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This judgment was delivered in private. The judge has given leave for this version of the judgment to be published on condition that (irrespective of what is contained in the judgment) in any published version of the judgment the anonymity of the children and members of their family must be strictly preserved. All persons, including representatives of the media, must ensure that this condition is strictly complied with. Failure to do so will be a contempt of court.

Neutral Citation Number: [2022] EWFC 191 (B)

IN THE FAMILY COURT Case No:BM21C00140

SITTING AT BIRMINGHAM

Birmingham Civil Justice Centre
33 Bull Street
Birmingham
B4 6DS

IN THE MATTER OF THE CHILDREN ACT 1989

AND IN THE MATTER OF:

'Y' DOB 2013

'H' DOB 2012.

Date: 15 August 2022

Before:

HER HONOUR JUDGE CARTER

- -

Counsel for the Local Authority: Miss Collinson

Counsel for the Mother: Mr Day, leading Mr Legg

Counsel for the Children: Mr Rogers

HER HONOUR JUDGE CARTER:

Introduction:

1. In this case I am concerned with two young girls, Y and H. Y was born in 2013 and is 8, nearly 9 years of age, and H in 2012, and she is 10. M is the mother of both children. Y's father is JL and H's father is GW. Neither father has played any role recently in the lives of the children and have not taken part in this hearing despite efforts made to include them.

The history of the family.

2. I do not need to set this out at length in this finding of fact judgment. There are a number of chronologies set out within the papers, and although elements of those are disputed by the mother, the mother has also filed a statement which is 68 pages long and contains a chronology and answer to the social work statement and chronology in 326 paragraphs. Y has obviously had substantial involvement with medical services and then social care since shortly after she was born. The first referral was received by social care in September 2014, when Y was only 1 year old. The prospect of there being fabricated illness (as it is referred to in the papers at that time) was raised from that time. Y has had very extended stays in hospital, including from approximately December 2014 to April 2016.

3. Although at times the concerns have abated, others have arisen. When the clinical paediatrician became Y's paediatrician in 2017 she clearly has attempted to clarify a number of issues, but has been increasingly concerned about some of the mother's behaviour. The prospect of public law proceedings being started has been a live one for a number of years.

These proceedings:

4. These proceedings commenced after the concerns rapidly escalated when mother reported that Y had had an 8 minute fit on the 24th April 2021 and she had not called an ambulance. The Local Authority requested that Y be admitted to hospital and the mother agreed to that on the 27th April 2021. When she was ready for discharge on 7th July 2021 Y moved to a Children's hospice facility with several sites in the Midlands. Y has had respite care there before. Y has not returned to her mother's care since that time. The local authority made an application for an interim care order in relation to both girls on the 25th June 2021, and did initially seek for H to be removed from her mother's care. It was heard initially at District Judge level but adjourned to heard by myself after some reports had been prepared upon the mother on the 28th July 2021.

5. On that date I made an interim care order in relation to Y, and an interim supervision order in relation to H. It was agreed H would remain in the Children's hospice.

6. Since that time there have been a number of agreed expert assessments undertaken. There had prior to these proceedings been a PAMS parenting assessment of the mother, after other assessments of her. These proceedings have had the benefit of the psychological report by the forensic psychologist, a report by Communicourt in relation to the mother dated 31 August 2021, and the medical report and chronology prepared by the independent expert paediatrician. Although I considered Part 25 applications on behalf of the mother for there to be further expert assessment, I refused those as being unnecessary

The Law

7. The law in this case is uncontentious. I have the benefit of an agreed document prepared by Mr Day, and agreed by all the advocates, I am very grateful to them all for their assistance. I shall not simply set that out again in this document. There is no dispute in relation to the law, apart from possibly in relation to the change to the interim care plan proposed by the local authority, and I shall set that out below.

The hearing:

8. This has been a finding of fact hearing, to consider the schedule of allegations made by the local authority.

The evidence in the case.

9. The evidence overall amounts to over 3,000 pages. I have read and reread to remind myself the entirety of sections A, B, C, D and E. I have not of course read the entirety of F, the 'other evidence filed in the bundle' which amounts to some 2,300 pages but have looked carefully at the sections and pages that the advocates have drawn to my attention, both due to them being noted in the schedules, and also in the course of the evidence in the hearing.

10. I heard evidence from the following people:

The previous social worker

Nurse (1) - at the Children's Hospice

The Community Nurse

The assistant headteacher at Y's school.

Y's clinical paediatrician.

Nurse (2) - employed as part of Y's home care package with a supervisory role.

