

## Stage 1 data collection instruments

### Survey of Autism Leads: text contained in electronic survey instrument

This questionnaire should take no longer than five minutes to complete. It asks about:

- the **types** of autism-specific / autism specialist services you commission (solely or jointly);
- whether some or all of these services/support are delivered, and/or coordinated, by a **single team**, or through a **formal partnership between two or more teams or services**.

1. Do you have a lead responsibility for commissioning services for **adults** with autism in your local authority (LA)?
  - Yes
  - No, and I would like to provide contact details for the correct person to complete the survey. [*Routed to provide relevant contact details.*]
  - No, but I have been identified as the most appropriate person to complete this survey
2. Do you **commission** any autism-specific/specialist services for adults jointly with one or more clinical commissioning group(s) (CCGs)?
  - Yes
  - No

If **yes**, please provide details of the names of these CCGs. [*Free text box provided*]

3. To the best of your knowledge, which of the following **autism specific/specialist services** are being commissioned in your locality for adults with autism, or a sub-group (e.g. those with Asperger syndrome)? (*Please tick as appropriate*)

	Commissioned by LA(s)	Commissioned by CCGs)	Jointly commissioned by LA(s)/CCG(s)	To my knowledge not commissioned in this locality
Diagnosis of Autistic Spectrum Condition				
Post-diagnostic assessment				
Post-diagnostic support for those with a recent diagnosis				
Social care support and/or services				
Mental health care and/or interventions				
Support accessing / maintaining contact with: housing, educational and/or employment services				
Support to families, partners and carers.				
Advice and/or training to other health and social care professionals on diagnosis, assessment, care and interventions				
Training, support and consultation for professionals working in community or mainstream settings (eg. employers, education community/public services etc)				
Care and/or interventions delivered in specialist residential accommodation				
Training, support and/or consultation for staff working in residential settings.				
Other autism-specific/specialist community based services for people with autism. <i>[Free text box provided]</i>				

4. With respect to the autism specific/specialist services which your local authority and/or CCG(s) commission, are some or all of these services collectively coordinated and/or delivered by a **single 'team'**? (This may be a physically colocated or a virtual team/service).
- Yes
  - No
  - Don't know

If yes, please provide the name of this team/service and the name and contact details of the service lead. [*Form provided*]

5. Please use this box if you would like to provide any further information about specialist provision for adults with autism in your locality (e.g. any other services you provide or alternative commissioning arrangements). [*Free text box provided*]

**THANK YOU FOR COMPLETING THIS SURVEY.**

## Interview schedule: Service Leads

### Introducing the interview

- Thanks for their time and confirm the time they have available.
  
- Explain that the purpose of this interview is to collect high level information with respect to organisation and delivery of their service and the population they serve. We will be using the information we gather to develop a typology of service models of Specialist Autism Teams.
  
- Note that we have already gathered some information about the service from a number of sources (our survey, web searches, their SAE submission etc). Note that we will ask at the end of the interview whether they have any further documentary evidence about the service which they would like to send us.
  
- Set out the structure of the interview (briefly):
  - Structure of the team and commissioning/funding arrangements
  - Eligibility criteria and referral and assessment processes
  - Staffing and the location of the service
  - What the team does
  - Caseload and discharge

**A. STAFFING, SKILL-MIX and LOCATION**

**1. What is the professional make-up of the Team/Service? (profession & f.t.e or sessions/week)**

<i>Staff Member</i>	<i>Number of staff</i>	<i>Overall total f.t.e. or sessions/week</i>	<i>Who funds post(s)</i>
Clinical psychologist			
Psychiatrist			
Nurse			
Social worker			
Occupational therapist			
Speech and language therapist			
Admin/support staff			
Other			

**2. Does the Team/Service have a physical base?**

- a. If yes.
  - i. Are all staff based there?
  - ii. Is this physical base used for service delivery too?
  - iii. Are services/interventions delivered anywhere else?
- b. If no.
  - i. Collect brief details re communication/liaison arrangements, how are case conferences carried out etc?
  - ii. Where are services delivered?

