



Northern Ireland

Public Services

Ombudsman

Investigation Report

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

NIPSO Reference: 19121

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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SUMMARY

I received a complaint about the Southern Health and Social Care Trust's assessment of a child for Autism Spectrum Disorder in 2014/15. The complainant, the child's mother, raised concerns that the Trust did not properly carry out the assessment and as a result her daughter was misdiagnosed as not having ASD traits. She was later reassessed and received an ASD diagnosis in June 2017. The complainant raised further concerns about the care and treatment her daughter received following her ASD diagnosis.

My investigation examined the details of the complaint, the Trust's response and both national and regional guidelines. I also sought independent professional advice from a Consultant Paediatrician. I concluded that the Trust's multi-disciplinary team involved in the child's ASD assessment on 16 March 2015 did not consider all of the cumulative information when making its diagnostic decision. I concluded also that the multi-disciplinary team failed to reach an appropriate and reasonable diagnostic conclusion in accordance with relevant guidelines. I considered these constitute failures in the child's care and treatment.

As a consequence of the failures identified, I considered that the child's reassessment for ASD was delayed and in consequence her ASD diagnosis was also delayed. This delay in diagnosis resulted in appropriate intervention and support not being available to the child sooner. I also considered the complainant experienced the injustice of upset, frustration and uncertainty as to the reason for her child's presenting difficulties and having the continued need to raise her concerns with the Community Paediatrician.

My investigation did not establish any failures in the care and treatment received by the child in 2017/18 following her ASD diagnosis. I considered the post diagnostic care and treatment was reasonable and in line with relevant guidelines. However it was clear from my consideration of the evidence that additional support to the family would have been beneficial and I encouraged the Trust to continue to develop services in this area.

I recommended that the Trust apologises to the child and the complainant for the injustice resulting from the failures identified, and that it discusses the findings of this investigation with relevant staff for learning. I also recommended that the Trust provides evidence of its previous reminders to staff relating to the importance of ensuring that ASD Diagnostic Assessment Reports reflect the information that is considered when reaching a diagnostic decision.

I was pleased to note that the Trust accepted my findings and recommendations.

THE COMPLAINT

1. The complainant submitted a complaint on behalf of her daughter (the child) about the actions of the Southern Health and Social Care Trust (the Trust). The complaint concerned the Trust's assessment of the child for Autism Spectrum Disorder (ASD)¹ in 2014/ 2015 when she was 10 years old. The complainant said that the Trust did not properly assess her daughter for ASD in 2014/15 when it concluded that she did not meet the criteria for an ASD diagnosis. Specifically, the complainant said that the Trust did not take into account all of the available information when it decided that her daughter did not have ASD traits. The complainant said that instead, the Trust based its diagnostic decision solely on the child's performance in the Autism Diagnostic Observation Schedule (ADOS) Module 3² tool which took place on 16 March 2015 and that this led to a misdiagnosis.
2. Due to further ongoing concerns raised by the complainant and the child's school, the child's Community Paediatrician referred her for ASD reassessment on 12 December 2016. Subsequently, she obtained an ASD diagnosis in June 2017. The complainant considered that, due to the Trust's '*misdiagnosis*' in 2014/15, her daughter missed out on intervention which she ought to have received at an earlier stage.
3. The complainant also raised concerns with the intervention and support provided to her child following her ASD diagnosis in June 2017. Specifically, the complainant said that the care and treatment provided by the Trust's Autism Service³ in 2017/18 was '*inadequate and inappropriate*'.
4. The complainant did not raise with the Trust the issue regarding the Autism Service's provision of intervention and support following the child's ASD diagnosis.

¹ Autism is commonly referred to in a variety of terms, including autism spectrum disorder (ASD), autistic spectrum condition, autistic spectrum difference and neuro-diversity. For clarity and consistency, in this investigation report the term 'ASD' is used throughout.

² ADOS is a standardised diagnostic test for Autism Spectrum Disorder. ADOS Module 3 is intended for children who are verbally fluent.

³ The Trust's Autism Service provides Autism assessment and diagnosis up to 12 years of age and short-term therapeutic intervention and support to children, young people (12 years to 18 years) and young adults in order to help them and their families understand how autism affects each individual and equip them to manage their Autism. It comprises a range of practitioners including Child and Adolescent Mental Health (CAMHS)/Autism Head of Service, Autism Clinical Lead, Autism Coordinator, Medical staff, Autism Intervention Therapists, Autism Specialist Support Workers, Speech & Language Therapist.

Notwithstanding, I decided to use discretion to consider this issue as part of my investigation. In deciding to use the discretion afforded to me, I took account of the impact of the Trust's complaints process on the complainant's health and that the complainant had raised her concerns regarding intervention and support with Trust staff directly. The investigation of this issue pertains to the period following the child's ASD diagnosis on 14 June 2017 until the complainant's submission of her complaint to this Office on 30 July 2018.

Issues of complaint

5. The issues of this complaint which were accepted for investigation are:

Issue one: Whether the autism assessment of the child in 2014/15 was reasonable and appropriate.

Issue two: Whether the care and treatment of the child following her autism diagnosis in 2017 was reasonable and appropriate.

INVESTIGATION METHODOLOGY

6. In order to investigate this complaint, the Investigating Officer obtained from the Trust all relevant documentation together with the Trust's comments on the issues the complainant raised.

Independent Professional Advice Sought

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

- **Consultant Paediatrician and Professor in Children's Neurodisability** – OBE MB BChir (Bachelor of Medicine, Bachelor of Surgery, Cambridge) FRCP (Fellow of the Royal College of Physicians) DCH (Diploma in Child Health) FRCPCH (Fellow of the Royal College of Paediatrics and Child Health): Professor with forty years' experience leading multi-disciplinary assessment which includes diagnosis of ASD, Attention Deficit Hyperactivity Disorder (ADHD), intellectual disability and specific learning difficulties,

language disorders and all associated neuropsychiatric disorders. Author of the National Autism Plan; Chair of NICE Autism Guidelines for children; Member of the working party for neurodevelopmental disorders for DSM-5 and ICD-11.

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

Relevant Standards

9. In order to investigate complaints, I must establish a clear understanding of the standards, both of general application and those which are specific to the circumstances of the case. I also make reference to relevant regulatory, professional and statutory guidance
10. The general standards are the Ombudsman's Principles⁴.
 - The Principles of Good Administration; and
 - The Principles for Remedy.
11. The specific standards and guidance referred to are those which applied at the time the events occurred. These governed the exercise of the administrative functions and professional judgement of the Trust staff whose actions are the subject of this complaint.
12. The specific standards relevant to this complaint are:
 - National Institute for Health and Care Excellence (NICE) Clinical Guideline CG128 - Autism spectrum disorder in under 19s: recognition, referral and diagnosis, September 2011 (NICE Guideline CG128);
 - National Institute for Health and Care Excellence (NICE) Clinical Guideline CG170 – Autism spectrum disorder in under 19s: support and management, August 2013 (NICE Guideline CG170); and

⁴ These principles were established through the collective experience of the public services ombudsmen affiliated to the Ombudsman Association.

- Health and Social Care Board (HSCB) - Six Steps of Autism Care (for Children and Young People in Northern Ireland). Regional Autistic Spectrum Disorder Network for Northern Ireland, October 2011 (HSCB Regional Pathway document).

13. I did not include all the information obtained in the course of the investigation in this report. However, I am satisfied that I took into account everything that I considered to be relevant and important in reaching my findings.

14. 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.

INVESTIGATION

Issue one: Whether the autism assessment of the child in 2014/15 was reasonable and appropriate.

Detail of Complaint

15. The complainant submitted a complaint on behalf of her child, about the Trust's initial ASD assessment of the child in 2014/15 when the child was 10 years old. Following this assessment the Trust concluded that the child did '*not display traits in keeping with autism*'. The complainant said that the Trust did not properly assess the child on this occasion and this resulted in a misdiagnosis. Specifically, the complainant said that the Trust concluded that the child did not have ASD on the basis that she had performed well in the ADOS which took place on 16 March 2015. The complainant said that the Trust did not consider or make reference in the Diagnostic Assessment Report, to the additional supplementary information which was available. The complainant said this supplementary information '*clearly highlighted ASD traits, but [these] do not appear to have been picked up on or properly considered [by the Trust] in the formal diagnosis... made in March 2015*'.⁵

⁵ This information included: a Speech and Language Therapist report; a school observation report completed by an Autism Intervention Therapist; further information provided by the child's school; an Occupational Therapy report; a Physiotherapist report; and additional information including a parent questionnaire provided by the complainant.

16. Following the child's ASD assessment in 2014/15, the complainant continued to have ongoing concerns about her child's presenting difficulties. She raised these concerns with the Community Paediatrician who referred the child for reassessment in December 2016. Subsequently, the child obtained an ASD diagnosis in June 2017.
17. The complainant was dissatisfied that her child was not diagnosed with ASD at the time of her initial ASD assessment in 2014/15. She considered her child's difficulties in 2014/15 did not differ from those at the time of her diagnosis in 2017. As a result of the delay in ASD diagnosis, the complainant considered that her child was disadvantaged as she missed out on intervention and support which she ought to have received at an earlier stage.

Evidence Considered

18. As part of my investigation enquiries I referred to the following guidelines and standards:
- NICE Guideline CG128
 - HSCB Regional Pathway document

Relevant extracts of these documents are reproduced at Appendix two to this report.

The Trust's response to investigation enquiries

19. As part of investigation enquiries the Trust was given the opportunity to respond to the complaint. In relation to the issues raised by the complainant, the Trust referred this Office to its correspondence with the complainant during its Complaints Process.
20. In its letter to the complainant dated 29 May 2018, the Trust confirmed that *'each member of the multi-disciplinary team contribute[d] fully to the clinical decision [made on 16 March 2015], therefore the decision... that [the child] did not meet the criteria for Autism was made by the multi-disciplinary team'*. The Trust confirmed also that *'following review of [the child's] initial assessment and the supplementary information, the outcome would not have changed given that the multidisciplinary team all agreed that [the child] had scored 0 in the ADOS assessment'*.

21. In relation to the Trust's ASD assessment process the Trust referred this Office to the record of a meeting between Trust staff and the complainant which took place on 22 January 2018. The record of this meeting states '*... the knowledge base in relation to assessing children for autism has changed considerably over time. There is greater understanding now about the complexity of assessing female children with autism.... The diagnostic process undertaken with [the child] was in keeping with practice at that time and... the assessment was undertaken in consultation with the multi-disciplinary team.*'
22. The meeting record states further, '*there have been significant changes made to the assessment approach since [the child's] initial assessment. These include completion of a more detailed developmental history with parents, clinicians seek more information if there is conflicting evidence before making a final diagnostic decision, the same clinicians are involved throughout the assessment process from observation to diagnosis.*'
23. In relation to whether the ASD assessment in 2014/15 took account of the supplementary multi-disciplinary information that was available, the meeting record states the Trust '*acknowledged that the assessment report focused on the child's strengths and did not reference the other assessment information available from other sources.*'
24. The Trust also referred this Office to its letter to the complainant dated 29 May 2018 in which it stated, '*As previously acknowledged [the child's] assessment report focused on [her] strengths and did not explicitly reference the other supplementary information which informed the overall assessment. The Trust apologises for the distress that this has caused [the complainant].*'
25. In its response to investigation enquiries, the Trust stated that, '*Learning within the [Autism] service has occurred over time based on best evidence and up to date research....*' The Trust continued, '*This has been implemented in current service delivery in that all families are offered an assessment slot of choice and at this point are allocated a keyworker [who] will follow the child through the assessment journey where possible. The assessments available and based on clinical need are the*

developmental history, a speech and language therapy assessment, school/home observation and an ADOS assessment. The multi-disciplinary team meet on a weekly basis and children/young people are discussed at this diagnostic meeting’.