Care worker (1) - for a care organisation who worked with the family

Care worker (2) - for a care organisation who worked with the family.

Nurse (3) - at the Children's Hospice.

Nurse (4) - a school nurse at Y's school.

The independent expert paediatrician.

The current social worker

The mother.

11. Before I make any findings in this case I remind myself of a number of very important matters.

12. Mother loves both her children very much. It is not suggested in this case that she would ever cause any harm deliberately to either Y or H.

13. I remind myself of course that medical knowledge moves on all the time, and that I must be aware that there may still be some aspects of Y's medical needs that are not fully known.

14. The mother has been the subject of an expert cognitive functioning assessment carried out by an experienced forensic psychologist. Importantly the psychologist sets out that the mother's ability to understand and respond to verbally presented material is within the borderline range, and above that of only 2% of her peers. The psychologist sets out at E101 of the bundle a list of issues in relation to individuals with a weakness in verbal comprehension. The mother's non-verbal fluid reasoning skills however are somewhat better and above those of 18% of her peers. This is a particularly relevant scale as it is described as the ability to examine novel problems, organise thoughts, examine rules and logical relationships and create and test solutions.

15. The mother's working memory however was again in the borderline range and she performed better than only 4% of her peers in relation to this. The examples of why this is important is that you might use this to solve problems, to encode store and retrieve information, to retain information, to acquire new skills and move information into long-term memory. The psychologist reported that the mother often forgot the question that she had been asked as she tended to begin her response and drift off topic, and explained that she had difficulty learning for example how to cook unless she could have a visual record of this and engage in lots of repetition.

16. The mother however performed better within the processing speed index, performing better than approximately 30% of her peers, and that is an indication of the rapidity within which the mother can mentally process simple or routine information without making errors. The mother's reading age is approximately 10 or 11 years old, and so she is likely to be able to read only basic texts with confidence.

17. The psychologist opined that professionals should be aware that the mother tends to overestimate her abilities and may be reluctant to report problems. She was often confident of an answer that was incorrect. The psychologist suggests that the mother is likely to need assistance in reading and understanding complex documentation with jargon and unusual vocabulary. She set out that when the mother was asked to read and comprehend new information, she was not always able to produce the correct answer, performing to the level of a 10-year-old.

18. I also remind myself that both the clinical paediatrician and the independent expert paediatrician, with their extensive experience accept that many parents exaggerate their children's symptoms, and I accept that will be out of worry and concern for their children. Almost all parents that do that, do so whilst trying to help their children to receive the best medical care. The clinical paediatrician and the independent expert paediatrician accept that parents often know their children best and they accepted that many parents are very apprehensive about taking children home from hospital.

19. I also remind myself of the evidence of the previous social worker, who was the social worker for the children between 2014 and 2021. She clearly knows the mother well, and tried hard to work with her over that lengthy period of years. She spoke sympathetically and knowledgeably about the mother and the children. She accepted that the mother cares deeply for both of her daughters, and that the mother had very little support. She accepted

that the mother was quite 'concrete', and that although she had high expectations of professionals this was only as much as the social worker would expect from any parent. She accepted that the mother was able to sit and listen and share perspectives in a calm manner at times, but not all of the time. Mother did get frustrated if professionals had a different view of Y's medical needs and that was one of her main sources of frustration. Mother would particularly become frustrated if she was given conflicting information, and the previous social worker was very clear that at times the mother would struggle to listen and understand meetings and so therefore she would follow that up with her. The previous social worker emphasised that over a substantial period of time, she would speak to the mother if she could prior to meetings, and then afterwards if that was necessary. She accepted that at times mother would follow professional advice, and accepted that some of mother's behaviour was understandable as she was frustrated. She went on to say however that mother would sometimes dismiss advice that was given, or take matters into her own hands. She accepted that the mother does not intentionally harm the children, her concern was that harm was being caused by the mother to the children.

20. All the professionals involved with the mother said that she was at times cooperative and engaging with them. They also all agreed that when they were working with the mother they were not fully aware of her cognition difficulties, but when it was suggested to them that the mother likes routine and had some fixed and possibly concrete thinking they agreed with that.

21. The clinical paediatrician said that she was not surprised at the cognitive assessment of the mother, as it was clear to her that it was difficult at times for the mother to take on board new information, and to be reassured by explanations. She was reflective that with those difficulties the mother is a concrete thinker. The concern she expressed was that as Y's needs will continue to change, Y is likely to surprise everyone with new problems, which will need to be dealt with. Y will progress, and that is shown by the fact that she made very good progress recently, but she will never reach adult independence. It was suggested to her that Y was now becoming a more straightforward child, but she did not consider that was the correct way to categorize Y.

