

Date 10/12/2025  
Your Ref  
Our Ref 10821R

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Dear

## FREEDOM OF INFORMATION REVIEW – AUTISM

I write in response to your request for information in relation to Autism. I must apologise again for the delay in responding and for the response going to straight to Review because of our failure to respond. This was just to the complex nature of your request.

I am advised that we can only respond in relation to the Royal Edinburgh Hospital and Associated Services and that the Edinburgh Health and Social Care Partnership / Edinburgh Council will be responding separately with information not held by NHS Lothian.

### Question

- With reference to my Freedom of Information request dated 30 September 2025 **Ref: 10631** concerning the commissioning and oversight of autism spectrum disorder (ASD) diagnostic services delivered by Number 6 One Stop Shop (Autism Initiatives UK) under the Edinburgh Health and Social Care Partnership (EHSCP), governed by the Edinburgh Integration Joint Board (EIJB), and involving NHS Lothian, iThrive, and CAMHS, between 2019 - 2025:

Please treat this as a supplementary clarification to ensure full compliance with the Freedom of Information (Scotland) Act 2002. This addendum seeks specific, unambiguous, and binding answers to five outstanding factual and ethical questions not explicitly covered in my original request.

### Answer

I am advised that Edinburgh Health and Social Care Partnership received the same request, and they are in the process of replying.

As Edinburgh Council has received this directly and is responding we will only respond in relation to information held by NHS Lothian and CAMHS. The Council holds the information for the HSCP not NHS Lothian.

As per Section 17 of the Freedom of Information (Scotland) Act 2002 formally I must advise that we do not hold information in relation to EHSCP.

Headquarters  
Mainpoint  
102 West Port  
Edinburgh EH3 9DN

Chair Professor John Connaghan CBE  
Chief Executive Professor Caroline Hiscox  
*Lothian NHS Board is the common name of Lothian Health Board*

## I. Recognition and statutory validity of diagnoses

Question:

- For each ASD diagnosis issued by Number 6 OSS to a patient referred by NHS Lothian, iThrive, CAMHS, or any NHS or public body under any formal commissioning, contractual, or referral arrangement between 2019 - 2025:

Does NHS Lothian currently recognise these diagnoses as clinically valid and equivalent to those issued by NHS Lothian mental health teams? Please answer "Yes" or "No".

If "No", please specify:

- The exact date on which recognition was withdrawn or limited.
- The documented clinical, legal, or governance rationale for that decision.
- A copy of any internal guidance, circular, or instruction issued to NHS staff, GPs, or external bodies (e.g. DWP, Access to Work, local authorities) stating that such diagnoses are not valid or only valid for limited purposes.

Answer:

NHS Lothian recognises these diagnoses as clinically valid, noting that any diagnosis may need to be revised if someone's presentation significantly changes and that few diagnostic processes are 100% accurate.

Question:

- For each statutory purpose below, please confirm whether NHS Lothian accepts these diagnoses as sufficient for eligibility: Please complete this table. If "No" for any, provide the reason and date of change.

Answer:

|    | <b>Purpose</b>   | <b>Accepted? (Y/N)</b> |
|----|--|------------------------|
| a. | NHS care planning and referrals                                      | Yes                    |
| b. | Personal Independence Payment (PIP) / Adult Disability Payment (ADP) | *                      |
| c. | Access to Work (AtW) reasonable adjustments                          | *                      |
| d. | Social care support  | *                      |
| e. | Housing assessments  | *                      |
| f. | Education (further/higher)   | *                      |
| g. | Employment rights under the Equality Act 2010                        | *                      |

\*From (b) to (g) are not for NHS Lothian to consider. It is up to the bodies who own these to consider what they think is an acceptable level of assessment – e.g. DWP, housing, employers etc.

## II. Volume of NHS-commissioned assessments

Question:

For the period 2019 - 2025, please provide:

1. The total number of ASD diagnostic assessments undertaken by Number 6 OSS for patients referred under any NHS Lothian commissioning, contract, SLA, pilot, or formal referral pathway.
2. A year-by-year breakdown (2019, 2020, 2021, 2022, 2023, 2024, 2025).
3. The number of completed diagnostic reports sent to:
  - GPs
  - NHS Lothian teams
  - Patients
4. A breakdown by referral source:
  - CAMHS
  - Adult Mental Health
  - iThrive
  - Other (please specify)
5. A breakdown by age group:
  - Children (under 16)
  - Adolescents (16-17)
  - Adults (18+)

If any data is estimated, please state the methodology used.

