You can contact me on: [redacted] Our reference: [redacted]
[redacted]

Parliamentary and Health Service Ombudsman

In Confidence
Dr Melanie Mahjenta
[redacted]

2 March 2017

Dear Dr Mahjenta

Your complaint about Virgin Care - Integrated Children's Services

Thank you for your comments on our draft report, which we have taken on board. As you know we also received comments from Virgin Care.

You will see that we have made some changes to the report. However, none of these changes are substantive, they are there to clarify our findings and to reflect the additional information you and Virgin Care provided. I hope that you find these useful to understand our decision.

We have considered the comments you made carefully. I should explain that while I understand your deep sense of injustice around the delay in diagnosis and the fact that professionals thought you were exaggerating Rosie's symptoms, our role is more limited to looking at how the diagnosis was reached and the relationship with you was managed. As you know, we found failings around that.

We have looked in detail at your comments about the injustice to you and to Rosie. However, having done that, we are not persuaded that we should change the report. I do not think that we can connect many of the injustices you claim to the failings we have found. We have tried to make this section of the report clearer so that you can understand what we have found.

Having looked at the responses to our draft report, our final decision is that we have decided to uphold your complaint.

Please find our final investigation report enclosed with this letter.

I[redacted]SMillbank Tower
PEOPLE
[redacted]
London SWIP 4QP

What happens now?

We •are also sending a copy of our final report to Virgin Care. We recommended that Virgin Care - Integrated Children's Services take action to improve their service [redacted] They have agreed to do that. We asked that Virgin Care - Integrated Children's Services complete these within three months of the date of the report. We will let you know when this has been done.

Some important information you need to know

There are legal restrictions on sharing the information we give you with other people. Our reports often contain confidential information too.

You can share our final report with others if you want to. However, please do not share any documents we may have given you during our investigation, which includes copies of our draft investigation report. If you have any questions about what you can share, please contact me using the details given above.

How did we do?

If you have any feedback about our service or decision, we would like to hear from you. [redacted]

We would like to remind you that an independent research company acting on our behalf may contact you in the future in connection with surveys or research to help us improve our services. If you would prefer not to take part, please let us know by [redacted]

If you have already told us that you do not want to take part, then you do not need to tell us again.

Information passed to and collected by the research company is kept in the strictest confidence and is used for research purposes only.

[redacted]

[redacted]

Date: 1 March 2017

Case reference: [redacted]

Health Service Commissioners Act 1993

Parliamentary and Health Service Ombudsman

Report by the Health Service Ombudsman for England into a complaint made by

Dr Melanie Mahjenta
[redacted]

Complaint about

Virgin Care - Integrated Children's Services

Summary

1. Dr Mahjenta complains that her daughter, Rosie, was incorrectly diagnosed after an Autistic Spectrum Condition Assessment in 2013. Dr Mahjenta says that the assessments showed that Rosie was on the autistic spectrum yet the multidisciplinary team (MDT) failed to diagnose her with autism. Dr Mahjenta believes that the diagnosis was not made because of a lack of understanding with diagnosing autism in

2. Dr Mahjenta also complains that the multidisciplinary team failed to recognise that she was also on the autistic spectrum and failed to meet her needs. She has said that the team started to accuse her of fabricating Rosie's symptoms and eventually made a referral to children's services, which led to Rosie being made a 'child in need'.

3. Dr Mahjenta has said that the lack of diagnosis meant that Rosie was not as well supported as she should have been. Dr Mahjenta says it left her unsupported as well, which has also led to her becoming stressed and physically ill, particularly when Rosie was made a child in need. Dr Mahjenta has also described a number of financial and non-financial injustices arising from these events, including: managing Rosie's collection from school, lack of benefits, lack of emotional and carers support.

Our decision

4. We have decided to uphold this complaint because we have found that there was sufficient evidence for the diagnosis to be made sooner than it was. We have found

that there was no clear reason for extending the assessment beyond December 2013 and that the assessment that did take place after that would not have provided any significantly new evidence. We have found that the MDT did not afford Dr Mahjenta the support that she needed and did not fully take into account her claim that she may also be autistic, which was not in line with established clinical practice. We have found that Dr Mahjenta has been caused a significant period of stress and has meant that she has not been given the support she needed to look after Rosie and that, in turn, Rosie may also not have been given all the support she required.

