



Northern Ireland

Public Services

Ombudsman

Investigation of a complaint against the Belfast Health & Social Care Trust

Report Reference: 202003279

The Northern Ireland Public Services Ombudsman

33 Wellington Place

BELFAST

BT1 6HN

Tel: 028 9023 3821

Email: nipso@nipso.org.uk

Web: www.nipso.org.uk



@NIPSO_Comms

The Role of the Ombudsman

The Northern Ireland Public Services Ombudsman (NIPSO) provides a free, independent and impartial service for investigating complaints about public service providers in Northern Ireland.

The role of the Ombudsman is set out in the Public Services Ombudsman Act (Northern Ireland) 2016 (the 2016 Act). The Ombudsman can normally only accept a complaint after the complaints process of the public service provider has been exhausted.

The Ombudsman may investigate complaints about maladministration on the part of listed authorities, and on the merits of a decision taken by health and social care bodies, general health care providers and independent providers of health and social care. The purpose of an investigation is to ascertain if the matters alleged in the complaint properly warrant investigation and are in substance true.

Maladministration is not defined in the legislation, but is generally taken to include decisions made following improper consideration, action or inaction; delay; failure to follow procedures or the law; misleading or inaccurate statements; bias; or inadequate record keeping.

The Ombudsman must also consider whether maladministration has resulted in an injustice. Injustice is also not defined in legislation but can include upset, inconvenience, or frustration. A remedy may be recommended where injustice is found as a consequence of the failings identified in a report.

Reporting in the Public Interest

This report is published pursuant to section 44 of the 2016 Act which allows the Ombudsman to publish an investigation report when it is in the public interest to do so.

The Ombudsman has taken into account the interests of the person aggrieved and other persons prior to publishing this report.

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Case Reference: 202003279

Listed Authority: Belfast Health and Social Care Trust

SUMMARY

This complaint was about the Belfast Health and Social Care Trust's (the Trust) decision not to assess the complainant's son (the child) for ADHD or prescribe him medication, until he was six years old. The child's GP first referred him for an ADHD assessment when he was four years and nine months. However, the Trust declined the referral. The GP referred the child for assessment again when he was five years and three months. The Trust again declined to assess the child.

The investigation recognised the Trust's reasons for its policy not to assess children for ADHD until they reach six years old. It based its policy on financial constraints, number of applicants and its interpretation of guidelines. However, the investigation found information the Trust provided to the complainant was not wholly accurate. The Trust told the complainant it could not accept referrals for an ADHD assessment or prescribe medication for children under the age of six. The investigation found the guidance relevant to this area did not absolutely prevent the Trust from assessing and medicating the child, or from exploring other options for support. The investigation found this failing constituted maladministration.

I recommended the Trust apologise to the complainant for the injustice sustained. I also recommended that the Trust undertakes a review of the information provided to applicants regarding its policy and criteria for conducting ADHD assessments. In particular, the options for assessment, or alternative support, for children under the age of six. I also recommended that it highlights the gap in funding identified in this report as part of its commissioning discussions and resource bids to the Department of Health.

THE COMPLAINT

1. This complaint is about the Belfast Health and Social Care Trust's (the Trust) decision not to assess the complainant's son (the child) for Attention Deficit Hyperactivity Disorder¹ (ADHD) based on his age. It is also about its decision not to prescribe medication for the child.

Background

2. The child's GP first referred him for an ADHD assessment in November 2021 when he was aged four years and nine months. The complainant said that at the time of the referral, the child had no '*impulse control*'. The Trust informed the complainant it would not assess the child until after his sixth birthday. However, the child's GP referred the child again when he was aged five years and three months. The Trust again declined the referral on the basis of the child's age.

Issue of complaint

3. I accepted the following issue of complaint for investigation:

Whether the Trust's decision not to refer the child for an ADHD diagnostic assessment was appropriate and in accordance with relevant guidance.

INVESTIGATION METHODOLOGY

4. In order to investigate this complaint, the Investigating Officer obtained from the Trust all relevant documentation together with its comments on the issues the complainant raised. This documentation included information relating to the Trust's complaints process.