26. The Trust also confirmed to this Office that *‘Further learning for the Autism Service has been identified in relation to the importance of ensuring the final assessment report explicitly reflects the multi-disciplinary supplementary assessment information. Staff within the Autism Service have been reminded to ensure that assessment reports reflect the full breadth of the assessment process’.*
27. Further enquiries were made by this Office as to whether the Trust considered a developmental history as part of the child’s ASD assessment in 2014/15. In response, the Trust confirmed that *‘both...the referral for assessment form along with the parent questionnaire completed by [the complainant]...formed the basis of the developmental history which was in keeping with practice at that time’.*
28. Overall, in relation to the child’s ASD assessment in 2014/15, the Trust confirmed that *‘The Trust consider[s] that the assessment made in March 2015 took account of available information and concluded that [the child] did not have ASD’.* The Trust concluded, *‘The Trust does not consider that there was misdiagnosis made following assessment in 2014 [/ 2015]’.*

Relevant records

29. The child’s records from the Trust’s Community Paediatric Services and Autism Services (the relevant records) were obtained and examined. The extracts which I considered to be of particular relevance to my investigation are included in Appendix three to this report.

Relevant Independent Professional Advice

30. The IPA was asked to explain the diagnostic process undertaken in 2014/15 to assess the child for ASD. The IPA advised, *‘The referral was made by [the child’s Community Paediatrician] whose letter (2014) contained details of her assessment including a history relevant to ASD features. The referral letter also contained the*

SCQ [Social Communication Questionnaire] score⁶. In the report of March 16th 2015, the SLT [Speech and Language Therapist], EP [Educational Psychologist] and school observation ADIS [Autism Diagnostic and Intervention Service] report... are referred to as available 'prior to the ASD assessment' on March 16th 2015 at which the ADOS (direct observation using a standardised assessment relevant to ASD) was carried out, scored and the diagnostic decision made. The Trust subsequently confirmed that [the complainant's parental] report was also available'.

31. The IPA continued, 'Many services do conduct the elements of ASD assessment serially rather than simultaneously and then integrate all sources of information. Thus this assessment was similar to that in many services'.
32. In relation to the child's autism assessment in 2014/15, the IPA advised, 'The multidisciplinary team involved in assessing and making a clinical judgement about diagnosis on the day of [M]arch 16th 2015 was a paediatrician and two other professionals (intervention ASD therapists, one a speech and language therapist and the other from a nursing background). This is consistent with the recommendation in the NICE guidelines (CG128 and Northern Ireland guidance).' The IPA continued, 'Assessments from other professionals had also been completed (...the observation in school by [an Autism Intervention Therapist staff member] from the ASD team and the SLT... These were all available thus meeting the recommendations in the NICE guidelines of information from other settings being available...'
33. In relation to the Trust's use of the ADOS Module 3 in the child's ASD assessment, the IPA advised 'It is recommended that systematic observations of features of ASD in the individual are made as part of all ASD assessments. The ADOS is the only instrument that has established reliability through rigorous standardisation so is the method recommended'. The IPA also advised, 'the judgment to use the ADOS 3 was appropriate [on this occasion] given the [Educational Psychologist reports] of some academic learning difficulties and [the child's] language fluency'. She further advised, 'the ADOS... [is] recommended in all guidelines NICE CG 128 and NI 6 Steps [HSCB's Regional Pathway document]'.

⁶ The Social Communication Questionnaire (SCQ) is an instrument for screening autism in individuals over the age of four with a mental age over two years. The SCQ contains 40 yes/no items, which are completed by a parent or other caregiver.

34. The IPA was asked how the child's ASD assessment in 2014/15 differed from that in 2017. In response she advised, *'It does not appear that the ADOS was used in 2017. The 2017 assessment is more comprehensive and ASD focused in its developmental history...but the presenting situation had changed. [The child] was also displaying increased impairment associated with the move to secondary school as detailed in the 2017 pre-assessment reports...'*
35. In relation to the child's ASD assessment carried out by the Trust in 2014/15, the IPA was asked whether the diagnostic process for children at that time, was adhered to. The IPA advised, *'In 2014/15 the standard used for ASD diagnostic assessment would have been the NICE guideline [CG128] ... from which the Northern Ireland standards are derived (the 6 steps of [A]utism Care...)'*. The IPA referred to the documents which were listed as available to the multi-disciplinary assessment team on 16 March 2015 (Appendix two refers). In doing so, she advised, *'Not specifically listed in the 2015 Assessment report was the Parent questionnaire primary school child completed 30/8/2014 by [the complainant] for ADIS⁷ detailing her concerns and listing particular problems under a range of developmental headings with supplementary pages of hand written comment... The latter detail a number of unusual behaviours, repetitive, routinised and sensory sensitivities. This was [subsequently] referred to by the Trust⁸ as having been used by the assessment team'*.
36. The IPA also advised, that *'the medical assessment / clinic letter dated 18 February 2014 from the [child's Community Paediatrician] describe[s] behaviour concerns about [the child]'*. The IPA advised that while this was not listed in the Assessment report, the Trust later referred to it as having been considered by the ASD assessment team.
37. The IPA advised *'the elements for diagnostic assessment described in the NICE and*

⁷ ADIS refers to the Autism Diagnostic Intervention Service within the Trust's Autism Service.

⁸ The IPA raised queries regarding whether a developmental history was considered by the multi-disciplinary assessment team on 16 March 2015. In response to further enquiries by this Office, the Trust confirmed in an email on 21 January 2020, the documents *'which formed the basis of the developmental history which was in keeping with practice at that time'*. These documents were the Community Paediatrician's letter dated 18 February 2014; Educational Psychology report dated 17 June 2013 and; Parent Questionnaire Primary School Child.

NI standards were available. The autism diagnostic team of March 16th 2015 relied upon the developmental history of [child's Community Paediatrician] and the Parent questionnaire primary school child (confirmed by the Trust to the Ombudsman)... [However they] did not carry out their own 'developmental history focused on development and behaviour concerns and based around the DSM5⁹ and ICD11¹⁰'. The IPA advised further, 'While it is desirable practice, the ASD focused developmental history does not have to be carried out at the same time as the observational assessment—and in many services, is not'. The IPA concluded, 'the assessment was conducted according to the relevant standards assuming that the unlisted parent report was available –as indicated by the Trust'.

38. The IPA was referred to the pre-clinic assessments and observations carried out as part of the overall autism assessment in 2014/15. Advice was sought from the IPA as to the appropriateness of these assessments. In response, she advised these *'were appropriate and reasonable and done in accordance with prevailing standards (NICE CG 128) ...'* In explaining this view, the IPA advised, *'...the SLT and ADIS reports systematically described features of behaviour relevant to ASD assessment as did [Community Paediatrician's] referral letter'.*
39. The IPA was asked whether the pre-clinic reports were considered by the Assessment team when the decision was made that the child did not show traits of ASD. In response, the IPA advised *'the pre-clinic reports are commented on in the assessment report (although not specifically referred to by name) and thus were taken into account. However, what is less clear, since not specifically mentioned until the Trust's response to a further Ombudsman question, is whether the reports from [the complainant] outlining her concerns including the SCQ were fully taken into account'.*
40. The IPA advised further, *'There is reference to other reports in the Assessment Process section of the Diagnostic Assessment Report which is written using the*

⁹ DSM-5 refers to the Diagnostic and Statistical Manual of Mental Disorders Fifth Edition.

¹⁰ ICD-10 refers to the International Statistical Classification of Diseases and Related Health Problems. NICE Guideline NG128 states *'the term autism describes qualitative differences and impairments in reciprocal social interaction and social communication, combined with restricted interested and rigid repetitive behaviours. Autism spectrum disorders are diagnosed in children, young people and adults if these behaviours meet the criteria defined in ICD-10 and DSM-5 and have a significant impact on function'.*

ICD10 criteria for ASD. For each statement of the ICD10 there are examples of the behaviour. In many instances eg ability to use eye contact, share enjoyment, use of language, make believe play and response to people's overtures... there is an emphasis on the ADOS findings although the pre-clinic observations are in some instances, different. The restricted repetitive interests and behaviours were not observed in the ADOS, which is not unusual, but were reported by [the complainant]'

41. On review of the Diagnostic Assessment Report, the IPA advised further, *'the extent to which [the complainant's] observations and concerns were taken into account is less clear. Although some examples ARE quoted in the report eg distress with changes in the environment and drawing repetitively, they were not considered to be examples of ASD behaviours in 2015 but were interpreted differently in 2017'*.
42. The IPA was asked to what extent an ASD assessment should take into account a parent's viewpoint. The IPA advised, *'In ASD assessment the developmental history from a reliable informant who knows the individual well is a key part of diagnostic assessment and parental concerns should always be taken seriously. However, ultimately, diagnosis is a clinical judgement after synthesis of all sources of information and diagnosis of disorder requires 'impairment' across a range of areas of function'*. The IPA pointed out in her advice, *'The Trust says that the assessment process has now changed (letter dated 22/1/18) with 'completion of a more detailed developmental history with parents and more information if there is conflicting evidence before making a diagnostic decision''*.
43. The IPA was asked to what extent autism diagnostic assessments rely on pre-clinic assessment reports when an ADOS assessment is also carried out. The IPA referred to NICE CG 128, which she explained *'states that the diagnosis of ASD is based on clinical judgement and not on any single test'*. The IPA referred further to NICE Guideline CG 128 as follows, *'1.5.10 Use information from all sources, together with clinical judgment, to diagnose autism based on ICD-10 or DSM-5 criteria; and 1.5.11 [of NICE CG 170, states] 'Do not rely on any autism specific diagnostic tool alone to diagnose autism'*.