Answer:

|    |  |
|----|--|
| 1. | 386  |
| 2. | 2019 - <b>5</b> <, 2020 - <b>5</b> <, 2021 – <b>67</b> , 2022 – <b>172</b> , 2023 – <b>28</b> , 2024 – <b>0</b> , 2025 – <b>0</b> . Years are year of referrals into CAMHS<br>To protect the identity of the individuals involved any figure of 5 or less has not been shown in the table above. Since we do not have their consent to release this data from their records, the information is exempt under section 38(1)(b) of the Freedom of Information (Scotland) Act i.e. to provide it would breach the Data Protection Act (2018). |
| 3. | This will need a review in TRAK of all 376 patients and cannot be carried out with confidence  |
| 4. | All from CAMHS   |
| 5. | Under 16 - 0<br>16 and 17 - 376<br>18+ - 0   |

### III. Compliance with full SIGN 145 requirements for adult and female diagnoses

Question:

- SIGN 145 (2016) and NICE CG142 (2012) require that autism assessments for adults - particularly late-diagnosed individuals and females - include:  
Differential diagnosis to rule out or identify co-occurring conditions such as:
  - ADHD
  - Anxiety disorders
  - Personality disorders (e.g. BPD)
  - Trauma-related conditions (e.g. C-PTSD)



- Psychosis
- Intellectual disability
- Language disorders

Gender-sensitive assessment tools to account for camouflaging, social mimicry, and atypical presentation in females, such as:

- RAADS-R (Ritvo Autism Asperger Diagnostic Scale - Revised)
- AQ-10 or AQ-28 with gender-normed scoring
- CAT-Q (Camouflaging Autistic Traits Questionnaire)
- EQ (Empathy Quotient) and SQ (Systemising Quotient) with clinical interpretation
- Structured clinical interviews assessing social exhaustion, masking, and late-onset burnout

Comprehensive developmental history, including:

- Childhood social, emotional, and sensory experiences
- Educational and occupational challenges
- Family history of neurodivergence

Multidisciplinary team involvement, including:

- Consultant psychiatrist
- Clinical psychologist
- Speech and language therapist (SLT)
- Occupational therapist (OT)

Please confirm:

- Did NHS Lothian require or verify that Number 6 OSS assessments included all of the above elements?
  1. If not, why were these core SIGN 145 requirements not mandated for adult and female patients?
  2. Were any gender-sensitive tools (e.g. CAT-Q, RAADS-R) used in assessments?
  3. Was a formal differential diagnosis conducted and documented in every report?
  4. Was a multidisciplinary team involved in diagnostic formulation and sign-off?
  5. If any of these components were not used, please state:
    - a. The clinical rationale for their omission.
    - b. Whether patients were informed that their assessment did not meet SIGN 145 standards.

Answer:

|      |   |
|------|---|
| 1.   | We cannot find evidence that NHS Lothian required or verified these criteria. As per Section 17 of FOI(S)A this information is not held by NHS Lothian  |
| 2.   | No 6 are a trusted organisation with a track record of good practice.   |
| 3.   | We cannot find evidence that NHS Lothian required this. As per point 1 above, S17.  |
| 4.   | No. Young people were assessed or their referrals reviewed prior to referral to No 6, anyone with significant com-morbidities would not be referred on to No 6. If No 6 found any co-morbidities during their assessment they were asked to feed that back to NHS Lothian for further NHS assessment. |
| 5.a. | This is an internal issue for No6; it was not required by the SLA.  |
| 5.b. | Not possible to answer. Section 17  |



**IV. Public clarification of diagnostic validity**

Question:

[Autism Initiatives UK, in its submission](#) to the Scottish Parliament’s *ADHD and ASD Pathways and Support* inquiry (23 Jul - 18 Aug 2025), stated that:

- “Number 6 has been delivering a diagnostic and post-diagnostic support service in partnership with NHS Lothian since 2019.”
- “Our assessments follow NICE and SIGN guidance.”
- “We work in close partnership with iThrive, CAMHS, and GP practices.”

