Freedom of Information Act 2000 disclosure log entry

Reference

18-19298

Date sent

03/01/2019

Subject

Autism Waiting Times

Details of enquiry

1. What is your current autism waiting time (average, shortest, longest) referral to diagnosis for children?
2. Can you break this down to referral to first appointment and give the waiting time (average, shortest, longest)?
3. How many children are awaiting diagnosis currently? Please can you break down the number of children with a booked future appointment and those waiting without an appointment?
4. Can you provide a copy of the diagnosis pathway, please?

Response Sent

1. What is your current autism waiting time (average, shortest, longest) referral to diagnosis for children?

   Definition: Our Waiting times are calculated from date of referral to attendance at assessment clinic, where the family is seen for the 3di (developmental, dimensional and diagnostic interview), developmental history, and ADOS II (autism diagnostic observation schedule) individual assessment.

   The following data is from a recent audit of the period October 2017 to October 2018)

   a) Average waiting time to assessment clinic 37 weeks
   b) Shortest waiting time to assessment clinic 18 weeks
   c) Longest waiting time to assessment clinic 57 weeks

2. Can you break this down to referral to first appointment and give the waiting time (average, shortest, longest)?

   Cases seen during the period October 2017-October 2018

   a) Average waiting time from assessment clinic to first appointment 6.8 weeks
   b) Shortest waiting time from assessment clinic to first appointment 1 week
   c) Longest waiting time from assessment clinic to first appointment 15 weeks

3. How many children are awaiting diagnosis currently? Please can you break down the number of children with a booked future appointment and those waiting without an appointment?

   a) 39 Children are currently awaiting diagnosis
   b) 6 of the above 39 children have booked appointments for the new year
   c) 33 of the above 39 children have no booked appointment as of yet.

4. Can you provide a copy of the diagnosis pathway, please?
   This is as follows:

CAMHS LIFESPAN ASC AND LD TEAM ASD CLINIC
ASC CLINIC ASSESSMENT PATHWAY
October 2018 Version 15

1. Completed referral form received, with relevant screener attached

Case is passed from Intake coordinator to ASC Clinic Coordinator

Multi-disciplinary review of referral, including review of screening assessments at Thursday morning ASC Clinic Intake Meeting

Case returned with outline of decision to either accept or reject the referral to Intake Co-ordinator – all cases discussed at ASC Clinic Intake Meeting are logged on relevant spreadsheet

If accepted, ASC Clinic Coordinator allocates the case for triage

Admin transfers details of the case to clinic spreadsheet

Admin sends patient info form, SDQs, ASC intake form and any other forms requested by clinician completing triage

Admin to open folder for client and store all returned documents – intake record, SDQs, etc. Triage Clinician is recorded on C/N as Case Co-ordinator whilst triage is undertaken

Once intake form is received, admin to send school questionnaire [where consent has been ticked on form]

2. Initial triage telephone consultation with parent/carer/young person (Triage Clinician to complete within 8 week breach period)

Admin to book an initial triage consultation, in discussion with Triage Clinician, and record this onto C/N before the breach date

Admin to prompt family to return all forms if not already done so

Triage clinician to review intake/screening information when this has been returned

During triage phone consultation:

Clarify information provided on intake form as necessary/gather additional detail – consider collecting information regarding:

- *Background/what has led up to the referral to Lifespan*

- *Who else has been/is currently involved (i.e., previous and current CAMHS/social care/other specialist services history)*
- *Presenting issues*
- *Questions that the family feel could be answered/addressed by assessment at the clinic*
- *Family history [e.g., who lives at home with the client, who they consider to be in their family, contact, any family history of neuro-developmental/other concerns]*
- *Current educational/employment placement [please ensure school contact details are up-to-date and any changes flagged – will support trainees in scheduling school-based work if necessary]*
- *Medical history [e.g., any current medication, any psychiatric involvement, etc.]*

Where relevant, explore client's knowledge of ASC and awareness of assessment, what the diagnosis might mean for young person and the family; how information would be shared with the client/within the family and wider context (e.g. school); as well as what meaning may be made if no diagnosis is given, etc.