44. In relation to the outcome of the child's ASD assessment in 2014/15, the IPA advised, *'The observational assessment such as the ADOS is just one tool contributing to diagnosis. In this assessment it appears to me that the findings of the ADOS of no ASD traits was a decisive influence on the decision that [the child] showed to [sic] traits of ASD. I conclude that greater weight was placed on a single assessment, the ADOS, than the cumulative reports from other sources, not only but including [the complainant]'*. The IPA continued, *'This view is supported by the letter of 29/5/18 from... [D]irector of Children's [S]ervices –who comments 'the outcome would not have changed given that the MDT [multi-disciplinary team] all agreed that [the child] scored 0 in the ADOS'*.
45. The IPA continued, *'While it is unusual to make a diagnosis of ASD when the ADOS has a zero score, the evidence of other sources should have suggested discrepancy and an 'inconclusive' diagnostic conclusion'*. The IPA explained, *'As was commented on by the Trust in a meeting with [the complainant], it is important in assessment to bear in mind that individuals of average ability working one to one with skilled adults can 'mask' impairments. The latter has been increasingly recognised as a characteristic of girls of average cognitive ability but was less obviously realised in 2015'*.
46. In relation to the masking of difficulties, the IPA advised, *'it takes considerable awareness and skill to detect underlying deficits if the individual is skilled at masking them. Hence the need to fully take into account information from more challenging social environments over a period of time in making a diagnostic conclusion. Masking of impairment is now more widely recognised and diagnosis in girls with ASD is much more common than it was in 2015. However... disorder diagnosis requires functional impairment to be demonstrated, not just the presence of some traits'*.
47. The IPA was referred to the information which was available to the Assessment Team on 16 March 2015. The IPA was asked whether, on the basis of this information, the Assessment team's decision that the child *'does not display traits in keeping with autism'*, was reasonable and appropriate. The IPA advised, *'The most secure ASD diagnosis is made when ICD10 criteria are met both in the ASD focused*

history and in the observation—the ADOS is the recommended assessment. If sources of information are discrepant this should be further explored’.

48. In outlining her rationale for the above advice, the IPA continued, *‘The ADOS on [M]arch 16 showed no traits of ASD...Based on the observations of school and SLT and ADIS... including [the complainant’s] Parent questionnaire for primary school children and notes, [the complainant’s] completed SCQ and her comments to [the child’s Community Paediatrician] over a period of time, there would appear to be a number of ASD traits reported consistently’.* The IPA provided detailed examples to support her view in her full IPA report at Appendix five.
49. The IPA referred to the information contained in a number of sources including the child’s Paediatric records, the ADIS report and the SCQ as well as a school report from the child’s class teacher. She advised that each of these sources provide *‘supporting evidence of traits that could be due to ASD’.*
50. The IPA also advised, *‘accepting that the 2015 ASD assessment process relied upon the previous developmental history reports and [the complainant’s] questionnaire responses, my view is that the information from other sources and the ADOS were discrepant and I would have expected the conclusion on [M]arch 16th to have been ‘inconclusive.’ This would have led to further observation and assessment....’* In reference to the HSCB Regional Pathway document the IPA continued, *‘This would have led to further ASD assessment over time [and] not immediate ASD intervention as described in 4.3i but more similar outcome to 4.3ii and 4.3iii¹¹...’*
51. In relation to reassessment in this instance, the IPA further advised, *‘This could have included a focused developmental history from [the complainant], the principal informant and/or review assessment including a second opinion...’* The IPA pointed out, *‘It is, however, important to note that the 2015 assessment report states that [the*

¹¹ HSCB Regional Pathway document: *‘4.3 ii: The diagnosis is not confirmed. The child/young person will be discharged from the AST after consideration of possible differential diagnoses. Where appropriate onward referral to other services/agencies will be made. 4.3 iii: The diagnosis may be inconclusive at this stage of the child/young person’s development. This group of children... may require a review assessment to allow for their development to mature. The time frame for repeat assessment should be agreed between professionals and families. Consideration should be given to the ongoing child... and family needs and interventions’.*

complainant] agreed with the conclusion that [the child] did not display traits of ASD’.

52. In relation to whether the child would have benefited from an ASD reassessment sooner, the IPA reiterated her advice that *‘The report of March [16] 2015 states that [the complainant] agreed with the conclusion that [the child] did not display traits of ASD. Hence, it was reasonable not to proceed to reassessment’.*
53. The IPA advised further, *‘Had [the complainant] expressed dissatisfaction with the diagnostic conclusion of ‘no traits of ASD’ at the time then the NICE guidelines 1.6¹²... should have been followed—also described in [HSCB Regional Pathway Document] [at] 4.3 [ii and iii]. The IPA advised further, ‘The outcome for [the child] would thus not have been very different from that in 4.3i and 6.0 that[sic] if a diagnosis of ASD is not confirmed, this is explained to the individual and family, differential diagnosis is considered and onward referral made to other agencies’.*
54. Following the outcome of the 2014/15 ASD assessment, the IPA advised that onward referral to other agencies was done *‘as follows: The [Lead Examiner Paediatrician], referred in the outcome assessment report to ongoing OT, SLT and school support, also follow up by [the child’s Community Paediatrician].’* The IPA advised, *‘My reading of the school reports both in primary and secondary, is that they were aware of [the child’s] difficulties (she had an education plan that was frequently updated) and thus that the intervention and support in school may not have been very different had an inconclusive diagnosis been made in 2015. School based intervention and additional supports are based on need rather than diagnosis’.*
55. The IPA also advised that the complainant *‘was well supported by the [the child’s Community Paediatrician]’ with referral to CAMHS planned for help with the child’s behaviour, blood tests were carried out, and when the child... started at secondary school and was having increasing problems, reassessment for ASD was made*

¹² NICE Guideline NG128 at 1.6 states, *‘If there is uncertainty after the autism diagnostic assessment about diagnosis, consider keeping the child or young person under review, taking into account any new information’.* 1.6.2 states, *‘If any of the following apply after assessment, consider obtaining a second opinion (including referral to a specialised tertiary autism team if necessary): continued uncertainty about the diagnosis; disagreement about the diagnosis within the autism team; disagreement with parents or carers, if appropriate the child...,about the diagnosis...’*

appropriately by the GP¹³.

56. The IPA proceeded to refer to NICE CG128 1.2.2 which recommends, *'Always take parents' or carers' concerns and, if appropriate, the child's or young person's concerns, about behaviour or development seriously, even if these are not shared by others'*. She also referred to 1.6.2 *'If any of the following apply after assessment, consider obtaining a second opinion (including referral to a specialised tertiary autism team if necessary):*

- *continued uncertainty about the diagnosis*
- *disagreement about the diagnosis within the autism team*
- *disagreement with parents or carers or, if appropriate, the child or young person, about the diagnosis'*. In doing so, the IPA concluded with emphasis,

'NB it should be noted that the ASD Assessment report of March 2015 states that: [the complainant] agreed that [the child] did not display traits in keeping with an ASD...'

57. The IPA concluded her advice by identifying a number of learning and service improvements for the Trust. These included: *'the need to check discrepant history carefully as part of ASD assessment and review if in doubt...; [ensure] that all sources of information should be used to make a diagnostic decision and that any single tool should not be relied on, and; [the need to recognise] the importance of a lifetime history on features of ASD from the main informant who knows the individual well [and] which is ideally carried out contemporaneously with the observational assessment... during which all parental (in the case of a child) [concerns] are explored'*. The IPA acknowledged that *'the Trust have indicated that this [latter] change in practice has already been made'*.

The Trust's response to Independent Professional Advice

58. As part of this investigation, the advice obtained from the IPA was shared with the Trust for its comment. In its response dated 19 March 2020 the Trust stated, *'The Trust consider[s] that in 2015, based on the evidence available to the Trust at that time, it would have been difficult to give an outcome of inconclusive given that the*

¹³ The child's referral for ASD reassessment was made by the Community Paediatrician, and not her GP.

ADOS was a score of zero by all practitioners’.

The Trust’s response to the draft report

59. The draft copy of this report was shared with the Trust for its comment. In relation to the child’s initial ASD assessment in 2014/15, the Trust said that *‘if the Trust had reached a determination of inconclusive there is no guarantee that a diagnosis of Autism would have been made. This has been recognised by the IPA’*. The Trust said further *‘as such the Trust does not consider that this constitutes a failure in care and treatment.’* The Trust also said it *‘note[s] the... finding that the child experienced the injustice of a loss of opportunity to have had a timely referral made for ASD assessment and also that the complainant experienced the injustice of upset, frustration and uncertainty’*. The Trust continued, *‘the Trust wish[es] to apologise for the upset and distress caused to the complainant and child in relation to the ASD assessment’* in 2014/15. The Trust further confirmed, that it *‘accepts the Ombudsman’s recommendations’*.

Lead Assessor Community Paediatrician’s response to the draft report

60. In relation to the child’s ADOS undertaken on 16 March 2015, the Community Paediatrician who led this assessment said the child *‘was given a score of zero by all three clinicians. As far as I am aware, there had never been any cases where this led to a full or inclusive [ASD] diagnosis, although I understand that this has happened recently’*. He continued *‘Although ADOS is a well-established system, it has a false negative of approximately 6 [per cent]’*. In relation to the delay experienced by the child in being referred for ASD reassessment, the Lead Assessor Community Paediatrician said *‘When a child I referred to the Autism Service from my community clinic in Lurgan did not receive a diagnosis, I would re-refer them if they had on-going difficulties in keeping with autism. In the initial years of the Autism Service, this could be sent immediately, although an enforced delay of one year was introduced prior to 2015’*.

Complainant’s response to the draft report

61. In response to the draft report, the complainant said *‘I am glad that the Ombudsman has made a preliminary finding that my complaint in respect of the failure of the Trust to properly assess... [the child’s] autism has been upheld’*. The complainant also

said '*I... disagree with the suggestion in the report that I agreed that the child had no autism traits, as this is completely contradictory to everything I have done in this case which was geared towards convincing educational and medical authorities that she had autism*'.

Analysis and Findings

The ASD assessment

62. I note the complainant's concerns that following the child's ASD assessment in 2014/15 the Trust concluded she did not meet the diagnostic criteria for ASD diagnosis at that time. This ASD assessment consisted of a clinic based assessment on 16 March 2015 which comprised the ADOS; a school visit and formal language assessment undertaken by a Specialist Speech and Language Therapist on 10 February 2015 and; a consultation with school staff and a school observation undertaken by an Autism Intervention Therapist on 3 October 2014.
63. In addition to the above, as part of the child's ASD assessment and referral, I note that additional information was gathered to inform the assessment. I note this information provided details and observations of the child's functioning and behaviour across different settings including at home and in school. This included: A 'Parent questionnaire primary school child' completed by the complainant on 30 August 2014 and supplemented with handwritten notes; an SCQ completed by the complainant on 18 April 2014, and a school report provided by the child's class teacher dated 27 March 2014. An Educational Psychology report dated 17 June 2013 and an Occupational Therapy Report dated 23 June 2009 were also available.
64. In addition, I note the Community Paediatrician's ASD assessment referral form dated 27 May 2014 and her letter of 18 February 2014 to the child's GP, which identify concerns regarding the child's presenting difficulties. I note the severity and duration of the child's difficulties and symptoms, and the level of parental concern are documented in further detail, in the child's paediatric records. In relation to the information that had been gathered prior to the ASD diagnostic assessment, I accept the IPA's advice that this met '*the recommendations in [1.4.7 of] the NICE guidelines of information from other settings being available*'¹⁴.