Background

5. Rosie was initially assessed in April and June 2013 and found to have difficulties with speech and language and, in August 2013 was referred to the MDT for assessment. The assessment process was to include five sessions, culminating in a review. At the time the assessment was planned, Dr Mahjenta informed staff that she herself was being assessed for Asperger's syndrome.

6. Rosie had five appointments (four assessments and one review meeting) in November 2013 including one home visit and three assessments at the MDT assessment centre (called Honeylands). During that time she had an ADOS [1] assessment and a music assessment. A speech and language assessment and an educational assessment at her nursery had already been done. The ADOS scored 14, with scores above 12 being suggestive of autism spectrum disorder (ASD). The music assessment scored 7, with a score of 6-10 being suggestive of autism traits. All the other reports suggested at least some degree of difficulty with speech and language, understanding, and social skills.

7. On 5 December 2013, at the scheduled review meeting, all the above assessments were considered. The report concluded, '[Rosie's] assessments are suggestive of a diagnosis of autism spectrum disorder...'. Nevertheless, the decision was taken that Rosie should continue to attend Honeylands and also have further specialist assessments: a referral to an educational psychologist, cognitive assessment, speech and language assessment and occupational therapy assessment. There is no explanation in the report of the review as to why the scores on the ADOS and music tests, alongside evidence from other professionals and Dr Mahjenta did not allow a diagnosis.

8. On 1 1 December 2013 Dr Mahjenta wrote to the MDT to express her concerns about the lack of diagnosis. In that letter she said that she was undergoing assessment for Asperger's. This was the start of increasingly frequent contact from Dr Mahjenta in which she often included papers and articles that she had found on the internet about the under-diagnosis of autism in girls. She also asked for various types of financial and respite support.

1 Autism Diagnostic Observation Schedule - a tool for assessing individuals suspected of having autism.

9. An Educational Psychology assessment conducted over two days in January 2014 supported Dr Mahjenta's concerns that Rosie relied significantly on copying others to cope and had variable eye contact. This was part of a behaviour that Dr Mahjenta thought to be a 'masking' behaviour in Rosie, and one of the reasons she believed autism to be underdiagnosed in girls.

10. Thereafter, Rosie attended weekly sessions at Honeylands. There is no evidence that these were planned to continue for a set amount of time. Rosie appears to have stopped going in April 2014. There is no evidence on file that Virgin Care attempted to re-engage Dr Mahjenta in the nursery sessions at this time.

11. The continued contact from Dr Mahjenta and her desire to get a diagnosis for Rosie apparently prompted a 'professionals meeting' on 25 March 2014. The notes of that meeting suggest it was focused on the MDT's concerns that Dr Mahjenta was exaggerating or fabricating Rosie's symptoms. During the meeting it was apparently 'confirmed' that a diagnosis of autism was not appropriate. However, again, there is no record as to why that was and there is no evidence this was a formal review. Among the agreed actions was one for all professionals to be vigilant of safeguarding issues.

12. There is no evidence of any formal review of the further educational psychology, cognitive, speech and language and occupational therapy assessments that were undertaken. The cognitive assessment was completed on 12 May 2014, the speech and language review was done in April 2014 and the OT assessment was completed on 15 July 2014. Instead of any formal review of those assessments and the nursery attendances, it appears to have been decided, on 16 May 2014, (that is, before the assessments were complete) that Rosie should be listed for an over 5's autism assessment - for which the waiting list was two years. Virgin Care has told us that this was intended to be a referral for a second opinion given Dr Mahjenta's ongoing concerns about diagnosis.

13. Dr Mahjenta continued to try to correspond with the MDT, which led to a child protection strategy meeting. It appears that Dr Mahjenta requested a second opinion at this time, but one was not secured. Virgin Care has said that Dr Mahjenta 'disengaged' with the service in July 2014, but it is not clear what she disengaged with, as the OT assessment was the only thing outstanding and was completed in July.