Independent Professional Advice Sought

5. After further consideration of the issues, I obtained independent professional advice from the following independent professional advisor (IPA):

¹ A behavioural disorder in which a child has a consistently high level of activity and/or difficulty in attending to tasks.

- A Consultant Paediatrician with extensive experience of assessing children with a wide range of developmental issues, including attentional problems.

I enclose the clinical advice received at Appendix two to this report.

6. I included the information and advice, which informed the findings and conclusions, within the body of this report. The IPA provided 'advice'. However, how I weighed this advice, within the context of this particular complaint, is a matter for my discretion.

Relevant Standards and Guidance

7. In order to investigate complaints, I must establish a clear understanding of the standards, both of general application and those specific to the circumstances of the case. I also refer to relevant regulatory, professional, and statutory guidance.

The general standards are the Ombudsman's Principles²:

- The Principles of Good Administration

8. The specific standards and guidance referred to are those which applied at the time the events occurred.

The specific standards and guidance relevant to this complaint are:

- The National Institute for Health and Care Excellence's Attention deficit hyperactivity disorder: diagnosis and management, NICE Guideline 87 (NG87);
- National Health Service (NHS) : ADHD Treatment (2023)
- British National Formulary for Children³ (BNF) 2022
- General Medical Council (GMC) Guidance Good Practice in prescribing and managing medicines and devices (April 2021)
- www.nhs.uk/medicines/methylphenidate (2023)
- The Trust's ADHD Referral Criteria – who do we see

² These principles were established through the collective experience of the public services ombudsmen affiliated to the Ombudsman Association.

³ A medical and pharmaceutical publication that contains information and advice on prescribing and on pharmacology.

I enclose relevant sections of the guidance considered at Appendix four to this report.

9. I did not include all information obtained in the course of the investigation in this report. However, I am satisfied I took into account everything I considered relevant and important in reaching my findings.
10. A draft copy of this report was shared with the complainant and the Trust for comment on factual accuracy and the reasonableness of the findings and recommendations. The complainant did not make further comment on my conclusions. The Trust provided comments, which I fully considered and reflected in the report where I considered it appropriate. The Trust has accepted my findings and recommendations.

THE INVESTIGATION

Whether the Trust's decision not to refer the child for an ADHD diagnostic assessment was appropriate and in accordance with relevant guidance.

Detail of Complaint

11. The complainant said her son, at the time of the events described, was aged four years and nine months and displayed signs of ADHD. She explained the Trust would not assess her son for this condition until he was six years old.
12. The complainant said the NICE guidelines did not state that a child had to be 'six years old' before undergoing assessment. She explained that when she informed the Trust of this, it said that medicating children under the age of six was '*off label*'⁴. The complainant said this prevented her from availing of '*the key early interventions needed for her son's development*'.

⁴ Off label prescribing means that the person prescribing the medication wants it used in a different way than that stated in its license. This could mean using the medication for a different condition or a different group of patients or it could mean a change in dose or that the medication is taken in a different way.

Evidence Considered

The Trust's response to investigation enquiries

13. The Trust stated its ADHD clinic only accepts referrals for children aged six years and over. This is because the '*standardised assessments*' it uses to diagnose ADHD are valid from this age.
14. The Trust stated that NICE NG87 guidelines refer to children aged five years and above to '*help guide clinicians*'. The guidelines state that prescribing medication for children aged five years is '*off label*'. This means that whilst doctors can prescribe medication, it is not '*regular practice*'. The medication the Trust prescribes for ADHD is licensed for children aged six years and above.
15. The Trust stated it is aware of the '*long waiting list*' for ADHD assessment. This is due to '*increased demand versus the available resources*'. Its paediatric service is currently engaged with the emotional health and wellbeing project to '*address the gap*' in the provision of behavioural support. It appointed two ADHD Clinical Nurse Specialists who will hold nurse-led clinics to assist with waiting times.
16. The Trust stated the child has since been diagnosed with autism (13 September 2022) and can now access its autism intervention team for behavioural support.
17. The Trust stated it is '*truly sorry*' for the wait the child experienced to receive an ADHD assessment. It '*fully acknowledges*' the impact this had on both the child and the family. The ADHD assessment was completed on 8 March 2023, shortly after the child's sixth birthday. The Trust stated that he '*does not currently meet the criteria for a diagnosis of ADHD, however due to ongoing parental concerns over attentiveness, he remains under review with the ADHD clinic*'.