22. I also bear in mind that the mother was understandably nervous in giving her evidence, and that this was a very stressful and difficult process for her.

The agreed or partly agreed matters:

23. I shall use the same numbering below as within the schedules. At times although the mother accepted some aspects some of the allegations, it is necessary to consider further some parts of those partly accepted allegations and the evidence connected with those.

24. Given the breadth of the initial allegations, it is inevitable that there were schedules prepared which were then responded to and then further revised schedules prepared. I have attempted to use the same numbering and set out within my analysis each numbered allegation, the written responses from mother, then where there are further amendments and responses, and then the oral evidence in relation to each one below. There are some allegations which have grown and had other examples added to them, and some which have changed slightly as the evidence has been received. Some have been abandoned by the local authority for a variety of reasons. Inevitably at times the oral and written evidence is lengthy and from different sources. I have deliberately set out the written responses and then what in my view is the relevant oral evidence in full to try and assist the mother in particular in this case, and those reading this potentially in the future to understand how the family came to be before the family court, and why I have made the findings I set out below.

25. I then go on in relation to each allegation to set out my analysis and conclusions and then at the end of this finding of fact judgment I draw together my conclusions to try and assist in terms of the next steps in this case.

Allegation 1. Y has had complex health needs since birth in 2013.

26. In December 2017, after considerable medical uncertainty, it was diagnosed that she has two very rare gene abnormalities. One is an HNRNPU gene disorder which causes learning and physical disabilities, hypotonia, together with complex and unusual forms of epilepsy. She also has a KCNJ11 gene disorder which affects the potassium channels and can cause problems with blood sugar regulation. Her difficulties are anticipated to be life-long and her treatment has been geared to managing her symptoms as she has grown older. She has experienced some medical problems which have resolved and others which have evolved. These are set out, together with her overall medical history, treatment, and the interactions between her mother, and professionals, in the reports of the treating clinical paediatrician, of the 11th April 2021 and 15th July 2021 There are also over 12,000 pages in the medical evidence bundle, predominantly relating to Y. Due to the

rarity of her gene disorders, and their unpredictable course, treatments have had to be tailored to her needs and on occasion there has been some disagreement between medical professionals about precise treatment options.

27. Response from the mother: I accept that this is a fair reflection of the situation.

28. Subsequent to the reports of the clinical paediatrician being filed, but before she gave her evidence, she had received information about the impact of the particular type of KCNJ11 gene variant that Y has, and confirmation that it would not impact upon Y's diagnosis and would not lead to her having diabetes later in life. The clinical paediatrician set that out in her oral evidence by way of an update. No party sought to dispute that.

Allegation 2. Y was making some progress at school with movement, standing and walking by March and April 2021. At the Continuing Health Care meeting preceding the Child Protection Conference on the 20th April 2021, it was discussed whether the level of supportive care provided should be reduced because of the progress Y was making.

29. The mother said she accepted this overall. She said in her written response that she was 'extremely pleased that Y was reported to be making progress. My concern and anxiety is that when she has a seizure, her development can take a backstep'.

30. I asked the independent expert paediatrician in relation to this, and whether a seizure would have an effect on Y's development. He said that a short lived seizure would have no effect on Y's development, there was no evidence that Y had any profound prolonged hypoxaemia, and therefore there was nothing that would cause her to suffer developmental regression.

31. The mother was asked about this in more detail in her oral evidence by Mr Legg, and she responded that when Y suffered a seizure, her development goes 10 steps back. The mother said that Y starts to forget things when she has a seizure, and the mother gave examples, saying that could be 'feeding or playing' and they have to re- teach her all the same things. She said it is like 'starting all over again'.

32. This was revisited by Miss Collinson in cross examination with the mother. It was put to her that the independent expert paediatrician was not of the view that Y's development

would be affected by the type of seizure that she had. The mother responded that it was a 'hard one', but gave as an example that even though Y had a seizure 3 years ago, she still does not crawl. Mother was challenged that Y does not now need to crawl, at her age and given the developments she had made, and the mother responded, 'but she has the mental age of a 12 month old baby, you would expect a child with a mental age of 12 months to be crawling'.

33. When Miss Collinson suggested to the mother that she may be underestimating what Y could do, the mother said that she was not, she was pleased at what Y could now do. Mother added that when she saw Y walking in the Children's Hospice she cried as she had missed that. When Miss Collinson reminded the mother that Y had been walking before April 2021, Mother accepted that was true but said that Y kept falling over.