14. There was a safeguarding meeting on 5 August 2014 due to concerns over the exaggeration of Rosie's difficulties by Dr Mahjenta. This led to a referral to

children's services. Again, there appears to have been no formal review of the additional assessments carried out at that time.

15. An Educational psychologist report written for the purpose of an Educational
Health and Care needs Assessment (a way of securing additional funding for support at school) in November 2015 said that the assessments that had so far been done were 'highly suggestive' of autism.

16. In 2016 a Rosie was diagnosed with autism by the over 5's team.

Evidence we considered

17. We looked at Rosie's complete medical file including all the correspondence that Dr Mahjenta had with the service. We looked at all the papers Dr Mahjenta sent and talked with her at length. We took advice from a Consultant Community Paediatrician with over twenty years paediatric experience and 17 years' experience of undertaking assessments of children with difficulties that may be explained by an ASD.

18. We looked at the relevant guidance. In particular, we looked at the NICE guidance 'Autism Spectrum Disorder in under 19's: recognition, referral and diagnosis' [1] . One of the reasons NICE gives for producing the guidance is to 'improve the early recognition of autism'. Section 1 .2.2, refers to the involvement and importance of the parents' views and taking those views seriously; section 1.6.1 says that if there is uncertainty after the diagnostic assessment, consider keeping the child under review; section 1.6.2 says to consider obtaining a second opinion if there is disagreement with the parents about diagnosis; and section 1.8.4 says the written report of the assessment should explain the findings of the assessment and the reasons for the conclusions drawn.

19. In responding to the draft report, Virgin Care also asked that we take sections 1 .5.7 to 1.5.10 of the NICE guidance specifically into account:

> 1.5.7 Consider the following differential diagnoses for autism and whether specific assessments are needed to help interpret the autism history and observations:
>
> Neurodevelopmental disorders:
>
> specific language delay or disorder intellectual disability or global developmental delay developmental coordination disorder . . .

[1] https://www.nice.org.uk/guidance/cgl 28/ evidence/ full-guideline-183228445

Other conditions:
severe hearing impairment severe visual impairment
maltreatment selective mutism.

1.5.9 If there are discrepancies during the autism diagnostic assessment between reported signs or symptoms and the findings of the autism observation in the clinical setting, consider: gathering additional information from other sources; and/or carrying out further autism specific observations in different settings, such as the school, nursery, other social setting or at home.

1.5.10 Use information from all sources, together with clinical judgement, to diagnose autism based on ICD- 10 or DSM IV[2] criteria.

20. These recommendations also appear in sections 5 and 6 of the full guideline. Relevant parts of that say:

'The GDG's (guideline development group) consensus was that there may be benefit in undertaking observations of the child or young person in different settings if no definitive diagnosis has been reached but that this does not have to happen for every child or young person. Such observations should take place in a variety of settings and healthcare professionals should listen to parents and carers about how the child behaves in different settings to determine the observation that would provide the most useful information, for example school, nursery, other social settings or the home ...

'If there are discrepancies during the autism diagnostic assessment between reported signs or symptoms and the findings of the autism observation in the clinical setting, consider: gathering additional information from other sources and/or carrying out further autism specific observations in different settings, such as the school, nursery, other social setting or at home...

'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•...

[2] These are methods of categorising different mental health conditions.

'If there is uncertainty after the autism diagnostic assessment about the diagnosis, consider keeping the child or young person under review, taking into account any new information... '

21 . In respect of differential diagnoses the full guideline recognises that language delay, cognitive delay or behavioural concerns are all common presentations of autism but

are also all common neurodevelopmental problems and disorders in their own right. It says that it should be considered both whether these are differential diagnoses and whether they are a coexisting condition.

22. Virgin Care also asked us to look at the information which comes with the ADOS assessment, This says that information from the ADOS assessment should not be used in isolation to reach a diagnosis.

23. We have also considered the Ombudsman's Principles of Good Administration. 'Getting it right' includes taking all relevant considerations into account when making decisions, and discounting irrelevant ones; balancing evidence appropriately; and giving reasons for decisions. 'Acting fairly and proportionately', includes understanding and respecting diversity and ensuring equal access to services regardless of background or circumstance.