¹⁴ Nice Guideline CG128 at 1.4.7 states '*Once it has been decided to carry out an autism diagnostic*

65. In submitting her complaint to this Office, the complainant said she had *'serious concerns about the level of... assessment that [her child] received in 2014, which resulted in a misdiagnosis...'* The complainant said that the assessments and reports which were gathered as part of the assessment process and referral, *'clearly highlight ASD traits, but they do not appear to have been picked up on or properly considered in the formal diagnosis... made in March 2015'*. I note in particular, the complainant's concerns that in making the decision to exclude a diagnosis of Autism following the child's assessment in 2014/15, the Trust based this decision only on the child's performance in the ADOS Module 3 tool.
66. I note the Trust's response to the complainant's concerns dated 29 May 2018, in which *'it acknowledged that the Diagnostic Assessment report focused on [the child's] strengths and did not explicitly reference this [supplementary] information...'* I note that the Trust apologised to the complainant for the distress this had caused her. The Trust also confirmed that staff are now reminded to ensure that Assessment Diagnostic Reports explicitly reflect the supplementary information and *'the full breath of the assessment process'*.
67. I note also the Trust's position that, when making its decision that the child did not meet the criteria for ASD diagnosis, the multi-disciplinary assessment team did consider the supplementary information available and that this information had *'informed the overall assessment'*. However, the Trust also confirmed to both the complainant and this Office *'the outcome would not have changed given that the multi-disciplinary team all agreed that [the child] had scored 0 in the ADOS assessment'*.
68. I considered carefully the Trust's position on this issue, and in doing so reviewed the guidelines relevant to ASD assessment. I refer to NICE Guideline CG128 which outlines at 1.5.5 the elements that ought to be included in every autism diagnostic assessment (Appendix two refers).¹⁵ I note these elements include an observation

assessment... seek a report from the preschool or school if one has not already been made available; and gather any additional health and social care information...'

¹⁵ These elements include *'an assessment (through interaction with and observation) of social and communication skills and behaviours focusing on features with ICD-10 or DSM-5 criteria (consider using an autism specific tool)'*. In addition, pursuant to 1.5.5 every autism assessment should include *'detailed questions about parent's or carer's concerns...; details of the child's... experiences of home life, education and social care;*

assessment of social and communication skills and behaviours using an autism specific tool, such as ADOS. They include also *‘detailed questions about parent’s or carer’s concerns...; details of the child’s... experiences of home life, education and social care; a developmental history, focusing on developmental and behavioural features consistent with ICD-10 or DSM-5 criteria’*. I note that these elements which are to be included in every ASD assessment, are consistent with those outlined in the HSCB Regional Pathway Document. I note further, that none of the elements is indicated as having greater weight in an ASD assessment than others.

69. Moreover, I note that NICE Guideline CG 128 at 1.5.10 requires that assessors for ASD ought to *‘use information from all sources, together with clinical judgment, to diagnose autism based on ICD-10 or DSM-5 criteria’*. 1.5.11 states *‘Do not rely on any autism-specific diagnostic tool alone to diagnose autism’*.
70. Based on the above requirements of NICE Guideline CG128, I accept the IPA’s advice that *‘ADOS is just one tool contributing to diagnosis’* of ASD. I accept also her advice that *‘diagnosis of ASD is based on clinical judgement’* and involves the synthesis of evidence from all sources, and thus is not based *‘on any single test’*.
71. Therefore I am both concerned by and critical of the Trust’s position that despite the content of the supplementary information, *‘the outcome [of the child’s ASD assessment] would not have changed given the multi-disciplinary team all agreed that [she] had scored 0 in the ADOS assessment’*. In this regard, I accept the advice of the IPA that while *‘the elements for diagnostic assessment described in the NICE and NI standards were available... it appears... that the findings of the ADOS of no ASD traits was a decisive influence on the decision that [the child] showed no traits of ASD’*. In explaining her rationale for this view, I note the IPA examined the Diagnostic Assessment Report and the content of the supplementary information available. In doing so, the IPA identified a number of ICD-10 behaviours in the Report, for which she advised *‘there is an emphasis on the ADOS findings although the pre-clinic observations are in some instances different’*. These behaviours include: the ability to use eye contact; share enjoyment; use of language; make

a developmental history, focusing on developmental and behavioural features consistent with ICD-10 or DSM-5 criteria’.

believe play and; response to people's overtures. Having examined the supplementary information, in particular the content of the school observation report, I accept the IPA's advice in this regard.

72. Following further detailed review of the supplementary information¹⁶, I note the IPA also advised while the ADOS showed no traits of ASD, *'there would appear to be a number of ASD traits reported consistently'* in these additional information sources. In particular, I note the IPA advised that although *'restricted repetitive behaviours were not observed in the ADOS, which is not unusual... they were reported by [the complainant]'*. I note the IPA advised further that a number of additional sources of information including the school report, SCQ and the complainant's questionnaire *'provide supporting evidence of traits that could be due to ASD'*. In particular, I note the IPA advised, the SCQ completed by the complainant *'gave a score of 28 which is very high (the higher the score, the more likely ASD).'* In addition, the IPA advised the complainant's parent questionnaire *'detail[s] a number of unusual behaviours, repetitive, routinised and sensory sensitivities...'* However, these were not reflected fully in the Diagnostic Assessment Report. Having examined the available evidence, I accept the IPA's advice in this regard.

73. Pursuant to NICE Guideline CG128, I am satisfied that parental information is a critical and important component of children's ASD assessments, in particular in establishing a developmental history. This is highlighted by the IPA who advised that *'the developmental history from a reliable informant who knows the individual well is a key part of [ASD] diagnostic assessment and [thus] parental concerns should always be taken seriously'*. However, I note and accept the IPA's advice that it is unclear to what extent the assessment team on 16 March 2015, took into account the complainant's concerns when it determined the child did not meet the criteria for ASD diagnosis.

74. I am also concerned that on initial review of the evidence, the IPA was unable to discern whether a developmental history was used by the multi-disciplinary assessment team on 16 March 2015. In response to further enquiries by this Office, I

¹⁶ This information included: the observations of the child's school, SLT and ADIS therapist, the Parent Questionnaire for primary school children completed by the complainant and her accompanying notes, the complainant's SCQ and the complainant's comments to the Community Paediatrician.

note the Trust said that a developmental history was considered as part of the child's ASD assessment. The Trust identified the following documents as having been used to comprise this element of the assessment: the child's ASD assessment referral form dated 27 May 2014; the Community Paediatrician's letter dated 18 February 2014, and; the complainant's parent questionnaire primary school child dated 30 August 2014. However, I note that these documents were not listed on the Diagnostic Assessment Report as having been referred to by the multi-disciplinary assessment team on 16 March 2015.

75. Furthermore, I note the IPA examined the Diagnostic Assessment Report which explains the findings and reasons for the conclusion reached. Having done so, I am satisfied that the IPA found little reference to the child's symptoms, signs and observations which were documented in these information sources. Therefore I am not persuaded that appropriate consideration was given to these sources of information or to the importance of the developmental history as an element of the child's ASD assessment. I note the IPA concurs with this view.
76. Overall, following detailed analysis of the supplementary information, the ADOS documentation and the Diagnostic Assessment Report, I accept the IPA's advice that *'the information from other sources and the ADOS were discrepant'*. Furthermore, I note the IPA concluded *'that greater weight was placed on a single assessment, the ADOS, than the cumulative reports from other sources'*. On the basis of the available evidence including the Trust's position on this matter, I accept the IPA's advice in this regard.
77. Accordingly, I am satisfied the available evidence indicates that in making its diagnostic decision the multi-disciplinary team failed to consider appropriately the cumulative information available. Furthermore, I consider the Trust's response and the accompanying evidence indicates that the multi-disciplinary team based its diagnostic decision that the child did not have ASD on the child's zero score in the ADOS. I am satisfied that the multi-disciplinary team's approach in this regard was neither reasonable nor appropriate. In my view, this constitutes a failure in care and treatment. Therefore I uphold this element of the complaint. I acknowledge that the Trust since confirmed to this Office that learning has occurred within its Autism

Service. This includes changes to the ASD assessment process so that it now includes undertaking a focused developmental history with parents/carers using an autism specific tool. The Trust also confirmed that since its investigation of this complaint, *'clinicians seek more information if there is conflicting evidence before making a final diagnostic decision...'*

The diagnostic conclusion

78. I note the complainant's concern that her child was *'misdiagnosed'* following assessment in 2014/15. Specifically, the complainant believed the child ought to have received an ASD diagnosis. In response to this element of the complaint I note the Trust confirmed to this Office its *'position that there was no misdiagnosis following assessment in 2014[/15]'*. I note also the Lead Assessor Community Paediatrician's comments on the draft report, that at the time of undertaking the child's initial ASD assessment in 2015, *'as far as [he] was aware, there had never been cases where a zero score [in ADOS] led to a full or inclusive ASD diagnosis'*. As part of my consideration of this element of complaint, I note the IPA advised that *'the most secure ASD diagnosis is made when ICD-10 criteria are met both in the ASD focused history and in the observation' [ADOS]*. However, I note the IPA also advised, *'if sources of information are discrepant this should be furthered explored'*. In this instance, I note the IPA pointed out in her advice that she was *'not suggesting that the diagnosis should have been ASD'* on 16 March 2015. Rather, the IPA advised that it ought to have been *'inconclusive'*. I note the IPA explained further, *'while it is unusual to make a diagnosis of ASD when the ADOS has a zero score, the evidence of several other sources [of information] should have suggested discrepancy of findings and hence an 'inconclusive conclusion' ought to have been reached.*
79. I note the divergence in opinion between the IPA and the Trust on the outcome of an ASD assessment where a child has attained a zero score in ADOS Having considered the matter and in particular, the relevant NICE guidelines and NI Regional Pathway document¹⁷ I accept the advice of the IPA. As such, I consider

¹⁷ 1.6 of NICE Guidelines CG 128 which provides that *'if there is uncertainty after the autism diagnostic assessment about diagnosis, consider keeping the child under review, taking into account new information'*. In addition, 1.6.2 states, *'consider obtaining a second opinion...'* if, inter alia, there is *'continued uncertainty about the diagnosis...; disagreement with parents... about the diagnosis'*. 4.3 of the HSCB Regional Pathway

that the overall diagnostic conclusion ought to have been inconclusive or uncertain.

80. Accordingly, I do not uphold the complainant's concern that following the ASD assessment in 2014/15 she ought to have received an ASD diagnosis and thus was misdiagnosed. However, I am satisfied that the diagnostic decision of the multi-disciplinary team, that the child did not have ASD traits and that therefore ASD should be ruled out, was neither appropriate nor reasonable. In this regard, I uphold the complainant's concerns about the appropriateness of the outcome of the Trust's initial ASD assessment and the manner in which this was reached. As such, I am satisfied the Trust failed to reach an appropriate diagnostic conclusion when it determined to exclude ASD following its assessment of the child in 2014/15. In my view this constitutes a failure in care and treatment. I thereby uphold this element of the complaint.

81. Overall, I consider the multi-disciplinary assessment team failed to reach an appropriate diagnostic conclusion following the child's ASD assessment in 2014/15. Furthermore, I consider the outcome ought to have been inconclusive or uncertain. Thus, for the reasons outlined above I partly uphold issue one of this complaint. In doing so, I had due regard to the impact an autism diagnosis can have on a child and their family. This impact is emphasised in NICE Guideline CG128 which states *'when autism is diagnosed, families and carers of the child or young person themselves can experience... profound sense of relief that others agree with their observations and concerns'*. Furthermore, NICE Guideline CG128 highlights that *'Diagnosis and the assessment of needs can offer an understanding of why a child or young person is different from their peers and can open doors to support and services... and contact with other children and families with similar experiences. All these can improve the lives of the child or young person and their family'*.

