

[Home](#) > [Autism self-assessment framework](#)



Public Health  
England

Guidance

# Autism self-assessment exercise 2018: executive summary

Updated 20 June 2019

## Contents

- [1. Response and overall pattern](#)
- [2. Context and senior leadership](#)
- [3. Planning](#)
- [4. Training](#)
- [5. Diagnosis](#)
- [6. Care and support](#)
- [7. Other services](#)
- [8. Local innovation questions](#)

The Autism Self-Assessment is intended to review progress, around the country, in implementing the Government's Autism strategy 'Think Autism'.

Organisations asked to review progress on the principal areas covered by the strategy:

- local authorities as local leaders
- relating health commissioners
- other statutory partners (notably in the employment and criminal justice areas)
- local autistic residents and family carers

The exercise comprises just over a hundred questions in a variety of formats. Many involve measuring local performance in relation to specified green, amber and red benchmarks. This report looks at the patterns of responses around the country. It compares them to responses to the same questions posed 2, and in some cases 4, years ago. This was the fifth self-assessment exercise.

## 1. Response and overall pattern

141 out of a possible 152 English upper tier local authorities responded, smaller proportions in more southerly regions. Overall, 91% of questions posed were answered.

The range of stakeholders involved in the exercise locally varied. Adult social care and clinical commissioning groups almost always participated, health and wellbeing boards and court services in a quarter and a third of cases respectively. Autistic adults and informal carers were involved by 65% and 70% of local authorities, in each case by a smaller proportion of responding authorities than in the 2016 exercise.

For 1 of the 8 sections of the self-assessment (housing and accommodation), the position improved in that more local authorities reported positive movement from their position in 2016 than reported negative movement. For 5 it worsened, with the employment and planning sections showing the largest net negative movement in local responses.

The responding authorities in the South West region showed the largest number of sections with overall net positive movement, (although the South West also had the largest proportion of non-responding local authorities). The responding authorities in the South East showed the largest number of sections with net negative movement. In the training and planning sections, a majority of regions showed net negative movement whilst in the diagnosis section, a majority showed net positive movement.

Details of how these summary scores were calculated are given in the full report. The rest of this executive summary reports on the various sections of the self-assessment.

## 2. Context and senior leadership

The overall national pattern of movement in this section showed no net change.

Most responding authorities (95%) reported having a strategic lead officer for autism. The proportion reporting that the strategic lead was also the strategic joint commissioner fell. A slightly increased proportion reported having a separate operational lead.

## 3. Planning

Seven questions covered the information available for planners and the information published by the local authority. To 3 of these, the proportion of local authorities rating their position as good or adequate was smaller than in 2016.

These covered the:

- 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

Four questions covered the community involved in planning. Three of these were established questions and to all 3, smaller proportions of responding authorities gave themselves the more satisfactory ratings. In 1 case it was noted that the assigned ratings seemed worse than the descriptive comments suggested was appropriate.

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.

The first 3 showed some movement towards less satisfactory ratings, the fourth towards more satisfactory ratings. A new question asked whether autistic people were encouraged to participate in culture, leisure, sports and other activities. 70% of responding authorities reported that there were some examples of this, 25% that there was a substantial programme of work in this area.

Authorities were asked about numbers of children identified as autistic in the school years around the age when transition to adult social care is normal. More than 90% provided numbers.

These showed a strikingly wide variation in relation to local population numbers. In school year 10, the median number identified represented 1.4% of the population in the age band but a quarter of local authorities reported 1% or fewer whilst a quarter reported 1.9% or more. Numbers were similar in year 11 but about 40% lower in years 12 and lower again in year 13, suggesting that autistic children are less likely to go on to schooling in the sixth form years and less likely to continue with it if they do.

Further questions in the planning section covered services for:

- autistic women
- members of black and minority ethnic communities
- hate crime statistics.

Some progress had been made since 2016 in planning for older autistic people.

## 4. Training

48% of responding authorities reported having a multi-agency autism training plan, almost unchanged from 2016.

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.

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.