What we found

Autism diagnosis

24. I n November 204 10, nosie D scored highly on the ADOS test. Our clinical adviser said that, in addition to the history reported, the observations of other professionals and the other assessments, there was evidence that Rosie met the diagnostic criteria for Autism Spectrum Disorder and it is not clear why she was not given a diagnosis at this time. While Virgin Care has expressed concern that our adviser has relied too heavily on the ADOS test, the advice we have received clearly takes account of the other information available at the time. Indeed, the professionals noted at the time that the assessments were 'suggestive' of autism.

25. The record of the review in December 2013 does not record the rationale of the MDT not giving a diagnosis at that time. Virgin Care has said that the reason a diagnosis was not given because clinical staff considered there to be 'differences between reported symptoms and observed behaviours'. Virgin Care clarified that the additional period of observation was recommended by the clinical psychologist because of the possibility of the effects on Rosie's development of relationship breakdowns, social isolation and mood difficulties that Dr Mahjenta had reported. Also, some of the assessments were not conclusive of autism.

26. Our clinical adviser considered whether there was a persuasive alternative diagnosis for the outcome of Rosie's assessments. The adviser suggested there may be two other alternatives: there were features of Rosie's presentation that suggested that there may either be a cognitive or learning disability reason for her problems; secondly, there may have been concerns about parenting. These alternative diagnoses appear to us to coincide with the alternative diagnoses that Virgin Care has now said are ones they were considering.

27. However, the clinical adviser has said that these were not likely alternative diagnoses. She has told us that there was very little evidence for either of these things. She also told us that features of Rosie's presentation such as the 'ASD like' intonation of her voice, could not be attributable to a cognitive disability or poor parenting. Also, Rosie was settled in nursery, which would not suggest that she was being caused any particular problems at home.

28. It is not clear - because of the lack of a contemporaneous record whether Rosie's ability to socialise played any part in the decision not to give a diagnosis. Dr Mahjenta has told us that she is concerned this was the issue. The clinical adviser has told us that with regard to Rosie's ability to socialise, her presentation was not particularly complex or atypical.

29. With autistic girls who are able to socialise, the clinical adviser said they sometimes come very close to, but do not pass, the cut off for ADOS, so the professional needs to be aware of that. However, Rosie's score was higher than the cut off, so her ability to socialise should not have been a particular issue, and the clinical adviser does not think that the fact that Rosie is a girl was relevant to the decision making.

30. The clinical adviser therefore concluded that the assessments that were done after December 2013 were in line with NICE guidance insofar as they were appropriate assessments done by appropriate professionals. However, the clinical adviser has said that they weren't appropriate in Rosie's case because they were unnecessary, and therefore delayed the diagnosis.

31 . In response, Virgin Care asked us to look more closely at NICE guidance which says further observations should be considered when there was doubt over the diagnosis. Even if we accept that there was doubt over the diagnosis, the additional observations that were planned, do not appear to be in accordance with the guidance. The guidance specifically says that observations should be done in the most appropriate setting. The observations that were planned were to be done in the same settings as the previous assessments. The clinical adviser has also said that it is not clear how the additional assessments would add to what had already been observed in the other assessments. The adviser said that if the MDT were concerned that there were other factors at play, then it would have been sensible to

carry out more observations at home or nursery (that is, rather than at Honeylands where most of the previous assessments had been done). This is because it is quite common for children to be able to cope for short periods in a clinical setting, mask their anxiety, and then their behaviour changes at home. We note that the educational psychologist did spend one day with Rosie at her nursery, but this appears to be the only observation which was done elsewhere.

32. In addition to all this, there is no evidence that any formal review of the information gained from the additional assessments was ever done. Virgin Care told us that this was because Dr Mahjenta had 'disengaged' from the service. However, there is no actual evidence of that given the key events (as described above) and given that Dr Mahjenta was continuing to seek a diagnosis. In fact, a decision appears to have been made in May 2014 - before the further assessments planned were complete that Rosie should await an over 5's assessment. While the additional assessments would clearly be helpful in determining Rosie's needs and framing support for her, it is not clear whether they were used to help reach a diagnosis.