Discuss ASC diagnostic assessment process

Prompt for any outstanding information from parent/school

Start completing C/N assessment forms, where possible to do so

Send triage letter to family, cc'ed to referrer and GP

3. Allocation of case at ASC Clinic Staff Meeting

Case is briefly discussed at ASC Clinic Staff Meeting (at outset of next cycle of 10 week clinic appointments)

Case allocated to next available clinician to be Assessment Lead

Admin updates spreadsheet and re-allocates CC on C/N

4. Review and reflection on case

Assessment Lead reviews all information collected thus far e.g., referral form, intake, triage, school questionnaire information and screeners

Reflect further on assessment questions, gaps, etc. and whether further liaison with local/other services required (e.g., reports on other assessments/treatment conducted elsewhere)

On the basis of this review, additional assessment may be indicated. If so, case is brought to ASC Clinic Staff Meeting for MDT consultation [especially where issues re co-morbidity need to be further explored]

Common issues may include:

- Mental health conditions (e.g., ADHD, anxiety disorders and phobias, mood disorders, oppositional defiant behaviour, tics or Tourette syndrome, OCD, etc.)
- Neurodevelopmental problems and disorders (e.g., global delay or a learning (intellectual) disability, motor coordination problems or DCD, speech and language disorder, etc.)
- Medical or genetic problems and disorders (e.g., epilepsy and epileptic encephalopathy, chromosome disorders, genetic abnormalities, including fragile X, tuberous sclerosis, etc.)
- Functional problems and disorders (e.g., feeding problems, including restricted diets, urinary incontinence or enuresis, constipation, altered bowel habit, faecal incontinence or encopresis, sleep disturbances, etc.)
- Vision or hearing impairment

The role of the Assessment Lead is not necessarily to diagnose/conduct further assessment of such conditions themselves – it may be that onwards referral is required (e.g., to Paediatrics). However, it should be discussed in the Clinic Staff Meeting to support use of other specialisms within the clinic (e.g., psychiatric/cognitive/neuropsychological/speech and language assessment)

Invite relevant clinician to join where indicated (e.g., if there is a need to further explore certain mental health conditions, liaise with psychiatrist to join initial meeting)

Some example scenarios of screening prompts and next steps are included in footnote below[i]

5. Initial family meeting attended by client and parent(s) [approximately 2 months before schedule clinic appointment]

Review current concerns of the family and gathers outstanding background information needed (e.g., physical health form)

Observe patterns of interaction and communication within the family

Complete goal-based measures completed (if not already in place)

If sufficient information has been gathered for a diagnostic opinion, Assessment Lead to arrange feedback meeting to discuss with family outcome and whether further support needed

If further assessment needed, then discuss with family going on ASC clinic waiting list for 3Di/ADOS-II/school obs/cognitive as necessary.

Assessment Lead provides family with clinic leaflet outlining assessment process

Assessment Lead writes assessment/interim assessment letter to referrer and family [can be cover letter for Care Plan]

Care Plan to be created for under 18s, and sent to family, cc'ed to referrer and GP

Assessment Lead notes with admin on spreadsheet if additional assessment is indicated (e.g., if a psychometric assessment would be of use as part of the ASC diagnostic assessment)

Further assessment required/considered may not be prompted by screening data (see 4) but may arise from the initial family meeting – as in 4, Assessment Lead brings case to ASC Clinic Staff Meeting for further exploration

6. School consultation/assessment

Assessment Lead discusses with trainee psychologist/practitioner completing the observation any specific issues re school that need to be followed up (e.g., if family report bullying in school and this needs to be further explored)

Trainee psychologist/practitioner reviews all information on file and prepare for the visit (include reviewing the school questionnaire)

School consultation/assessment

Trainee psychologist/practitioner conducts school consultation (may include observation, staff consultation and individual assessment and further consultation with the CYP, dependent on has been indicated in the initial assessment. This may include psychometric assessment if requested; or the use of an appropriate projective measure if this is relevant)

It is helpful at this point that checks are conducted regarding borough of residence for information regarding local ASC services and provision of SALT/OT services for the setting/school concerned (e.g. borough local offer and school offer/information report)