Relevant Independent Professional Advice

18. The Consultant Paediatrician (CP IPA) advised the NICE Guidance (NG87) is clear on the '*need for caution*' for treating children aged under five years.

However, the guidance does not state the age at which assessment is appropriate. Instead, it outlines an appropriate assessment process.

19. The CP IPA advised that the Trust is '*not correct*' in stating that assessment cannot take place purely on the basis of age. NICE NG87 provides specific guidance for children under five years. Sections 1.5.8 and 1.5.9 of the guidance suggest assessment in younger years is possible if concerns remain after implementing behavioural and training interventions. However, this should occur following receipt of advice from a specialist ADHD service.
20. The CP IPA referred to the Trust's response that its standardised assessments to diagnose ADHD, and the medication used, are only valid for children aged six years and above. The CP IPA referenced additional sources that provide conflicting guidance regarding age (summarised in Appendix four) and advised the Trust's reasons were '*valid*', however they are '*not absolute*'.
21. The CP IPA advised the use of medication in young children is unusual as specialists usually signpost the patient to education or parenting groups prior to a paediatric assessment. However, based on the guidance, and in consultation with a more specialist service (if necessary), the Trust could have offered to assess the child and provide appropriate guidance.
22. The CP IPA advised that when parents are concerned, it is '*not helpful to simply decline referrals*'. The Trust explained it provides support using Family Hubs⁵. However, it would be clearer if it suggested this as part of a defined pathway.
23. As a learning point, the CP IPA advised the Trust should review its process to ensure that GPs and families are clear about the role of the paediatric clinic in the pathway for children with attentional issues.

⁵ A family hub is a multi-agency network of statutory, community and voluntary organisations that provide early intervention services or work with families who need support.

Comments received from the Trust following receipt of the report in draft form

24. The Trust referred to the NICE guidelines and stated that while they *'are necessary'* they are *'not compulsory'*. It referred to its *'finite resources'* and stated these were *'outweighed by the demands of an exponentially growing waiting list'*. It explained *'it is not possible to provide service in line with guidelines.'*
25. The Trust referred to the NICE Guidelines, which state that the first line of treatment for a 5 year old child with potential ADHD is behavioural and environmental modifications. These are not available within the Community Paediatric Service. Therefore, they are outside the Trust's remit.
26. In response to the provisional finding that the Trust *'Failed ...to explore alternatives with a more specialist service'*, it stated it signposted the complainant to a family hub. It previously worked with a private healthcare provider to provide ADHD assessments. However, this is no longer available. Recently the Trust also developed webinar support to support behavioural challenges.
27. The Trust stated that due to its *'resource problems'*, it prioritised those *'most in need, to balance needs/equity of access for all children'*. Other Trusts within Northern Ireland experience similar concerns and do not accept referrals for children under six years. Therefore, *'there was no unfair treatment as compared to other children in Northern Ireland'*.
28. In relation to the provisional finding that it *'Could have assessed concerns ...and if necessary, provided consultation with a more specialised service'*, the Trust stated the correct diagnosis for the child is autism. The service diagnosed the child in September 2022 and offered support through the Trust's autism services. Therefore, it could not offer a *'more specialised service'*.
29. The Trust stated it assessed the child for ADHD after his sixth birthday. He did not meet its criteria and therefore, did not sustain a loss of opportunity to

receive earlier support. As the child did not have ADHD, medication would have been inappropriate.