## 5. Diagnosis

For the first time, all local authorities responded that they had a diagnostic pathway. However many downgraded their rating of their local diagnostic service from 'green' to 'amber', most commonly because the waiting time had risen to exceed the 3-month limit specified in NICE guidelines. There was a slight increase in the number of areas using out-of-area diagnoses (from 18% to 26%) and in these areas the proportion of their diagnostic work handled this way also appeared to be increasing.

The median reported waiting time from referral to diagnostic assessment was 30 weeks (up from 16 weeks reported in 2016). Among the 74% of responding authorities that provided figures for both years, 23% reported a fall in waiting time, 63% reported an increase. A substantially higher proportion of local areas reported that they were unable to foresee when they would be able to meet the recommended NICE standards.

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. Ninety-four local authorities provided usable data for this rate in both years. In 63% of these, the number rose, 35% at least twofold and 17% by 4 times.

A higher proportion of authorities than in 2016 reported that their diagnostic pathway was (as recommended) a specialist service and not part of mainstream mental health services. However, a smaller proportion reported that a positive diagnosis automatically triggered an offer of a care assessment. Access to psychology, speech and language, and occupational therapy services after diagnosis was reported to be similar or better than in 2016.

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.

## **6. Care and support**

The reported number of autistic adults assessed as eligible for adult social care services rose. The median of the reported rates went up to 32.3 per 100,000 population from the 2016 figure of 25.8. 116 local authorities provided usable figures in both years and for 66% of these, the numbers showed a rise. The proportions of these also having learning disabilities showed a very wide span ranging from all to none.

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.

There were 2 new questions in this section. Opportunities for low-level interpersonal and/or preventive support were reported as being available by 96% of respondents. A wide range of interesting examples were given. However, less positively, 74% of respondents reported that individuals diagnosed with autism had difficulty subsequently in getting access to mental health services.

## **7. Other services**

A slightly greater proportion of responding authorities reported that their local housing strategy identified the needs of autistic people. However, this was still satisfactory in only 13% of cases. Very little progress was reported in ensuring that social housing providers have autism-trained staff available.

Four questions considered employment initiatives. Two had been asked before. Local 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. Two new questions asked achieved more positive responses. 84% of responding authorities reported that tailored support for employment of self-employment was available for autistic people and 63% reported that they monitored the outcome of education programmes.

The 2 questions on the criminal justice service showed movement in opposite directions. A lower proportion of responding authorities reported that criminal justice agencies were acting as the principal partner in planning for autistic adults. A higher proportion reported that appropriate adult services for autistic people were available in custody suites.

## **8. Local innovation questions**

Three questions asked for free form descriptions of local innovations.

The first asked about work relating to the ‘Transforming Care’ initiative to bring long-stay inpatients home from psychiatric in-patient units. 136 councils responded. Most mentioned housing and support initiatives. These were at various stages: concept development, planning, building. Some respondents described supported living arrangements with a variety of configurations, 1 involving a substantial number of units on a single site. Many proposed developments were transitional homes for ‘step-down’ in preparation for more independent living.

A few respondents referenced specific solutions for young adults, crash pads for crisis accommodation and respite or short-term break accommodation. Many respondents discussed specialist types of support they planned to make available including forensic outreach teams, positive behavioural support, social workers and enhanced home care.

The second question asked for examples of successful initiatives to provide care or support or to promote independence of autistic people. 110 councils responded. Some described housing initiatives or individual care packages for individuals with very specific needs. Some described low-level support initiatives, some initiatives to support training, volunteering or employment. A few described technical innovations (commonly phone apps to support autistic people).

Others focussed on initiatives to make parts of the wider community more accessible, to enhance awareness of autism in the wider community or to engage the expertise of autistic people in local autism training or work on the local autism strategy.

The third question asked about initiatives to encourage private sector organisations to improve accessibility to employment opportunities or other important issues. 138 councils responded. A large majority (43%) focussed on employment initiatives. 17% described initiatives to enhance accessibility of various types of facility such as supermarkets and cinemas.

Taken together the responses provide a rich description of the large amount of work currently underway across the country.

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