In [FOI Ref: 8959 \(02/08/2024\)](#) NHS Lothian confirmed that 383 referrals were made from CAMHS to Number 6 OSS between 2020-2024.

In [FOI Ref: 10448 \(26/09/2025\)](#) NHS Lothian stated that:

*“Patients diagnosed with autism are offered Post Diagnostic Support from Number 6.”*

This described the arrangement as of 26 Sep 2025.

Please clarify for the public record:

1. Does NHS Lothian agree with Autism Initiatives’ characterisation of Number 6 as a provider of NHS-commissioned autism diagnoses under clinical governance and in partnership with NHS services?
  - for the period 2019-2025,
  - currently.
2. For the period 2019-2025, if not, please provide a public statement confirming:
  - The date when the formal commissioning agreement for autism diagnosis ended in 2025.
  - That diagnoses issued by Number 6 were not equivalent to NHS Lothian diagnostic reports under SIGN 145 or NICE CG142.
  - That no consultant psychiatrist was routinely involved in diagnostic sign-off.
  - That the assessments did not include the full range of tools and clinical practices required by SIGN 145 for adults and females, including ADI-R, ADOS-2, RAADS-R, CAT-Q, AQ-10/28 with gender-normed scoring, and structured clinical interviews assessing camouflaging, social exhaustion, and late-onset burnout.
  - That patients were not informed they were receiving a non-NHS diagnostic report.

Answer:

|      |   |
|------|---|
| 1.a. | Not possible to answer as not centrally held – different parts of NHS Lothian may have commissioned diagnostic work. CAMHS certainly had diagnostic work at No 6 from 2019 – 2024   |
| 1.b. | Not from CAMHS.   |
| 2.   | I must advise that creating a public statement (a new piece of work) is not covered under FOI(S)A, we can only provide existing recorded information.<br><br>We cannot go into detail of the exact standard of the assessment, as we did not specify. Patients were informed they were receiving a non-NHS diagnostic assessment. The No 6 assessments did note what assessments were used and these were typically the |



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|  | same standard assessments that the NHS would use, but not the full range of assessment that are indicated in the request. Psychiatrists were not involved. |
|--|--|

**V. Patient information, consent, and disclosure of service status**

Question:

To assess whether patients were fully informed about the nature of the service they were receiving during the 2019-2025 period, please provide:

1. Copies of all patient-facing information given at the point of referral, triage, or assessment, including:
  - Referral letters/confirmations from iThrive, CAMHS, NHS Lothian, or other relevant teams
  - Information packs, emails, or welcome letters from Number 6
  - Consent forms or statements explaining the nature of the service and clinical governance
2. Specifically, for every relevant document, did it clearly state:
  - That the assessment was not delivered by an NHS mental health team or NHS clinician?
  - That the diagnostic report would not be equivalent to an NHS Lothian/SIGN 145 or NICE CG142 diagnosis?
  - That a consultant psychiatrist was not responsible for sign-off?
  - Whether specific autism assessment tools (ADI-R, ADOS-2, RAADS-R, CAT-Q, AQ-10/28, or gender-normed tools) were or were not used?
6. That the diagnosis might not be recognised for statutory or legal purposes (such as PIP, Access to Work, NHS referrals, or social care eligibility)?
3. If such disclosures were not made:
  7. Please explain why patients were not informed about any aspect of service commissioning, clinical standards, or statutory status.
  8. Was NHS Lothian, or any lead clinician or administrator, aware of any risk to patient autonomy or valid consent under these arrangements?
4. Further, please disclose whether at any point patients were informed (in writing or verbally) that they were:
  - a. Participating in an experimental, pilot, or third-sector diagnostic pathway distinct from the standard NHS diagnostic process.
  - b. Likely to require further assessment or re-referral to NHS Lothian for a diagnosis that would be recognised for NHS care, statutory entitlements, or legal protections.
5. Did any internal NHS communications instruct NHS, iThrive, or CAMHS staff to describe Number 6 as an “NHS partner,” “NHS-commissioned diagnostic service,” or anything implying formal NHS diagnostic status - regardless of the actual contractual or clinical governance arrangement?