33. For all the reasons above, we have provisionally found that a diagnosis of autism should have been made in December 2013 and that not to have was not in line with established good practice. We have found that the MDT did not balance the evidence - which was supportive of a diagnosis, and not suggestive of an alternative diagnosis - appropriately and did not record their reason for not giving a diagnosis. This was not in accordance with the Ombudsman's Principles, 'Getting it Right'. The December 2013 report of the assessment was not in accordance with the NICE guidance insofar as there does not appear to be a contemporaneous record of why a diagnosis was not made or the rationale for further assessment.

34. We have not found that the failure to diagnose in December 2013 was as a result of Rosie being a girl. Her presentation was not such that her ability to socialise affected the result of the ADOS.

Interaction with Dr Mahjenta

35. Dr Mahjenta was clearly persistent in trying to obtain a diagnosis for Rosie. However, the evidence shows that the behaviours she was saying Rosie demonstrated were behaviours which the professionals themselves had recorded. NICE guidance is clear about the importance of listening to parents. In particular, it says a second opinion should be considered when parents disagree with the diagnosis. Therefore, a second opinion was indicated because of Dr Mahjenta's ongoing concerns and Dr Mahjenta did in fact request this as well. There is evidence this was considered, but no evidence one was secured. Virgin Care have told us that they consider the referral to the over 5's team a second opinion. However, this does not appear to us to be an effective or appropriate second

opinion given that Dr Mahjenta's concern was to secure a diagnosis for Rosie at that time - not to wait until she was older.

36. Further, at the very beginning of the assessment process, Dr Mahjenta said that she believed she was on the autistic spectrum. The clinical adviser has explained that it is quite common to find that one or other parents are on the spectrum and that can present in two main ways. First, the parents are not aware that their child has a problem as they are similarly affected. Second, the parent becomes quite intense and focused on the diagnosis. Parents in this second group who don't get a diagnosis are more likely, as Dr Mahjenta did, to provide more and more evidence. In that instance, a diagnosis can help make sure the parent, and therefore the child, gets the support they need. The professionals concerned should have been able to recognise the importance of a timely diagnosis in this instance.

37. Virgin Care said that they had no medical evidence that Dr Mahjenta was on the autistic spectrum. However, there is no reason to doubt that Dr Mahjenta thought she may have some traits. There is also no evidence that the types of behaviours Dr Mahjenta was describing in Rosie were wholly out of step with those recorded by professionals. On balance, and given that subsequent events have shown 1) Rosie has autism, and 2) the information available at the time was strongly suggestive of autism (both our clinical adviser and the independent EHC clinician thought this), we think that this indicates that there was scope for the relationship with Dr Mahjenta to have been better. The clinical adviser has explained that if Dr Mahjenta hadn't said that she may be on the autistic spectrum, then the professionals might have been more legitimately concerned by the type of behaviour she was demonstrating. As it was, and given the factors above, they should have recognised that some of Dr Mahjenta's behaviour may have been explained.

38. For all these reasons, we do not consider that the MDT placed enough weight on what Dr Mahjenta was saying and did not take into account whether she was also on the autistic spectrum. We have found this regardless of whether there was medical evidence of her being on the autism spectrum at that at the time. Virgin Care should still have been able to demonstrate that they took this possibility into account and addressed it. We have found that their actions were therefore not in accordance Ombudsman's Principles, 'Acting Fairly and Proportionately', or established good practice.

Injustice

Delayed diagnosis

39. The aim of making a diagnosis of autism is to make sure that children become settled into school or nursery with appropriate support and parents can

become skilled and receive the support they need in order to provide the support their children need. The longer a diagnosis is delayed the longer the parent and child are left without such support.