**3. Does the whole team meeting together (physically and/or virtually) on a regular basis? How often do these meetings take place?**

## B. THE STRUCTURE OF THE TEAM AND COMMISSIONING AND FUNDING ARRANGEMENTS

1. What are the geographical boundaries of the Team/Service in terms of CCGs, NHS trusts and/or LAs.
2. If the service is available in more than one locality, is what the Team/Service offers the same? *Collect details if not.*
3. Who commissions the Team/Service? *(We want to be able to assign to one of the following categories: ....)*
  - a. All services/functions commissioned by LA or NHS (Collect name of agency, eg.... NHS Trust).
    - i. CHECK: does the relevant co-terminus (ie same geographical area) NHS trust or LA contribute any funding or services offered by the team?
  - b. All services/functions of the team jointly commissioned *(this would mean there would be some sort of joint commissioning group with a pooled budget)*
  - c. Some services/functions commissioned by LA only. Check which ones 'separate' and which ones shared.
  - d. Some services/functions commissioned by NHS only. Check which ones 'separate' and which ones shared.
4. How long has this current arrangement in terms of commissioning been in place?
5. What is the balance of funding contributions from the different agencies?
6. Which agencies are involved in delivering services/interventions which the team offers (eg LA, NHS trusts, third sector )?
7. As service manager/clinical lead, does this mean the [LA /NHS trust] is regarded as the lead agency?
8. Do the different agencies have designated responsibilities or 'lead' on different aspects of the services/interventions provided by the team, OR is it a 'whole team' approach across all interventions/services offered?
9. Can I check, was the 'design of the service influenced or informed by any existing services elsewhere in the country?

## C: ELIGIBILITY CRITERIA AND REFERRAL

1. Does the Team/Service impose any eligibility criteria? Check:
  - i. age
  - ii. level of need
  - iii. for non diagnostic services, nature of ASC diagnosis (all autism, autism and LD, HFA etc) and/or functional ability
  - iv. are individuals with conditions other than ASC (eg ADHD) able to access the service
  - v. Have there been any changes to the eligibility criteria of the service (e.g. changed from ASC to all neurodevelopmental disabilities or vice versa)?
2. Who can refer to the Team? (check self-referral)?
3. Approximately, how many referrals did the Team/Service receive 12 months?
4. What is the most common reasons for referral?
5. What proportion of all referrals does this constitute? (estimate fine)
6. Are referrals for services other than diagnosis subject to some sort of assessment process by the Team/Service?
7. What does this assessment comprise?
  - a. How does the team decide how the referral will be managed (eg. are there (sometimes) case conferences?; and/or do individual practitioner doing the assessment make decision)
8. What is the average time between referral and first assessment/appointment (estimate fine)
  - a. Diagnostic service
  - b. Other services/interventions provided by the team. (Note this may vary: eg. drop-in service will be different to a MH intervention)
9. Can carers be referred to the service? How?

**D. WHAT DOES THE TEAM DO?**

**1. What role does [name of Team] play in providing a diagnostic service to adults with autism in your locality?** *(Assign response to one (or more) of the following and collect additional details if required: )*

- Provides diagnostic service.
  - o Does any other service offer this in your locality?
- Does not provide diagnostic service 'in-house' but refers on to another ASC specialist team/service for diagnostic assessment and who then refers individual back to Team once diagnosis is complete *(collect brief details: \_\_\_\_\_)*
- Supports other (non ASC specialist) professionals/services (eg GPs, generic MH teams) to carry out diagnoses? If yes, how?
- Does not provide diagnostic service or act as a pathway to a diagnostic service
- Other *(collect brief details: \_\_\_\_\_ )*

**Briefly, what is the diagnostic process?**

- How is the diagnosis reached?
- About how many referrals to the service/year are for diagnosis?
- What proportion of referrals are for diagnosis?
- About what proportion of referrals for diagnosis receive a diagnosis of ASC?
- What are these diagnoses (ASC vs HFA vs AS)? And approximate proportions of each

**2. What role does [name of Team] play in providing post-diagnostic assessments (following a diagnosis) to adults with autism in your locality?** *(Assign response to one of the following & collect additional details if required: )*

- Provides post-diagnostic assessments.
  - o Does any other service offer this in your locality?
- Post-diagnostic assessments are provide by the diagnostic service they refer to *(collect any further details not obtained in Q1: \_\_\_\_\_)*
- Does not provide post-diagnostic assessments or act as a pathway to a post-diagnostic assessment
- Other *(collect brief details: \_\_\_\_\_ )*



**3. What ASC specialist mental health interventions for adults with autism, delivered by a trained practitioner, does the Team provide?** *(Note, this question concerns psychological or psychiatric interventions delivered by a trained MH practitioner only) rather than 'softer' psychosocial support: see next question)*

- For each collect very brief details which cover:
  - o purpose/objectives (name should suffice)
  - o time-limited (typical duration) vs open-ended
  - o mode of delivery (eg. individual, group, provision of information)
  - o practitioner delivering
  - o any particular target population.
- Does (or is the Team able to) refer to (other) NHS mental health services? *(Collect name of service, nature of agreement with service)*

**OR**

- No: does not provide mental health support, nor act as a pathway to sources of mental health support.