Answer:

|    |   |
|----|---|
| 1. | We have enclosed a redacted letter. We could evidence it was sent to some patients but could not evidence it was sent to all. We do not have the internal comms from No 6.      |
| 2. | The attached letter may cover this but does not state all of these, i.e. equivalencies to NICE guidelines nor that a psychiatrist was not used in the assessment. Psychiatrists |



|      |  |
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|      | are not always required for NHS assessment either. The specific tools used were noted in the final assessment report. It would not be possible to state whether the report could be used for a range of external agencies. |
| 3.   | The attached document was considered appropriate for providing information and seeking consent.  |
| 4.a. | The attached letter makes that clear although we cannot evidence that it was sent in all cases.  |
| 4.b. | It is not the case that it is likely to require NHS assessment for these provisions.   |
| 5.   | There was no such instruction.   |

I hope the information provided helps with your request.

If you are not satisfied with this response you still have the right to make a formal complaint to the Scottish Information Commissioner who you can contact at the address below or using the Scottish Information Commissioner's Office online appeals service at <https://www.foi.scot/appeal>. If you remain dissatisfied with the Commissioner's response you then have the option to appeal to the Court of Session on a point of law.

Scottish Information Commissioner  
Kinburn Castle  
Doubledykes Road  
St Andrews, Fife  
KY16 9DS  
Telephone: 01334 464610  
e-mail: [enquiries@foi.scot](mailto:enquiries@foi.scot)

Yours sincerely

**Freedom of Information Reviewer/  
NHS Lothian**  
cc: Executive Nurse Director  
Enc.

As you know, you were referred to CAMHS North Edinburgh, [.....]  
for assessment of potential Autistic Spectrum Disorder (ASD). The waiting list for assessment by CAMHS is currently very long. We know that some young people aged 16 and above who have been referred for assessment, are unlikely to come to the top of the CAMHS waiting list before their 18th birthday. This would mean that when they were 18 they would require to have their referral transferred to Adult Mental Health Services.

When you spoke with a CAMHS clinician they told you about the option to be assessed by the team at Number 6 (run by Autism Initiatives). We have summarised the information below to remind you:

Number 6 is the one stop shop for young people and adults aged 16 and above with ASD. From the information we have received, we think that you could be assessed by them. This could provide you with an ASD assessment sooner than if you remain on our waiting list.

#### About Number 6

1. Number 6 is the main resource in the Lothians for young people and adults aged 16 + with ASD. It is run by Autism Initiatives, a voluntary sector organisation. It is not run by the NHS.
2. Number 6's staff have been trained to use established ASD assessment tools. They also have over 15 years of experience of helping adults with ASD. However, they are not mental health clinicians. They cannot diagnose other mental health conditions.
3. Number 6's staff have basic training about mental health conditions seen in mental health services. If Number 6's staff identify health concerns that they cannot manage, they will contact (with your consent) the appropriate services to discuss how best to proceed.
4. Number 6 will provide you and your GP with a standardised report following their ASD assessment. If ASD is confirmed in their assessment, you would then have the opportunity to access Number 6's services.
5. You can find out more information about Number 6 at [www.number6.org.uk](http://www.number6.org.uk). There is not currently information on the Number 6 website regarding the ASD assessment pathway, however they are in the process of updating their website and it is to be added.

When you spoke with the CAMHS clinician you said that you would prefer to have your assessment with Number 6. You completed some paperwork including a consent form that allows NHS Lothian CAMHS to share information with Number 6. This information will be sent to Number 6 so that they are able to carry out your ASD assessment.



As your assessment will now be carried out by Number 6 you will be discharged from CAMHS.

You and your GP will receive a letter to advise you that you have been removed from the waiting list. However, we know that this is an important decision and sometimes people need time to think about it. Also, sometimes people may change their mind.

If you have any questions about anything that has been written in your letter then please contact [...] at CAMHS North Edinburgh Team on[....]