access volunteering or learning – Durham Works held an Employer Event to promote the benefits of employing young people with Autism in an attempt to increase the opportunities available with County Durham and have employed a Supported Internship Co-ordinator. Currently a Team Leader (SEND Specialist) and our

Supported Internship Coordinator are supporting the Autism Employment Sub group to develop: *“the opportunities to seek and overcome historical barriers to enable a working group to develop a suitable range of employment opportunities for autistic people of all ages in Durham. This will focus on models of social enterprise(s), Community Interest Companies (CICs) as well as the realistic views of developing a mainstream business model and/or self-employment status.”* Some of these actions include the promotion of Social Enterprises for young people with SEND. The group hosted a partnership event on 4th October 2019.

A new strategic group led by DCC looking at Employment Opportunities for People with Disabilities, includes the needs of people with Autism, in line with the autism strategy

Appendix 3: Briefing on the Autism Self- Assessment Framework

Report of Paul McAdam Commissioning Policy and Planning Officer

Purpose of the report

- 1 This report provides an update on the 2018 Autism Self-Assessment Framework (SAF) including how Durham compared with other authorities.

Executive Summary

- 2 The 2018 Autism Self-Assessment Framework was the fifth autism self-assessment exercise on the implementation of the 2010 Adult Autism Strategy (as amended by Think Autism in 2014).
- 3 The purpose of the SAF is to enable local strategy groups to review their current processes in the implementation of the Autism Statutory Guidance and Autism Strategy locally, and to identify future priorities and plan in partnership with health partners, other key organisations and local people with autism and their families.
- 4 Completion of the SAF was co-ordinated by Commissioning in conjunction with staff from other stakeholders in DCC from Adult and Health Services, Children and Young Peoples Services, Culture and Sport and Housing. Health colleagues in Clinical Commissioning Groups and Tees Esk and Wear Valleys NHS Trust, other providers and service user and parent stakeholders also inputted into the SAF.
- 5 The SAF was completed and submitted in December 2018 and has been collated and analysed by Public Health England.

Background

- 6 The 2018 Autism Self-Assessment Framework was the fifth autism self-assessment exercise on the implementation of the 2010 Adult Autism Strategy (as amended by Think Autism in 2014).

- 7 Although the primary focus of the SAF is adults with autism it includes questions in relation to supporting young autistic people as they prepare for adulthood.
- 8 The purpose of the SAF is to enable local strategy groups to review their current processes in the implementation of the Autism Statutory Guidance and Autism Strategy locally, and to identify future priorities and plan in partnership with health partners, other key organisations and local people with autism and their families.
- 9 A large proportion of the SAF is RAG rated into Red, Amber and Green categories, with red being the poorest and green the best rating.
- 10 Completion of the SAF was co-ordinated by Commissioning in conjunction with staff from other stakeholders in DCC from Adult and Health Services, Children and Young Peoples Services, Culture and Sport, Housing.
- 11 Feedback was also received from other organisations such as Clinical Commissioning Groups, NECS, TEWV, Durham Police as well as providers such as MAIN.
- 12 The response was also discussed at Autism Strategy Implementation Group as well as stakeholder events with service users and parents of service users who were given the opportunity to contribute.
- 13 The SAF was completed and submitted in December 2018 and has been collated and analysed by Public Health England.

Current Position

National Level

- 14 Findings of the 2018 SAF have now been collated and shared by Public Health England and can be found at:
<https://www.gov.uk/government/publications/autism-self-assessment-framework-exercise>
- 15 Headline points from the SAF were

- 142 out of the 152 upper tier local authorities responded to the SAF
 - 55 local authorities reported on balance a net improvement (reported they had got better on more questions than they reported they had got worse)
 - 23 local authorities reported no net change
 - 74 reported a net worsening
 - Waiting times for diagnosis services rose in 63% of areas reporting the figure in both 2016 and 2018
 - The number of people receiving a positive diagnosis rose in 63% of areas, doubled or more in 35% and quadrupled or more in 17%
- 16 For 1 of the 8 sections of the SAF (housing and accommodation), the position improved in that more local authorities reported positive movement from their 2016 position than reported negative movement.
- 17 For 5 of the sections it worsened, with the employment and planning sections showing the largest net negative movement in responses.

Local Level

- 18 There were 2 questions where the Durham rating was Red
- Is specific training provided to staff that carry out statutory assessments on how to make adjustments in their approach and communication?
 - When will your area be able to meet NICE recommended waiting time and expect to be able to keep within them? (Red being : do not anticipate being able to reach NICE recommended waiting times by March 2019 and to be able to sustain this thereafter)
- 19 With regard to whole sections, it was found that in Durham the position regarding employment had deteriorated since 2016.
- 20 There were 4 questions in this section but only 2 of these had also been asked in the last SAF in 2016, and in both of these the self-assessment rating fell from green to amber.