30. The Trust stated that the main shortcoming is a lack of appropriate support services pre-ADHD assessment. Improvements, including an updated Emotional Health and Wellbeing framework, will enable a more focused support to children in the future. It also expanded its ADHD team to include two nurses and plans to bring ADHD referrals into a single point of triage with autism spectrum disorder services. This will help deliver a service that will target patient and family needs.

Further advice from the CP IPA

31. Following consideration of the Trust's further comments, the CP IPA did not amend his advice. He accepted that resources are a concern, but it does not override clinical guidance. He advised that the Trust should highlight this as part of commissioning discussions. However, it should not recognise resourcing as a constraint, or failing to provide a service as acceptable. The Trust should advocate with its commissioners to recognise the gap in funding.

Analysis and Findings

32. The complainant raised concern with the Trust's decision not to assess the child for ADHD, or prescribe him medication, until he reached the age of six. The Trust stated it could not assess the child as its standardised assessments are only valid from the age of six and ADHD medication is not licenced until the child reaches six years of age. However, the complainant did not believe relevant guidance supported the Trust's position.
33. I accept NICE NG87 does not give a specific age for ADHD assessment but rather outlines an appropriate assessment process. The Trust changed the age for assessment to six years in February 2020. It stated it primarily made this decision because of the NICE recommendation not to prescribe medication for children under the age of six. Additionally, the Trust stated it adopted a *'referral system and criteria which sought to balance the needs of all children who are referred in line with the finite resources available to it'*.

34. In its response to the draft report, the Trust raised concerns about its resources for the provision of ADHD services. A local newspaper article published at the time of this complaint (August 2023) stated it believed there were approximately 1000 children on the waiting list for a potential diagnosis of ADHD in the Belfast Trust area alone. It also reported an average wait time of five years.
35. This example of a lengthy waiting time is typical across the NHS and especially in Northern Ireland. Unfortunately, delays in health service provision have been the reality for several years. Rather than a failure to apply policy, it is regrettably a sign of the longer-term disparity between increasing (and more costly) patient needs and the limits on health service resourcing.
36. I accept that in constrained times, and in light of the severely restricted finances available to it, Trusts have to make difficult decisions relating to the allocation of scarce resources. Additionally, I acknowledge the current pressures within the NHS generally both locally and nationally have resulted in staff shortages and greatly increased waiting times across all sections of the NHS. The Trust's response to sight of the draft report indicates that '*consultation with a more specialist service*', as the CP IPA suggested, is not available to the Trust. I accept the advice of the CP IPA that this represents a gap in funding which in a large part has led to this complaint arising.
37. Whilst I sympathise with the complainant, it would not be conducive to general NHS morale to define this as maladministration, since all those enduring a lengthy wait for treatment could conceivably raise the same complaint. I consider the protracted timescale which the patient and complainant had to endure is a symptom of the reality of there being insufficient public funds to meet the demands currently placed on the health service. I therefore do not find a failure in care and treatment of the child.
38. However, the investigation identified a concern with information the Trust communicated to the complainant. In its letter to the complainant, dated 16 August 2022, the Trust stated, '*the assessments that Trust medical staff use to diagnose ADHD are not valid until 6 years, therefore the Trust **cannot*** (my

emphasis) *accept referrals below this age*'. However, NICE NG87 does not absolutely prevent the Trust from assessing children under the age of six as suggested by the Trust. I accept the CP IPA's advice that the Trust is incorrect to state that it could not assess the child based purely on his age.