Injustice

82. Accordingly, I considered the impact on both the child and the complainant of the failures I identified above. In doing so, I had regard to the complainant's concerns that, due to the Trust's failure to properly assess her child for ASD in 2014/15, the

document states: where *'the diagnosis is not confirmed, the young person will be discharged after consideration of possible differential diagnosis. Where appropriate, onward referral to other services/agencies will be made'*. 4.3 also states *'the diagnosis may be inconclusive at this stage... review may be required. The time frame for repeat assessment should be agreed between professionals and families. Consideration to the ongoing needs and interventions'*.

child missed out on intervention and support she ought to have received at an earlier stage.

83. I considered 4.3 of the HSCB Regional Pathway document and 1.6 of NICE Guideline CG128 (Appendix two refers). These sections outline the actions to be taken following the outcome of an autism diagnostic assessment. Having done so, I note the IPA's advice that had the assessment team's diagnostic conclusion been appropriately inconclusive, *'the outcome for the child would not have been very different'* than when ASD was not confirmed. In this regard, I accept the IPA's advice that the outcome in both cases would have included *'onward referral made to other agencies'*.
84. I note the IPA advised that in the child's case, in her view, onward referral to other agencies was done. I accept the IPA's advice that the child was followed up by the Community Paediatrician and the Diagnostic Assessment Report referred to ongoing monitoring by School, the Special Needs Co-ordinator and Educational Psychologist. Having examined the child's paediatric records I note the child was also referred to CAMHS for planned help with her behaviour, and for blood investigations including assessment for array-CGH¹⁸. I therefore accept the advice of the IPA that, following the child's ASD assessment in 2014/15, onward referral to other services and agencies was undertaken. In relation to school support in particular, I note the IPA advised that *'school based intervention and additional supports are based on need rather than diagnosis'* and *'thus the intervention may not have been very different had an inconclusive diagnosis been made in 2015'*. I accept the IPA's advice in this regard.
85. However, notwithstanding that referral to other services or agencies had been made, I refer again to both 4.3 of the HSCB Regional Pathway document and 1.6.2 of NICE Guideline CG128. I note they provide that reassessment ought to be considered where there is uncertainty about the diagnosis or where it is inconclusive. As previously discussed, I consider the multi-disciplinary assessment team failed to reach an appropriate diagnostic conclusion following the child's ASD assessment in

¹⁸ Array-CGH is a laboratory genetic test used to detect a chromosome change. It is presently used in clinical practice for diagnosis of ASD, patients with intellectual disability and multiple congenital anomalies.

2014/15. Furthermore, I consider the outcome ought to have been inconclusive or uncertain. Thus in my view, these failures resulted in a delay in referring the child for ASD reassessment.

86. I note the Lead Assessor Community Paediatrician's comments in relation to referring children for ASD reassessment who did not receive an ASD diagnosis but who had on-going difficulties in keeping with autism. He said that *'in the initial years of the Autism Service'* these referrals *'could be sent immediately'*, however there was *'an enforced delay of one year... introduced prior to 2015'*. Whilst I note this comment from the Lead Assessor Community Paediatrician and whilst I accept the advice of the IPA that reassessment may not have been immediate, I had regard to the length of time taken before the child's referral for reassessment was eventually made. Having examined the child's paediatric records for the period following the conclusion of her ASD assessment in 2014/15 I consider it evident the complainant and the child's school continued to have concerns regarding the child's behaviour and symptoms. I note the complainant raised her concerns with the Community Paediatrician who referred the child for reassessment in December 2016. I note this was nearly 22 months after the conclusion of her ASD assessment on 16 March 2015. I consider this to be a protracted period of time during which the complainant remained concerned and uncertain as to the reasons for her child's behaviour. I acknowledge that this would have caused the complainant considerable upset and frustration.

87. Having taken into account the one year delay in making re-referrals in 2014/15 as submitted by the Lead Assessor Community Paediatrician, in my view, on the balance of probability, I consider a referral for reassessment would likely have been made sooner had the diagnostic outcome on 16 March 2015 been inconclusive. While I am unable to conclude with certainty that a more timely reassessment would have resulted in an ASD diagnosis, I had due regard to the advice of the IPA. I note the IPA explained that referral for reassessment at this point, *'could have included a focused developmental history from [the complainant], the principal informant including a second opinion'* from an autism diagnostic multi-disciplinary team. In my view, this would have proved valuable to the complainant in terms of explaining her concerns and the child's behaviours, leading to a more detailed and targeted

developmental history to inform the overall ASD assessment.

88. I note that in commenting on the draft report the Trust said that had it reached a determination of inconclusive following the child's ASD assessment in 2014/15 and a referral for reassessment was made sooner, *'there is no guarantee that a diagnosis of Autism would have been made'*. As discussed in paragraph 88 above, I acknowledge that there is no certainty as to whether the child would have obtained an ASD diagnosis following an earlier reassessment. However, as previously discussed, I am satisfied that the supplementary information documented the child's reported and observed symptoms which the IPA advised indicated ASD traits. I accept also the IPA's advice that while masking of impairments amongst girls during ASD assessment was less obviously realised in 2015, this became increasingly recognised thereafter, as did under-diagnosis of ASD in female children. Thus on the basis of these preceding points, in my view I consider it likely on balance, that had the child received an ASD reassessment sooner she would have obtained an earlier ASD diagnosis. In my view this could have led to earlier provision of more targeted and appropriate intervention and support from the Autism Service.
89. I note the advice of the IPA that the Diagnostic Assessment Report documents that the complainant agreed with the outcome of the ASD assessment on the 16 March 2015. Thus the IPA advised it was reasonable that the child was not considered for referral for reassessment at this point. In commenting on the draft report, I note the complainant said she did not agree with the *'suggestion in the report that I agreed'* with outcome of the ASD assessment on 16 March 2015. On review of the Autism Diagnostic Report dated 16 March 2015, I note the conclusion states the child ***'does not display traits in keeping with Autism Spectrum Disorder and we have discussed this with her mother, who is in agreement'***. However, I do not doubt that the outcome of the ASD assessment on 16 March 2015, that the child had no autism traits, was neither concordant with the complainant's firm beliefs and experience nor consistent with the information she had provided to the assessment team on that day. I further acknowledge the complainant's comment on the draft report, that *'this is completely contradictory to everything [she] has done... which was geared towards convincing educational and medical authorities that [the child] had autism'*. I do note however, that in submitting her complaint to this Office the complainant acknowledged that *'the assessment was unchallenged at the time'*.

90. I acknowledge that the complainant said she did not challenge the diagnostic decision on the day of the ASD assessment outcome. However, I also acknowledge the difficulties in such circumstances in expressly disagreeing with and challenging expert professional opinion. Notwithstanding, I consider it evident that the complainant's concerns regarding the child's behaviours and difficulties were reported extensively in the supplementary information available which was gathered to inform the ASD assessment. I note further that the IPA was satisfied that this supplementary information, in particular the concerns raised by the complainant, indicated ASD features. I note that the IPA advised further that these ASD features were reported consistently in the supplementary information which was gathered across different settings over a period of time. Thus, I do not consider the complainant's failure to disagree with the assessment outcome on 16 March 2015 to be pertinent. This is because I am satisfied that the multi-disciplinary assessment team were required to reach an appropriate and reasonable outcome on the basis of all the cumulative evidence available.

91. Thus as a consequence of the failures identified above, I consider that the child experienced the injustice of a loss of opportunity to have had a timely referral made for ASD reassessment. I consider this in turn led to a loss of opportunity to receive an earlier ASD diagnosis and to avail of appropriate intervention and support sooner. As a further consequence of these failures, I consider the complainant experienced the injustice of upset, frustration and uncertainty as to the reason for her child's presenting difficulties and having the continued need to raise her concerns with the Community Paediatrician.

Issue two: Whether the care and treatment of the child following her autism diagnosis in 2017 was reasonable and appropriate.

Detail of Complaint

92. In submitting her complaint to this Office the complainant raised concerns regarding the care and treatment the child received following her ASD diagnosis in June 2017. The complainant said '*the level of care*' the child has received from Autism Services, '*has been inadequate and inappropriate to her serious condition*'.

93. Specifically, the complainant said she requested a referral to Children with Disability Service shortly after the child obtained her ASD diagnosis. However, *'there was considerable delay in providing this'*. In addition, the complainant said she requested assistance for the child from a mental health professional, but was advised she would only be eligible for *'behavioural therapy'*. The complainant also said, that at the time of the child's diagnosis *'we were in crisis...with [her] behaviour and her difficulties at school'*. As a result, the complainant said that she requested assistance from the Trust, *'including autism specific classes, resources for home schooling and family support'*, however *'nothing was provided in this regard'*.

Evidence Considered

94. As part of my investigation enquiries I referred to the following guidelines and standards:

- NICE Guideline CG170
- HSCB Regional Pathway document

95. Relevant extracts of these documents are reproduced at Appendix two to this report.

The Trust's response to investigation enquiries

96. As part of investigation enquiries the Trust was given the opportunity to respond to this complaint. Enquiries were made of the Trust as to the type and frequency of family / child intervention and support it provides when a child obtains an ASD diagnosis. In response, the Trust said *'The Trust provides assessment, diagnosis, therapeutic intervention and support for children, young people and adults. This is provided through a range of services based on assessed need. The intervention may change over time dependent on presenting need'*.

97. In relation to the intervention offered to the child following her diagnosis, the Trust said she *'was offered multi-disciplinary programmes, group intervention and one to one intervention as required'*. The Trust continued, *'[the child's] intervention programme was based on her presenting need, with regular review and intervention tailored to her specific needs'*. The Trust said *'on 17 August 2017 an assessment of need was completed by an Autism Intervention Therapist and plan of care agreed in*

partnership with parents'. The Trust continued, *'the assessment [of need] is an ongoing process based on presenting need and is reviewed and updated at each appointment*'.

98. The Trust referred this Office to its Autism Services Internal Operational Guidelines, December 2018 and the Pyramid of Intervention provided therein (Appendix six refers). The Trust said that whilst the Pyramid of Intervention was not in operation until December 2018¹⁹, [the child] *'was in receipt of services which would sit within levels 1 and 4*²⁰. *The intervention provided by the Autism Service is fluid and service users often receive services across the levels.*'
99. The Trust referred to the complainant's concern that she had requested mental health assistance for the child in June 2017 but was later told the child *'was only eligible for behaviour therapy*'. In response, the Trust said that Autism Services undertook a mental health assessment of the child on 26 June 2017 in response to the complainant's concerns regarding the child's mental health. The Trust said that following this assessment, *'it was agreed that [the child] should continue to receive intervention through the Autism Service*'.
100. In relation to the delay in referring the child to the Children with Disability Service, the Trust confirmed that this referral was made on 15 June 2018 for family support *'in response to [the complainant's] expressed need*'. The Trust said *'the referral was accepted for social work assessment on 2 July 2018. [The complainant] was informed of this and advised that the referral was on a waiting list pending allocation to a social worker*'. The Trust continued, *'On 11 September 2018 the referral was allocated to a social worker and a home visit was undertaken on 24 September 2018. The social worker identified support needs and it was agreed that 4 hours of Self Directed Support per week would be provided to help [the complainant] with her caring role and to encourage [the child] to engage in social opportunities in her local community*'. The Trust also confirmed *'the case remains open to the Children with Disability Service*'.