40. We do not think that had a diagnosis been made sooner, that Rosie would have necessarily been able to access any more support than she had. Rosie did have needs assessments and support was in place. That support largely appears to have been meeting her needs and has not been significantly changed since the diagnosis. The clinical adviser has explained that support is generally needs based so a diagnosis would not necessarily change the support in place. Dr Mahjenta describes incidents at

Rosie's first school where she was not helped with toileting and was bullied. However, those types of issues appear to have resolved now that Rosie attends a different school; the formal support she received was not changed. As such, these issues seem to be less to do with the diagnosis and support, than with the school. Nevertheless, we accept Dr Mahjenta's argument that a diagnosis would have given her more credibility and leverage when trying to meet Rosie's needs (for example being allowed to park on the school premises to mitigate the fact that Rosie had a low awareness of risk) and may have made some difference to the way in which staff responded to Rosie.

41 . A diagnosis would also have opened doors for Dr Mahjenta to access additional support which, in turn, would have allowed her to support Rosie even more than she was already. Dr Mahjenta thinks she would have clearly benefitted from additional support from parent groups and charities that she was unable to access, or felt unable to access, without a diagnosis. We see no reason to doubt that.

42. Dr Mahjenta has described instances where she has been caused financial loss by the events. First, she believes that Rosie would have qualified for higher rate mobility component of the Disability Living Allowance. It is impossible to say now whether an application for the higher rate mobility rate would have been successful, especially as Rosie has never been awarded that, either before her diagnosis or since. Similarly, Dr Mahjenta says that she was unable to access funded carers breaks and respite. However, we again have no evidence of any specific funds she tried to access or wanted to access, but couldn't. As such, while we accept that Dr Mahjenta may have missed out on the opportunity of applying for various financial benefits, we cannot conclude that she has been caused a direct financial loss.

43. Dr Mahjenta has also described how she damaged her car as a result of problems with arranging an appropriate drop off and pick up for Rosie at school. Unfortunately, the series of events involve so many factors: the decision of the school; the lay out of the car park; Dr Mahjenta's concentration; that it would be impossible to say that had a diagnosis of autism been made, this would not have happened.

Interaction with Dr Mahjenta

44. It appears that many of the contacts Dr Mahjenta had with the MDT after December 2013 were marred by their concern' that she was exaggerating or fabricating Rosie's behaviours. She was not clearly given credibility as her daughter's carer; and her comments and concerns appear to have been largely rejected as unreasonable in the light of the MDT's opinion that Rosie did not have significant problems. It is more likely than not the interaction with Dr Mahjenta would have been more positive had the MDT acted in accordance with established good practice as described by the clinical adviser. In turn, this would have been likely to have cause Dr Mahjenta less stress.

45. Dr Mahjenta has told us that the stress she was under caused her to have a number of physical health problems. However, while we can see that those health problems may have been stress related, there is no evidence that her dealings with Virgin Care were the sole or main cause of that stress.

46. Finally, we have considered whether the referral to children's services would have been made had the failings we have identified not happened. Virgin Care told us that they had legitimate concerns at the time and that professionals need to be free to make referrals when they have concerns. We agree. However, we have found that an earlier diagnosis could have been made (which is what Dr Mahjenta wanted at the time) and that it is possible that a better relationship could have been had with Dr Mahjenta. We also know that the professionals did not consider Rosie to be at risk of significant harm from Dr Mahjenta's behaviour. Therefore, it is far from clear that a referral would have been made in any event - the conclusion of the professionals that Dr Mahjenta was exaggerating Rosie's symptoms appears to have been based on their decision that Rosie did not have autism or problems as significant as Dr Mahjenta was saying - which we do not think was appropriate given the evidence.

47. On balance, we think that it is more likely than not that the referral would not have been made at the time it was, had the failings in this report not occurred.

Recommendations

48. Within one month of the date of this report, Virgin Care should write to Dr
Mahjenta to acknowledge and apologise for the failings described in this report. Virgin Care should pay Dr Mahjenta El 000 in tangible recognition of the upset and lack of opportunity they have caused her and Rosie.

49. Within three months of the date of this report Virgin Care should review the failure to make an earlier diagnosis in this case and determine the reasons why

a diagnosis was not made. They should also look at how their service engages with parents, particularly those with additional needs. Virgin Care should then create an action plan of service improvements and staff training to address these issues and to ensure a similar situation does not happen again. That action plan should be shared with Dr Mahjenta, PHSO, CQC and NHS Improvement.

Sarah Eynon
Investigator

1 March 2017