39. In the same letter, the Trust stated, '*in keeping with NICE Guidance, medication should **only** (my emphasis) be considered for children over the age of six years*'. I acknowledge the existence of conflicting guidance for the age at which it is appropriate to prescribe ADHD medication in children. However, I am satisfied that the Trust's suggestion that it can only consider medication for children over the age of six, is not wholly accurate. The CP IPA advised that while prescribing medication for children under six years is '*unusual*' and '*off label*', in accordance with NICE NG87, it is possible following specialist review.
40. I am disappointed the Trust did not communicate its reasons for not accepting the referral, or prescribing medication for the child, more clearly to the complainant. Rather, it told the complainant it cannot accept referrals for an ADHD assessment under the age of six and that it can consider medication only for children over the age of six. The information provided was not in accordance with relevant guidance.
41. The Principles of Good Administration require bodies to take proper account of established good practice and be open and clear about policies and procedures, ensuring that information and advice provided is clear, accurate and complete. I consider the Trust failed to follow these Principles when it issued its communication to the complainant. I am satisfied that this constitutes maladministration. I consider the maladministration identified caused the complainant the injustice of uncertainty, stress and frustration. I recommend a remedy at the conclusion of this report.
42. The Trust stated it assessed the child for ADHD in March 2023, shortly after his sixth birthday. Given the lengthy wait times for this service, I commend the Trust for conducting the assessment in such a timely manner. This assessment revealed that he did not currently meet the criteria for a diagnosis of ADHD but that due to ongoing parental concerns, he remains under review with the ADHD

clinic. The Trust stated it assessed and diagnosed the patient with Autism, for which he is receiving support.

CONCLUSION

43. I received a complaint about the Trust's decision not to assess a child for ADHD, or prescribe him medication, until after his sixth birthday. I consider there to have been a failure in communication on the part of the Trust concerning the information provided to the complainant which constitutes maladministration. I therefore uphold the complaint for the reasons outlined in this report.

44. I consider the maladministration identified to have caused the complainant to sustain the injustice of uncertainty, stress, and frustration.

Recommendations

45. I recommend within **one month** of the date of this report:

- i. The Trust provides the complainant with a written apology in accordance with NIPSO 'Guidance on issuing an apology' (June 2016), for the injustice caused to her and the child as a result of the failure identified; and
- ii. The Trust shares this report with staff involved.
- iii. The Trust should highlight the gap in funding identified in this report as part of its commissioning discussions and resource bids to the Department of Health

46. I further recommend that within **three months** of the date of this report, the Trust undertakes a review of the information provided to applicants regarding its policy and criteria for conducting ADHD assessments, in particular the options for assessment, or alternative support, for children under the age of six.

Margaret Kelly
Ombudsman

July 2024

Appendix 1

PRINCIPLES OF GOOD ADMINISTRATION

Good administration by public service providers means:

1. Getting it right

- Acting in accordance with the law and relevant guidance, with regard for the rights of those concerned.
- Acting in accordance with the public body's policy and guidance (published or internal).
- Taking proper account of established good practice.
- Providing effective services, using appropriately trained and competent staff.
- Taking reasonable decisions, based on all relevant considerations.

2. Being customer focused

- Ensuring people can access services easily.
- Informing customers what they can expect and what the public body expects of them.
- Keeping to its commitments, including any published service standards.
- Dealing with people helpfully, promptly and sensitively, bearing in mind their individual circumstances
- Responding to customers' needs flexibly, including, where appropriate, co-ordinating a response with other service providers.

3. Being open and accountable

- Being open and clear about policies and procedures and ensuring that information, and any advice provided, is clear, accurate and complete.
- Stating its criteria for decision making and giving reasons for decisions
- Handling information properly and appropriately.
- Keeping proper and appropriate records.
- Taking responsibility for its actions.

4. Acting fairly and proportionately

- Treating people impartially, with respect and courtesy.
- Treating people without unlawful discrimination or prejudice, and ensuring no conflict of interests.
- Dealing with people and issues objectively and consistently.
- Ensuring that decisions and actions are proportionate, appropriate and fair.

5. Putting things right

- Acknowledging mistakes and apologising where appropriate.
- Putting mistakes right quickly and effectively.
- Providing clear and timely information on how and when to appeal or complain.
- Operating an effective complaints procedure, which includes offering a fair and appropriate remedy when a complaint is upheld.

6. Seeking continuous improvement

- Reviewing policies and procedures regularly to ensure they are effective.
- Asking for feedback and using it to improve services and performance.
- Ensuring that the public body learns lessons from complaints and uses these to improve services and performance.