¹⁹ The Trust confirmed to this Office that it *'did not have Operational Guidance in place in 2014/15 or 2017. At this stage the Trust was operating to regional guidance*'.

²⁰ In reference to Level 5 on the Pyramid of Intervention, the Trust stated *'Level 5 (psychological services) has been operational since April 2019, when Autism Services restructured the service to meet the growing needs of children and young people known to the service*'.

101. The Trust confirmed that the child was referred to CAMHS on 15 June 2018 and a joint consultation with CAMHS and Autism Services was undertaken on 10 July 2018. In relation to the complainant's concern that she had requested school support, the Trust said *'The Autism Service does not have a specific role in relation to school matters. This intervention is accessed through the Autism Intervention Service (AAIS) under the Education Authority... The complainant frequently referred to the need for support within school and was advised by the Autism Service to contact AAIS...'*
102. In relation to the child's Intervention Care Plan, the Trust said *'the care plan was reviewed following each intervention' and 'is not outlined in a single document'*. In relation to the provision of an Autism Intervention Therapist, the Trust said the child *'received support'* from three therapists following her diagnosis up until October 2018. The Trust confirmed that an Autism Intervention Therapist was not available to the child during the summer 2018, *'however [the child] continued to avail of services'* during this time.
103. The Trust explained the role of an Autism Intervention Therapist as *'work[ing] as part of a multi-disciplinary team, assessing and diagnosing people with ASD, as well as providing autism-specific intervention and support to the person with ASD and their family following diagnosis.'* The Trust continued, *'In addition, the Autism Intervention Therapist has a role in the development and delivery of autism training programmes for families, professionals and other agencies, to help them understand autism and develop management strategies tailored to the individual...'*
104. In relation to this issue of complaint overall, the Trust said that *'prior to a confirmation of a diagnosis'* a practitioner in the Autism Service had *'agreed to provide support to [the child] as she had been out of school and acknowledged that support was necessary at this time and a total of [sic] reviews were provided'*. The Trust also said that following diagnosis on 14 June 2017, *'a referral was made for intervention which commenced immediately on 16 June 2017'*. The Trust continued, *'Intervention within the Autism Service commences within 13 weeks and we do not usually provide pre diagnostic intervention as this will only occur based on specific need'*.

Relevant Records

105. The child's records from Autism Services, Paediatrics and CAMHS were obtained from the Trust and were examined. The extracts I considered to be particularly relevant to my investigation are included at Appendix three to this report.

Relevant Independent Professional Advice

106. The IPA was asked whether she considered the care and treatment offered to the child following her ASD diagnosis, was reasonable and appropriate. In response, the IPA advised, *'the intervention following diagnosis was both prompt and appropriate in providing support to [the child] and her mother'*. She advised, this intervention was provided *'in a number of ways, individual and group intervention, assessment of health risk, repeat assessment to assess progress and appropriate subsequent CAMHS referral.'* The IPA continued, *'Three autism intervention therapists were involved with [the child's] care over a 2017-18 period of time. The post diagnostic service was in line with the Trust autism services Internal operational guidelines'*.

107. The IPA was asked whether, in her opinion, the child's post diagnostic support and intervention was based on and tailored to her presenting need. The IPA advised, *'[the child's] needs were fully assessed and intervention and support provided by ASD Services was appropriate and competent'*. In support of her advice, the IPA explained, *'Review showed [the child's] progress in mood. Initial support through individual and group work was based on an understanding of ASD and how it affects behaviour and that this would have supported [the complainant] in managing [the child's] behaviour and resulted in getting back to school and reduction in behaviour problems and mood. This appears to have happened'*.

108. The IPA continued, *'Additional appointments... with dietetics for her eating problem, genetics and CAMHS ASD (Face risk) to assess mental health concerns were all timely and appropriate.'* The IPA advised further, *'Opportunities for [the child] to extend her social interaction were in place. When by June 2018 it became clear that [the child] was showing increased anxiety, self-injury and aggression (forcing steering wheel when Mum driving) and high arousal levels, appropriate referral was made to CAMHS and...Children with Disability [Service]'*. The IPA

concluded, *'the interventions and care post diagnosis were based on need [and] were appropriate and timely'*.

109. The IPA was asked whether she considered the child presented with an evidenced mental health need which required CAMHS referral in June 2017 upon receipt of her ASD diagnosis. The IPA advised, *'[The child] was known to have had challenging behaviour at home over a long period. By June 2017 she was also school refusing. It is common for secondary school to be a precipitant for increased difficulties for an individual with ASD as the expectations for managing social, academic and adaptive function exceed capacity and result in stress. Increased emotional and behaviour problems are common. In June 2017, [the complainant] queried mental health problems and the FACE risk assessment was carried out by CAMH-ASD. This assessment appears timely, properly conducted and reasonable in its assessment of [the child]'s mental health and conclusion.'*

110. The IPA was referred to the Trust's decision that, following mental health assessment of the child on 26 June 2017, she should continue to receive intervention through the Autism Service. Enquiries were made of the IPA as to whether this decision was reasonable and appropriate. In response, the IPA advised, on the basis of the Face Risk assessment carried out on 26 June 2018, *'I consider the conclusion reached about [the child's] immediate presentation and her mother's query about psychosis to have been adequately assessed and that it was reasonable for the Autism team to continue intervention at this time.'* The IPA advised further, *'Understanding [the child's] behaviour through an understanding of ASD was reasonable management and seeking to modify her behaviour through ASD strategies was appropriate'*. The IPA pointed out in her advice, that *'the Face risk profile was updated with comment on 4/7/17 of no emotional or mental health concerns at this time...'*

111. It was pointed out to the IPA that the child was referred to CAMHS on 15 June 2018 and was initially assessed on 10 July 2018. The IPA was asked whether, based on the records available, this referral was appropriate and timely. The IPA advised, *Yes, [the child's] anxiety was judged by June 2018 to have worsened, she was showing evidence of heightened stress and potentially dangerous behaviour (forcing the steering wheel when her mother was driving) hence the referral to*

CAMH[S] was appropriate and timely. The response by CAMHS and gap between referral and initial assessment was impressively short.

112. The IPA was referred to the complainant's concern that she had requested a referral to see a Mental Health professional but was refused. She advised, *'the request I think [was] the concern [the complainant] expressed (documented in the Face Risk notes) about possible psychosis'. The IPA advised further, 'that [this] resulted in the Face-risk assessment which was an appropriate and competent health review. This response to [the] concern was timely and appropriate.'*
113. The IPA was asked whether the child's referral to the Children's Disability Service on 15 June 2018, was appropriate. In response, the IPA advised, *'[The complainant] had described long standing difficulties in coping with [the child] because of her behaviour at home. The referral [letter] states 'what support is available to her and [the child] because of [the child]'s behaviour and her mother's stress in coping with it'. This referral was appropriate.'*
114. In relation to the timeliness of the child's referral to Children's Disability Service, the IPA was asked whether the child ought to have been referred to this service sooner. In response, the IPA advised that *'it was reasonable that referral to the Children's [with] Disability Team was made when it was clear that the complainant needed more support than was being provided by the ADIS team and [when she] required referral to additional services.'*
115. It was pointed out to the IPA that that the child did not have an allocated Autism Intervention Therapist during the summer 2018. The IPA was asked whether the absence of an Autism Intervention Therapist during this time, could have caused the child any significant detriment or impact. In response, the IPA referred to the records of support offered to the child from May 2018 onwards. She advised, *'In May and June there were AIT visits. In 26/6 [there was] a DNA appt and 3/7 [there was] a telephone appointment. On 16/7, 23/7, 25/7 and 27/7 and 21/8 [the child] attended group sessions. These followed assessment with CAMHS and planned intervention and the [Children's with Disability Service] referral. Thus appropriate measures had been put in place for what was a stressful period of time. [The child] was attending groups through[out]. I do not think that the absence of the AIT therapist was*

significantly detrimental to [the child] (however [the complainant] remained stressed)'.

116. In relation to the support provided to the child in June 2018 and July 2018, when her Autism Intervention Therapist was absent, the IPA advised, *'[the child] was offered support through group activities... this support was reasonable pending CAMHS intervention'.*

117. The IPA was asked whether, in her opinion, the care and support the child received since her ASD diagnosis, was as the complainant described *'inadequate and inappropriate'*. In response the IPA advised, *'No'*. The IPA was also asked whether the care and treatment provided to the child following her ASD diagnosis, was reasonable, appropriate and in line with relevant guidelines or standards. The IPA advised, *'yes'*.

118. The IPA was asked what support the complainant received from Autism Service from when the child obtained her diagnosis in June 2017 until 30 July 2018. The IPA was also asked whether this support was reasonable, appropriate and in line with relevant guidelines. In response, the IPA advised *'NICE Guideline CG170 and the Northern Ireland [HSCB Regional Pathway document] describe the support and intervention management that should be offered following diagnosis. The child and [the complainant] were offered: A named person to follow up individuals (and families) at intervals needed for them – up to once per 2 weeks (who under some circumstances made contact prior to [ASD] assessment); Individual intervention with the individual; Group interventions for [the child]; Support groups for [the complainant]; Specialist services such as child health, genetics, dietician; Liaison with school and; Liaison and referral as needed to CAMHS and Children's Disability Services'.*

119. The IPA advised further, *'In my opinion, [the complainant] and [the child] were offered skilled and timely ASD specific support both before the 2017 ASD diagnosis [and after]. This did support both [the child] and [the complainant] and resulted in improvements that were documented although her behaviour remained challenging, and [the child] recommenced school attendance.'* She concluded her advice stating *'Yes support offered was reasonable and in line with relevant guidelines'.*

Trust's response to IPA Advice

120. The Trust was invited to comment on the advice obtained from the IPA in relation to the child's post diagnostic care and treatment. In response to the timing of the child's referral to Children with Disability Service, the Trust stated, *'the Trust can advise that during 2015 [the child] did not meet criteria for this service'*.

The Trust's response to the draft report

121. In commenting on the draft report, the Trust said it *'welcome[s] the Ombudsman's view that the Trust did not fail in the care and treatment provided to the child in 2017/18 and that the post diagnostic care and treatment was reasonable and within relevant guidelines.'* The Trust continued, *'The Trust welcome[s] the IPA's view that skilled and timely intervention was provided pre and post diagnosis of the child'*. In relation to the learning and service improvements made as a result of the complaint, the Trust said it *'wishes to highlight that some service improvements were made prior to receipt of this complaint. For example, the developmental history was completed within the Autism assessment prior to 2015. However in 2016, an Autism specific tool was introduced to gather this information'*. The Trust also said *'The Autism Service wish to provide assurance to the Ombudsman of their continued commitment to the delivery of a high quality service to support children with an ASD diagnosis and their families'*.