**4. What role does [name of Team] play in meeting social care needs to adults with autism in your locality** *(Assign response to one of the following & collect additional details if required: )*

- Conducts social care assessments: leading to care plan;
- Coordinates care plan: for example, organised services and/or supporting re personal budgets;
- Delivers 'social care' services (eg. personal assistant-type role; supporting independent living);
- Does not provide social care assessments/services but able to refer to local authority's adult social care services
- Does not provide social care assessments/services or act as a pathway to local authority social care services
- What other ways does the service meet clients' social care needs?

**5. Does your Team play any role in support adults with autism to access (or address problems with): housing, education or employment?**

- Yes, provides support, acts as a pathway to services/support, with respect to:

- housing (*ask for a couple of examples on activities/functions the Team fulfills*)
- education ( - ditto - )
- employment ( - ditto - )

**OR**

- **NO:** does not provide support, nor act as a pathway to support, with respect to:
  - housing
  - education
  - employment

**6. Does the Team provide any other services which aim to provide social, information and/or emotional support?**

- For each collect very brief details which cover:
  - purpose/objectives
  - time-limited (typical duration) vs open-ended
  - mode of delivery (eg. individual, group, provision of information)
  - practitioner delivering
  - any particular target population.
- Does (or is the Team able to) refer to non-statutory services which can offer these sorts of support? (*Collect name of service, nature of agreement with service*)

**OR**

- **NO:** does not provide any further forms of social, information and/or emotional support than already described.

**7. Does the Team provide support to parents / carers?**

- For each collect very brief details which cover:
  - purpose/objectives
  - time-limited (typical duration) vs open-ended
  - mode of delivery (eg. individual, group, provision of information)
  - practitioner delivering
  - any particular target population.

- Does (or is the Team able to) refer to any statutory services regarding parent/carer support? *(Collect name of service, nature of agreement with service)*
- Does (or is the Team able to) refer to non-statutory services regarding parent/carer support? *(Collect name of service, nature of agreement with service)*

**OR**

- **NO:** does not provide support to parents/carers, nor act as a pathway to sources of support for parents/carers.

**8. Does your Team deliver training or support to other professionals who care for adults with autism in community settings?**

- Yes *(ask for outline details on: professional groups, nature of training support (1:1 vs group), payment for/funding of this function)*
- No

**9. Does your Team deliver training of support to professionals who care for adults with autism in specialist residential settings?**

- Yes *(ask for outline details on: professional groups, nature of training support (1:1 vs group), payment for/funding of this function)*
- No

**10. Does your Team work directly with adults living in specialist residential accommodation?**

- Yes *(ask for outline details on setting, activities and functions)*
- No

**11. Finally, does the Team/Service offer a care/case coordination role?**

- If yes, how does this work and which other agencies/services are party to this?
- If no, does any other team/service in the locality assume this role?

**E: DISCHARGE AND CASELOAD**

**1. What is the Team/Service's discharge policies / processes?**

2. **What is the current 'open caseload'? Is this typical? Any changes envisaged in the future?**
3. **Are there services it routinely refers individuals on to? (Am guessing these are likely to be third sector)**
  - a. What sorts of services are these?
  - b. Are there any formal arrangements in place for this?
4. **Can individuals be re-referred to the service?**
  - a. Approximately what proportion of referrals are 're-referrals'?
  - b. Is there a pattern in terms of the sorts of needs associated with re-referral?

F: CLOSE

Many thanks for time

Check if OK to re-contact if we have any outstanding queries?

Check if any written material about the service they would like to send us?

Check if aware of whether/how multi-disc community-based specialist autism services in neighbouring areas ...elsewhere

Check, do they anticipate any changes to the services in the near-/middle future?

Check whether, in principle, they would be interested in being approached regarding Stage 2.

Many thanks again