Summary of Sections

Planning

- 21 Seven questions covered the information available for planners and the information published by the local authority and, for the 3 questions shown below, the proportion rating their position as good or adequate was smaller than in 2016
- Inclusion of autism in the local Joint Strategic Needs Assessment (JSNA)
 - Inclusion of the needs of autistic people in the local strategic commissioning plan
 - Overall assessment of the adequacy of available data for planning and commissioning services for autistic people
- 22 Four questions covered the community involved in planning. Three of these were established questions and to all 3, smaller proportions of authorities gave themselves the more satisfactory ratings.
- 23 Four questions asked about the extent of reasonable adjustments for autistic people in general council services, local health services, information support and advice for health and social care and other public services.
- 24 The first 3 showed some movement towards less satisfactory ratings, the fourth towards more satisfactory ratings.
- 25 Within the North East Region, Durham compared well with the other authorities and, in comparison with 2016, scored worse on 1 question with the others being unchanged.

Training

- 26 48% of responding authorities reported having a multi-agency autism training plan, almost unchanged from 2016.
- 27 A substantially increased proportion (75%, up from 66%) reported that they record the uptake of autism training by health and social care staff, but a substantially lower proportion (21%, down from 28%) reported a

satisfactory position on specific autism training for staff conducting statutory assessments.

- 28 42% (almost unchanged from 43%) of respondents reported that their CCGs ensured that health providers undertake autism training with their staff. However, for all three elements of the criminal justice system (police, court services and probation) a smaller proportion of responding authorities reported that their local service engaged in autism awareness training for staff.
- 29 Within the North East Region, Durham was similar to the other authorities although, in comparison with 2016, scored worse on 4 questions with the others being unchanged.
- 30 Durham scored 'Red' regarding there not being specific autism training for staff doing statutory assessments – with 5 of the other North East authorities also scoring red, making 6 out of 12 in total.

Diagnosis

- 31 For the first time, all local authorities responded that they had a diagnostic pathway. However, many downgraded their rating of their local diagnostic service, most commonly because the waiting time had risen to exceed the 3-month limit specified in NICE guidelines.
- 32 A major factor leading to increases in waiting times has been an increase in the volume of work. There was a 40% increase in the population-based rate of diagnoses. Of the 94 local authorities who provided usable data for this rate in both 2016 and 2018, 63% of them saw the number rise, 35% at least twofold and 17% by 4 times.
- 33 A higher proportion of authorities than in 2016 reported that their diagnostic pathway was a specialist service and not part of mainstream mental health services. However, a smaller proportion reported that a positive diagnosis actually triggered an offer of a care assessment.
- 34 Access to psychology, speech and language, and occupational therapy services after diagnosis was reported to be similar or better than in 2016.
- 35 Generally, access was reported to be better for people with learning disabilities than for those diagnosed with autism who do not have

learning disabilities. But access to psychology and occupational therapy assessments was reported to have improved in a substantial number of places for those without learning disabilities.

- 36 Within the North East Region, Durham was similar to the other authorities and scored a 'Red' regarding waiting times, as did 8 of the 12 authorities.
- 37 In comparison with 2016, Durham improved on 3 questions with the remainder remaining unchanged.

Care and Support

- 38 The reported number of autistic adults assessed as eligible for adult social care services rose. 116 local authorities provided usable figures in both years and for 66% of these, the numbers showed a rise.
- 39 Information availability, pathways to care assessments for autistic people without learning disabilities, information about support opportunities and access to carer assessments for carers of autistic people were all reported as satisfactory by smaller proportions of responding authorities than in 2016.
- 40 Within the North East region, results were quite similar overall, with Durham one of the better performers in most of the questions.
- 41 In comparison with the 2016 results there was no movement at all in Durham responses whereas overall for the North East there were 9 instances of a negative movement and 10 instances of a positive movement.

Housing and Accommodation

- 42 The number of authorities reporting that their local housing strategy identified the needs of autistic people rose slightly, although this was still satisfactory in only 13% of cases.
- 43 There has been very little progress since 2016 in ensuring that housing providers have autism-trained staff available.

Employment

- 44 Overall, efforts to promote employment of autistic people and the employment focus of transition from school to adult services were both

rated positively by a smaller proportion of responding authorities than in 2016.

- 45 Within the North East, Durham performance was quite consistent with other authorities, although reported performance was poorer than 2016 with 2 questions showing a negative movement.

Criminal Justice System

- 46 There were 2 questions on the criminal justice system – showing movement in opposite directions. A lower proportion of responding authorities reported that criminal justice agencies were engaged in local planning for autistic adults, while a higher proportion reported that appropriate adult services were available in custody suites.
- 47 Durham was the best reporting authority in the North East region in this area with performance unchanged since 2016.

Progress since the Self-Assessment

- 48 'Think Autism' in County Durham – An Autism Strategy for Children, Young People and Adults was launched in April 2019 and is an all-age strategy for 2018 – 2020.
- 49 The strategy was developed through partnership working between Children and Young Peoples Services and Adult and Health Services.
- 50 There have previously been 2 autism steering Groups – 1 for adults and 1 for children's – which include representation from social care, health, education, service providers, parents and carers.
- 51 A decision has now been taken to merge the 2 groups to have 1 Autism Steering Group with all-age membership.
- 52 A number of sub groups and Task and Finish Groups will meet and report to the Autism Steering Group.

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