Analysis:

34. The mother accepted the broad outline of this allegation. There are aspects however about how the evidence has developed which are relevant to the matters I need to determine. This allegation was it appears originally set out due to the concerns expressed by the local authority that the mother may have exaggerated issues with Y at a point when the package of support was being questioned with a view potentially to being reduced. Clearly that is likely to cause many parents concern, and perhaps worry. The local authority had originally pleaded that the mother may have fabricated the 8 minute seizure to bolster her case that the package of support should not be reduced, or that more time should be given to consider any reduction They no longer assert that however, and accept that seizure took place as the mother states.

35. It is relevant however still due to the mother's response to the allegation. I had not seen anywhere asserted or suggested that the type and duration of seizures that Y has would cause her development to regress. That was why I asked the independent expert paediatrician to consider that specifically, as this is in truth a very typical response given by the mother, and a typical type of assertion that she makes. The independent expert paediatrician was very clear that was not the case as I set out above, but when the mother gave her evidence later she insisted that she was right. Sadly, as with so many of her assertions, it in truth made little sense. The mother gave as an example to support her statement the fact that Y had a seizure, and now was not crawling. When she was

challenged that Y would not be expected to crawl at her stage of development, she did not reconsider her answer, but in fact sought to support it by other assertions as I set out above. Like many of the mother's responses it was given with great conviction, and an element of certainty that made it apparent the mother would not consider other options. As with much of the evidence as I shall set out in more detail below, the mother had an opportunity after the independent expert paediatrician gave his evidence on that to consider her view, but she was not able to adapt it even to admit an element of doubt or uncertainty.

36. Another example was the assertion by the mother that she had missed Y begin to walk whilst Y was at the Children's Hospice. There is a wealth of evidence that Y was making progress and taking steps before April 2021. Again, the mother's evidence that she had missed Y begin to walk was said with great assurance by the mother, but was not true.

Allegation 3. H was born in 2012. A diagnosis of coeliac disease was made in November 2015 which requires a life-long gluten free diet. She has had a number of assessments for other possible conditions which have not resulted in further current diagnoses. She has remained at home with Mother.

37. Response: Accepted by the mother.

Allegation 4. Mother accepts that:

a. when she experiences frustration during her interactions with professionals she can, on occasions, be assertive (which is, at times, regarded as aggressive behaviour by the professionals);

b. she may absent herself from meetings if she is feeling overwhelmed;

c. on occasions she says things which she does not mean (without it being made clear at the time that she does not mean the things she says)

38. Response: Accepted by the mother.

39. In her oral evidence, the mother was asked whether that was right that she accepted that sometimes she said things that she does not mean. The mother agreed that was true. It was suggested to her that it was difficult for people hearing her saying those things to know whether she meant them or not, and she said that she accepted that and agreed.

40. As I shall set out a number of times, the mother does accept sometimes that she has said things that she does not mean. Generally however she was clear in her evidence that she does mean what she says, and it was only sometimes when she was frustrated or upset she may say things she does not mean. She was asked for details of when she may say things she does not mean whilst she was giving her evidence, and was clear generally that she means what she says.

Allegation 6. Mother accepts that on occasions H and/or Y have been present during loud arguments between mother and her various partners or relatives or with one of the carers.

41. Response: Accepted by the mother.

42. The mother also accepted that this behaviour had continued until very recently when the Children's Hospice complained about her behaviour in the foyer of the Children's Hospice that she was on the telephone to the 16 year old son of her partner and swearing and shouting at him. Although H was present the mother asserted that H had her headphones on.

43. The evidence presented by the mother at the hearing was that she continued to experience difficulties in her current relationship, and given the history, and the ongoing situation that seems very likely to continue. There are more details of that in the next allegation.

Allegation 7. Mother accepts that she has entered into a number of relationships which have included instances of domestic abuse, and that on occasions H has been physically affected by domestic abuse.

44. Response: Accepted by the mother.

45. In her evidence the mother accepted that she had been in three domestically abusive relationships. She denied stalking her most recent partner, and said that they were now in an on and off relationship. She clearly found that painful to talk about, and said that at

the moment he had blocked her. She said it was overwhelming for both of them, and that it was very frustrating.

46. The local authority do not currently assert that this aspect would meet the threshold to prevent her caring for H, but given the other findings that I shall make in this judgment it is clearly a concern going forward that the mother clearly struggles to be able to learn new ways of managing those problems. This will be a matter that the local authority will need to keep under consideration of how to support the mother in the future and ensure that does not occur again to impact upon any child in her care. I accept the mother has undertaken various courses such as the Freedom project, the difficulty is whether the mother is able to have learnt from the courses and apply that learning to ensure her children are not exposed to any more domestic abuse.