Trainee psychologist/practitioner writes up record and adds to shared drive

7. ASC Clinic assessment and formulation (Thurs am/Tues pm)

If other assessments are required e.g., a projective, strengths assessment, etc. – Assessment Lead should consider ensuring these have been commissioned prior to clinic appointment or offer an extended appointment that morning [to ensure a more informed formulation meeting]

3Di/ADOS-II completed by Assessment Lead plus another appropriately trained clinician [see separate clinic schedule re outline/structure of clinic morning]

Clinicians/trainees involved in the assessment meet for integrated formulation, complete formulation record

Admin scan formulation record, upload to C/N and client folder

Admin update clinic spreadsheet

8. Feedback and planning meeting with client +/-family [within 6 weeks of ASC Clinic]

ASC Assessment Lead +/- other team member where relevant meets with client and family to feedback results of assessment, share formulation and invite comment/discussion

ASC Assessment Lead and client/family discuss recommendations/options regarding patient choice and involvement in treatment decisions (where clinically relevant)

Offer post-diagnostic Parent Workshop if relevant

Offer separate follow up meeting for the client to meet team member to discuss assessment outcome, provision of psychoeducation and exploration of client's unique profile of strengths/areas of need

ESQ to client/parent/carer; plus other relevant OMs [e.g., follow up SDQs]

9. Prepare full draft of report [within 4 weeks of feedback meeting]

Assessment Lead prepares draft of full report – check shared drive for relevant information re evidence-informed interventions for the client's profile

Admin sends to family to check for accuracy – suggested 3 week turnaround [i.e., family are provided with 3 weeks to review report, check accuracy issues, highlight any questions/queries they may have, etc.]

10. Follow up / finalised report

Assessment Lead/other team member meets with client +/-family for follow up

ESQ provided to client/parent/carer to evaluate assessment process [if not provided at end of feedback meeting] (dependent on discussion re 6 month cycle of ESQ provision and implications for providing ESQ at end of assessment and intervention cycle, rather than diagnostic assessment alone)

If ESQ has been administered as part of feedback meeting, Assessment Lead/team member to use Session Outcome Rating Scale or similar to gather service user feedback on follow up session(s)

Finalise report and send to family, cc'ed to referrer and GP

11. Post assessment

If no further work required, discharge

If further work required, discuss with Team Manager; CC role will need to be re-allocated

[i] **Screening example scenarios**

1. **Example scenarios include:**

- **Emotional symptoms score on SDQ elevated – consider use of RCADS to gather further specific detail on mood and worries (self and parent versions available) and use this plus clinical observation and information shared by young person/family to inform consultation in ASC Clinic Staff Meeting**
- **Hyperactivity/inattention score on SDQ elevated (combined with clinical observation and information shared by young person/family) – consider whether ADHD assessment may be indicated alongside diagnostic assessment of ASC/in place of. Additional information from the school on inattention, hyperactivity, impulsivity, etc. is included on the school questionnaire; all of this information will inform consultation with psychiatrist**

  If ADHD assessment is required, inform admin – appointment with psychiatrist for ADHD assessment to be made, plus Connors sent to parent/carer and school

- **Further cognitive assessment may be required/indicated – this can be discussed with any of the psychologists at ASC Clinic Staff Meeting but some possible prompters may include:**

1. **what comes up in the history as regards brain injury, any illnesses known to affect brain function, prenatal exposure to drugs/alcohol, pregnancy/labour (e.g., ex-prem), etc.**
2. **what comes up in the school questionnaire/from the initial: e.g., very behind age related expectations in achievement, very significant difficulties with accessing the curriculum, level of *SEN Support* specified, etc.**
3. **what comes from your own clinical judgement/impression of the CYP e.g., significant difficulties in the initial assessment phase with processing / understanding / memory / attention / etc.**
4. **no recent assessment (within last 18 months-2 years) in this area from local service (either CAMHS or local EP service if the CYP was recently assessed)**

   and possibly:

5. **where a CYP is actually likely to be more able and is under-achieving/in significant behavioural difficulties in school or risk of exclusion because their learning potential has not been recognised/addressed**