Complainant's response to the draft report

122. In response to the draft report, the complainant reiterated her concerns that she had requested a mental health specialist to see the child *'immediately after diagnosis'*. She also said she *'subsequently sent written request [sic] for the child to be seen by mental health services but no significant action was taken by the Trust in this regard'*. The complainant said she made *'numerous and repeated requests for mental health treatment from the Trust which were refused and/or ignored'*. In relation to the care and treatment provided to the child following her ASD diagnosis, the complainant said *'There was a lack of support provided to the family... No point of contact was provided in relation to an emergency situation and no proper advice or assistance was provided to me about how I should handle the child's behaviour. Especially given she was a teenager at that stage'*. In relation to the Trust's position that the

child did not meet the criteria for an earlier referral to the Children with Disability Team, the complainant said *'I completely disagree with this as there was no significant change in her circumstances which would have led to the support of the Children's Disability Team being finally provided...'* In relation to the type of intervention the child received during 2017/18 the complainant reiterated her concern that this was *'therapy'* and said it was *'inexcusable'*. The complainant also said the child experienced on-going difficulties following her ASD diagnosis and that *'the lack of proper care and treatment of her condition following... diagnosis is directly responsible for these difficulties'*. The complainant also said that *'no appropriate support and assistance was provided to the school until around 2018'*. The complainant concluded her comments on the draft report by asking *'if [her] complainants could be upheld in their entirety'*. In support of her response to the draft report, the complainant provided copies of several letters, including a letter from the child's school and the AAIS dated 16 December 2020.

Analysis and Findings

Request for mental health assistance

123. I note the complainant's concerns that she requested mental health assistance for her child in June 2017 following receipt of the child's ASD diagnosis but she was refused this. The complainant said that instead, her child was *'told that she was only eligible for behavioural therapy'*. The complainant reiterated these concerns in her response to the draft report. In response to this element of the complaint, I note the Trust said that it had carried out a FACE Risk profile assessment for the child on 26 June 2017. The Trust confirmed that following this FACE risk profile it was agreed that the child should continue to receive intervention through the Autism Service.
124. Having examined the FACE Risk profile assessment I note it documents that the complainant *'requested a mental health assessment from the team as she had concerns'*. Under the section entitled *'concerns expressed by others'* I note the assessment documents that the complainant reported concerns about the child's mental health and *'queried if [the child] was psychotic'*. I note the assessment, which was carried out by ASD-CAMHS²¹, documents the child as having no emotional or

²¹ ASD-CAMHS Connect sits within the Trust's Autism Service. It works with young people aged 12 to 18 years and provides support including one to one engagement for young people who are not yet ready to engage in

mental health risk factors in respect of each assessed item and domain. I note further, a record on the assessment which documents the outcome as *'Plan to discharge [the child] and only to complete mental health assessment on request. [Child] to continue 1:1 work with [AIT]'*.

125. The relevant records indicate that the complainant and child attended a review appointment on 4 July 2017 at which the outcome of the FACE risk profile was discussed. I note the record of this review meeting documents *'no emotional or mental health concerns at this time'*. The record further documents, that both the child and complainant were *'advised... that [AIT] will continue with 1:1 intervention. [Complainant] happy with same'*. In submitting her response to the draft report and in reference to the decision to continue with one to one intervention, I note the complainant said this *'therapy' was 'inexcusable'*. Having examined the available records I found no evidence to indicate that the complainant expressed dissatisfaction or disagreement with this decision to continue with one to one intervention as the child's plan of care. I also found no evidence to indicate that the complainant, on being notified of this plan of care, continued to consider that further mental health assistance was required. In submitting her comments on the draft report, the complainant said she *'sent several written requests for the child to be seen by mental health services but no significant action was taken by the Trust' and that these requests 'were refused and/or ignored'*. Having carefully reviewed the available evidence I found no record of written requests having been made to the Trust for mental health assistance for the child or any evidence to indicate that such requests were repeatedly made and were refused or ignored.

126. I note the complainant's concerns that her child was offered *'only... behavioural therapy'* on receipt of her ASD diagnosis, when she felt the child required assistance from a mental health professional. I consider it important that the first-hand account of family member's experiences is given weight and it is integral that family concerns are listened and responded to. On review of the available evidence I note that following the child's ASD diagnosis, the complainant had requested mental health assistance for the child due to her concern that the child may have psychosis. Thus a FACE Risk profile was carried out in response to this concern. The outcome of this

group programmes.

assessment indicated that *'current symptoms are behavioural and not related to auditory or visual hallucinations'* and I note the complainant was informed of this at a meeting with the Autism Service Co-ordinator on 4 July 2017.

127. I accept the advice of the IPA that the FACE risk assessment was *'timely, properly conducted and reasonable in its assessment of the [the child's] mental health and [in its] conclusion'*. Furthermore, following detailed analysis of the child's records and in particular, the FACE Risk profile assessment, I accept the IPA's advice that *'it was reasonable to continue with [Autism Service] intervention at this time'*. In explaining her view, I accept the IPA's advice that *'understanding [the child's] behaviour through an understanding of ASD was reasonable management and seeking to monitor her behaviour through ASD strategies was appropriate'*. I do not therefore uphold this element of the complaint.

Timeliness of CAMHS referral

128. The available records indicate the child was referred to CAMHS by her AIT on 15 June 2018. I note from the available records this referral was made following a telephone call appointment between the complainant and the AIT on the same date. The record of this appointment documents that the child was experiencing escalation in anxiety presentation, and resistance to engage in intervention due to heightened distress. I note the child attended CAMHS for initial assessment on 10 July 2018. I examined the letter dated 19 July 2018, to the referring AIT from the CAMHS Practitioner who assessed the child. The letter documents a treatment plan for the child which includes *'the offer of a professional consultation as a starting point in planning appropriate services for her'*. (I note the complainant expressed dissatisfaction with the treatment subsequently offered by CAHMS and the timeliness of later accessing a mental health professional. However, these issues are beyond the time frame and scope of this investigation.)

129. In relation to the timeliness of the child's referral to CAMHS I note the IPA advised that the child's *'anxiety was judged by June 2018 to have worsened'* and *'she was showing evidence of heightened stress and potentially dangerous behaviour'*. Thus the IPA advised, the child's referral to CAMHS in June 2018 was both *'appropriate*

and timely'. I note further, the IPA advised that the timeliness of initial assessment following referral to CAMHS '*was impressively short*'. I accept the IPA's advice in this regard. Therefore I do not uphold this element of the complaint.

The availability of an AIT during July 2018

130. I note the complainant's concerns that her child '*was left without a[n] [Autism Intervention] therapist or any form of support*' during summer 2018²². The complainant said '*this has thrown [the child] out of her routine and she is struggling to reengage with services as a result*'. I note the Trust's response to this element of the complaint in which it confirmed that the child's AIT was not available during the summer 2018, '*however [the child] continued to avail of services*'.
131. Having examined the available records I note the child received one hour of one to one intervention with her AIT on 1 June 2018 and further AIT intervention via a telephone call on 15 June 2018. I note also the child attended group sessions including Drama Group, Creative Therapy and Social Group during July 2018. I note and accept the IPA's advice that she did '*not think the absence of the AIT [during the summer 2018] was significantly detrimental*' to the child. In explaining this view, I note the IPA advised that the child had received AIT visits in May and June [2018], while on 16 July, 23 July and 27 July [2018], the child attended group intervention sessions. I therefore accept the advice of the IPA that, while the child did not have access to an AIT, she '*was offered support through group activities*' during this time and '*was attending groups through[out]*'. Thus, while I consider it would have been better if the child had access to an AIT during July 2018, I found no evidence to indicate that she was '*left without... any form of support*'. I accept the IPA's advice that '*appropriate measures had been put in place*' for the child during the period when no AIT was made available to her. I accept the IPA's further advice, that '*this support was reasonable pending CAMHS intervention*'. Therefore, I do not uphold this element of the complaint.

Timeliness of referral to the Children with Disability Service

132. I note the complainant's concern that, shortly after her child's ASD diagnosis, she

²² Although the complainant referred to July and August 2018, the scope of the investigation of issue two of this complaint is confined to the period from the child's ASD diagnose on 14 June 2017 until 30 July 2018.

had *'made enquiries in respect of a referral'* to the Children with Disability Service. The complainant said a referral did not occur at this time and *'there was considerable delay in providing this'*.

133. In response to this element of the complaint, I note the Trust confirmed to this Office that the child did not meet the criteria for referral to the Children with Disability Service before the referral was made on 15 June 2018. In addition, I note the Trust said that *'families can also self-refer to the Children with Disability Service'*. In commenting on the draft report, I note the complainant said she *'completely disagreed'* with the Trust's position that the child did not meet the criteria for the Children with Disability Service. On examination of the relevant records I note the complainant was advised by the AIT on 1 June 2018 on how to make a self-referral to this service. The records document that the complainant was provided with the telephone number for doing so. I note the available records further indicate that the complainant did not subsequently self-refer to this Service and later asked that the AIT do this on her behalf.

134. On review of the records I note a referral to the Children with Disability Service was made by the child's AIT on 15 June 2018. I note the reason for the referral is documented on the UNOCINI referral form as *'the child's behaviour and her mother's stress in coping with this'*. I note the UNOCINI referral form documents the child's *'struggles with social and emotional aspects of the environment'*, the challenges posed by her sensory difficulties and *'in managing appropriate responses'*. I note the complainant's comments on the draft report that *'there was no significant change in [the child's] circumstances which would have led to the support of the Children with Disability Service being provided'*. However, the UNOCINI referral form also documents the child's increased aggression, escalation in anxiety and inability *'to regulate timely'*, particularly when at home. It further documents that the *'complainant is very stressed over the same and has asked for a referral to be made to consider supports that may be available to her and [the child]'*.

135. As part of my consideration of this element of the complaint, I referred to the

HSCB's Children with Disability Social Work Service Criteria²³ which the Trust provided in support of its position. I note in particular, 'The Hardiker Threshold of Needs Model'²⁴ (Appendix seven refers). Pursuant to the Threshold of Needs Model, I note that referral to the Children with Disabilities Service is a Level 3 provision and is for children with multiple and complex needs. At this level I note *'there is substantial risk to the parent/carer's ability to sustain some aspects of their caring role and parents can only meet their child's essential needs to the detriment of their own physical or mental health, or those of other children within the family'*. Furthermore, the criteria for Level 3 state *'The majority of social support systems and relationships are, or could be, at risk without support/intervention. The impact of the child/young person's disability significantly restricts siblings' personal or social life and parental ability to meet all the significant needs of the siblings.'*

136. In relation to the timeliness of the child's referral, I note it was the IPA's considered view that the referral to the Children with Disability Service in June 2018 *'was appropriate for the higher level of need'* [Level 3]. I note that in support of her view, the IPA advised, that in June 2018 *'it was clear that the complainant needed more support than was being provided by the ADIS team... and required referral to additional services'*. Therefore the IPA advised that at this point in June 2018 *'it was reasonable that the referral to the Children with Disability Service was made'*. I accept the IPA's advice in this regard.

137. I note the complainant's concern that she made enquiries about a referral to the Children with Disability Service shortly after the child's ASD diagnosis. Having examined the relevant records I found no evidence to indicate the complainant made such a request for referral to be made by the Autism Service at that time. Notwithstanding, in considering whether the referral should have been made at the time of the child's ASD diagnosis or at any time prior to the 15 June 2018, I had regard to the IPA's advice. In doing so, I accept the IPA's advice that the support and intervention provided in 2017/18 prior to the referral having been made was

²³ Although this criteria document post-dates this complaint, its model of needs which is used by the Trust's Children's with Disability Service to support practice, does not. The Hardiker Threshold of Needs model forms the basis of work within the Northern Ireland Family Support model and the Northern Ireland Threshold of Needs model which both predate the complaint.

²⁴ The Hardiker Threshold of Needs Model (1991) is based upon the work of Pauline Hardiker. The model outlines four levels of intervention and is used widely as a planning framework in both the UK and Ireland.

'appropriate' to the child's presenting needs at that time.

138. However, I note the IPA advised that the child's difficulties escalated in June 2018 and thus this *'resulted in CAMHS referral'*. She explained that in June 2018 *'not only had the child had difficulty accessing education and attending school and engaging with ASD services but was not managing her own stress and anxiety arousal levels'*. In addition, I note the IPA advised that at this point, the child *'was self harming and aggressive to her mother resulting in increased stress'* for the complainant. I accept the IPA's advice in this regard. I therefore consider the timeliness of the referral to Children with Disability Service in June 2018 to be appropriate and reasonable. As such, I do not uphold this element of the complaint.

Autism classes and family support

139. I note the complainant's concern that she requested *'autism specific classes, resources for home schooling and family support'*, however *'nothing was provided in this regard'*. However, on examination of the available records I note that on 1 August 2017 the child and complainant were invited to attend three days of core multi-disciplinary workshops to learn about Autism and its impact on the child and her family. These included 'Understanding ASD, a Parent and Young Person' session, and two workshops for the child including sessions on 'Sensory Processing' and 'Anxiety and Emotional Wellbeing'. The available records also indicate that the complainant attended a Focus on ASD parent workshop on 23 June 2017. I note these were information and support sessions to enhance parental knowledge of ASD and of ASD specific strategies to help parents to support their child's development. I am therefore satisfied that the complainant and child were offered ASD Information Sessions' in line with the provisions outlined on page 24 of the HSCB Regional Pathway document²⁵. I am further satisfied that this support was in line with NICE Guideline CG170. I note the IPA concurs with this view.

140. On examination of the Autism case records I also note that prior to and following her ASD diagnosis in June 2017, the child and her family were allocated an AIT for

²⁵ Page 24 of the HSCB Regional Pathway document outlines 'interventions that individuals and their families will be offered' following an ASD diagnosis. These include 'ASD Information Sessions', Family Support, and Specific or targeted interventions'.

family support. I accept the advice of the IPA that this was in line with NICE Guideline CG170. I note that in commenting on the draft report, the complainant said *she had received 'no emergency contact and no proper advice or assistance... ,about how I should handle the child's behaviour'*. However, I am satisfied that the Trust confirmed to this Office that the AIT was the family's 'named contact' person whose role remained a central point of contact. The available evidence indicates that the AIT provided regular support to the complainant, at in-clinic and at home appointments and via the telephone. I note this support included provision of advice and information on strategies to employ to help promote positive change in the child's behaviour. I discuss the AIT support further later in this report. In addition, when the complainant was documented in June 2018 as being distressed by the escalation in the child's behaviour, I note a referral was made to the Children with Disability Service for further family support. As previously discussed, I accept the advice of the IPA that this referral was both appropriate and timely. Having carefully examined the available records I did not find any evidence to support the complainant's concern that she had requested autism specific classes and family support and that these were not provided. I do not therefore uphold this element of the complaint.

141. I note in response to the draft report, the complainant said there was *'no appropriate support and assistance provided to the school until around 2018'*. I also note the complainant's concern that she requested resources for home schooling but was not provided these. Having examined the relevant records I found no evidence in relation to any such request for home schooling or in relation to school support during the time frame under investigation. I am therefore unable to conclude on this particular matter which the complainant has raised. Notwithstanding, I note that the Trust confirmed to this Office that the Autism Service does not have a specific role in relation to school matters but that intervention such as home schooling and school support are accessed through the Education Authority's AAIS.

Overall care and treatment post diagnosis

142. I note the complainant's concern that the care and treatment provided by the Autism Service following her child's ASD diagnosis was *'inadequate and inappropriate to [the child's] condition'*. As part of my consideration of the child's

post-diagnostic care and treatment I referred to the HSCB Regional Pathway document. This pathway document emphasises that key support, including '*the level and type of intervention*' provided following ASD diagnosis, '*will be dependent on the assessed need of the child/young person*'. The pathway document provides that '*support will be... flexible and vary*' according to the child's changing needs. It states further, that post diagnostic intervention can include support for families/carers, training, direct individual and group interventions and as well as access to social activities.

143. I examined the relevant records of intervention and support provided to the child by the Autism Service from the date of her ASD diagnosis until 30 July 2018 (Appendix four refers). In doing so, I note that the child received specific / targeted intervention in the form of one to one support from an AIT prior to her ASD diagnosis. Following her ASD diagnosis on 14 June 2017 I note the child and complainant continued to have regular appointments for one to one / individual intervention with allocated AITs both in clinic and at the child's home, and via telephone over the course of 2017/18.

144. I examined the contemporaneous case records of the child's AIT appointments which were also attended by the complainant. I note these appointments included detailed discussion and advice on the use of different strategies to help enable the child and the complainant to meet the child's needs at the relevant time. I note these included strategies to support the child's communication and to help manage her behaviour, anger and anxiety. The case records further evidence that these strategies were reviewed and adjusted by the AIT at each appointment in response to the child's presenting need at that time.

145. In addition to targeted intervention with an allocated AIT and attendance at ASD information sessions (discussed above), I note the child received special interest group intervention. On examining the available records I note they document the child's attendance at social and leisure activities such as drama group, craft workshops and social group sessions (Appendix four refers). Furthermore, as previously discussed, the child received onward referral to CAMHS in June 2018 which the IPA advised was appropriate to her presenting needs at that time. Thus, having considered the available evidence I am satisfied that the child received as

part of her post diagnostic care and treatment, a combination of specific and targeted intervention, as well as family support and ASD information sessions. I accept the IPA's advice that this intervention was both reasonable and in line with the HSCB Regional Pathway document and NICE Guideline CG170.

146. In considering the overall care and treatment provided by the Autism Service, I accept the IPA advice that '*[the complainant] and [the child] were offered skilled and timely ASD specific support both before the 2017 ASD diagnosis [and after].*' I note that the IPA also advised, '*This [care and treatment] did support both [the child] and [the complainant] and resulted in improvements that were documented although her behaviour remained challenging, and [the child] recommenced school attendance.*' I accept further, the IPA's advice, that the '*support offered was reasonable and in line with relevant [NICE CG170 and HSCB Pathway document] guidelines*'. I hope the complainant is reassured by this advice. Accordingly, I do not uphold this element of the complaint.

147. I note the complainant's response to the draft report that a '*lack of care and treatment following [the child's ASD] diagnosis is directly responsible for the... difficulties*' she continued to experience. I acknowledge the on-going difficulties the child and her family experienced in 2017/18 despite having received an ASD diagnosis. I acknowledge also the considerable strain this caused them. However, I found no evidence to support the complainant's assertion that the care and treatment received from the Autism Service '*was directly responsible*' for these. Overall, I found no evidence to support the complainant's assertion that there was '*a lack of support*' offered by the Autism Service, nor that the support and intervention provided to the child following her ASD diagnosis was not adequate or appropriate. Furthermore, I did not identify any failures in the post-diagnostic care and treatment provided to the child by the Trust's Autism Service from June 2017 to July 2018. I thereby do not uphold issue two of this complaint. I do nevertheless, acknowledge the need for continued development of services and intervention to provide much needed support to children with autism and their families.

CONCLUSION

148. The complainant submitted a complaint on behalf of the child, in relation to the Trust's assessment of the child for ASD in 2014/2015. The complainant said that the Trust failed to properly carry out the child's ASD assessment on this occasion and as a result, the child received a misdiagnosis. The complainant also raised concerns regarding the post diagnostic care and treatment provided to her child from 14 June 2017 until 30 July 2018.

149. I investigated the complaint and found a failure in care and treatment in relation to the following:

- Failure of the Trust's multi-disciplinary assessment team to consider appropriately all the cumulative supplementary information when making its diagnostic decision that the child did not have ASD in 2014/15; and
- Failure of the Trust's multi-disciplinary assessment team to reach an appropriate and reasonable diagnostic decision of '*inconclusive*' following the child's ASD assessment in 2014/15.

150. I am satisfied that the failures in care and treatment that I identified caused the child to experience the injustice of a loss of opportunity to have had a timely referral made for ASD reassessment. I consider this in turn led to a loss of opportunity to receive an earlier ASD diagnosis and to avail of appropriate intervention and support sooner. As a further consequence of these failures, I consider the complainant experienced the injustice of upset, frustration and uncertainty as to the reason for her child's presenting difficulties and having the continued need to raise her concerns with the Community Paediatrician.

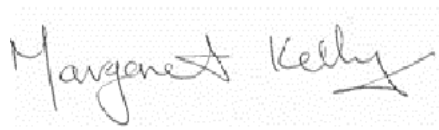
151. I did not find a failure in care and treatment in relation to the following:

- The Trust's provision of support and intervention following the child's ASD diagnosis in June 2017.

Recommendations

152. I recommend that the Trust provides the child and the complainant with a written apology in accordance with NIPSO 'Guidance on issuing an apology' (June 2016), for the injustice caused as a result of the failures identified in this report. This apology should be issued within **one month** of the date of the Final Report.
153. I welcome the learning and service improvements which the Trust has already implemented as a result of this complaint. These include reminding staff that Autism Diagnostic Reports should reflect the breadth of the assessment process and the information that has been considered when reaching a diagnostic decision. They also include changes to ASD assessments so that, inter alia, a detailed developmental history takes place with parents/carers using an autism specific tool. I further recommend that:
- (i) The Trust provides this Office with evidence of how it has reminded staff of the importance of ensuring that Diagnostic Assessment Reports reflect the information that is considered when reaching a diagnostic decision; and
 - (ii) The Trust discusses the findings of this report with the relevant multi-disciplinary assessment team involved in the child's initial ASD assessment on 16 March 2015. Furthermore, that it shares the issues identified in this report with relevant staff within the Autism Service for learning, service improvement and to prevent future recurrence of the failings identified.
154. I recommend that the Trust implements an action plan to incorporate these recommendations and should provide me with an update within six months of the date of my Final Report. The action plan should be supported by evidence to confirm that appropriate action has been taken (including, where appropriate, records of any relevant meetings).
155. Although I did not uphold the issue relating to the child's post diagnostic care and treatment (issue two), I acknowledge the significant difficulties experienced by the child and the complainant during this time and the clear need for both to be

supported. I would encourage the Trust to continue to develop services in this area to support children and their families with an ASD diagnosis.

A handwritten signature in cursive script that reads "Margaret Kelly". The signature is written in black ink on a light-colored background.

**Margaret Kelly
Ombudsman**

January 2021

PRINCIPLES OF GOOD ADMINISTRATION

Good administration by public service providers means:

1. Getting it right

- Acting in accordance with the law and 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.