Allegation 8. The exposure to such behaviour in Paragraphs 6 and 7 will have frightened either of the girls in their own way and will have led to emotional harm.

47. Response: Accepted by the mother.

Allegation 12. Refusal to accept that the administration of oxygen in appropriate circumstances was a proper form of treatment for Y:

48. There is a long history of disagreement between the medical staff and mother about the appropriateness of oxygen administration. Mother accepts on two occasions in the past that she interfered with the oxygen therapy hospital notes, when she should not have done so on the 19th January 2015, and she cut the green lead to the bag and mask on the 5th January 2018.

49. Response: Accepted by the mother.

50. The clinical paediatrician sets out recent events in her 2nd written report for the court, in which she explains that the mother entered into conflict with clinical staff a number of times when Y was administered oxygen during a seizure. The mother continues to express the view that oxygen is dangerous for Y despite her being given an explanation on many occasions that this is not the case. The mother believes that oxygen could cause Y to have a cardiac arrest. The clinical paediatrician sets out that she has not been able to identify the reason for the mother holding that fixed belief.

51. The clinical paediatrician was asked specifically about this example, although the mother accepts some of the facts of it. The clinical paediatrician emphasised that despite her having many discussions with the mother, the mother still thinks that oxygen during a seizure is dangerous for Y. The clinical paediatrician gave evidence that when Y has a seizure, and requires a bag and mask, oxygen will make no difference, but it is not harmful to Y. Although the hospital seizure plans say that there should be "no oxygen", that does not mean oxygen should not be given, it means that it is not required. The clinical paediatrician explained at length that it was standard procedure in hospital if someone has a seizure for them to be given oxygen and that could be important for some people. Y does not need that, but it is not harmful for her, and it is better overall that in hospital there is always one plan for every patient, otherwise it could impact negatively on someone who does require oxygen. I asked the clinical paediatrician in relation to this, and what the continued difficulty was. I asked if she had explained that in simple terms to the mother. She said she had, on many occasions. She was at a loss to tell me what the continued difficulty had been, or why she had been unable to persuade the mother that she was mistaken, and why this continues to be a problem.

52. The independent expert paediatrician was asked about this and the mother's belief that Y having oxygen could lead to her having some form of cardiac arrest, or respiratory arrest. His evidence was absolutely clear, that there is no basis for that belief at all. He reminded the court that Y suffered a seizure at school earlier this year, she had a reduction to 85% of her oxygen levels, and the oxygen that was administered by the school bought her up to her correct saturations.

53. The independent expert paediatrician was asked about low oxygen saturation levels, and he was clear that in order for there to be some form of physical change that would be noticeable they would need to drop quite significantly, he said probably less than 85% and probably less than that. He said they would have to be quite low before you saw any physical change in colour. He was clear that low oxygen levels did not predict a seizure happening.

54. He said that in his experience the vast majority of children who have seizures do not have oxygen monitoring.

55. The mother was asked carefully about this. She was absolutely certain and immovable in

her evidence that if Y had a seizure and she was given oxygen when she had a seizure, that could put her at risk of going into what the mother referred to as 'respiratory distress' which could lead to cardiac arrest. Mother said it had happened in the hospital, although she could not recall when. She asserted that was why it was written in one of Y's seizure plans 'no oxygen'. She was reminded that both the clinical paediatrician and the independent expert paediatrician had said that she was wrong in relation to this, and the clinical paediatrician gave a simple and clear explanation of why that was written, but she responded that she was 'not wrong'. She went onto say that she would not be moved from that view, and it had happened on several occasions when Y had a seizure in hospital. The mother went on to say that Y can use oxygen after a seizure, suggesting that one of the medications can cause lower oxygen levels, but repeated that during a seizure it can put Y more at risk of cardiac arrest. Mother accepted that in the past she cut the green tube to Y's oxygen, adding that 'if you give her air and oxygen in that chest wall that will put her into cardiac arrest' – adding that that had actually happened, and 'they' (referring to the clinical paediatrician and the independent expert paediatrician) are 'wrong'.

56. It was then suggested to the mother that Y had been given oxygen by Nurse 4 when she had the seizure in January 2021 at school. The mother corrected Miss Collinson saying that Y had a seizure in January and February. Y was given oxygen then, and Miss Collinson suggested to the mother that Y was given oxygen successfully and it increased her oxygen saturation levels successfully. The mother responded that the oxygen puts Y more at risk of respiratory distress. Miss Collinson asked the mother if she accepted that her views put Y at risk of having worse outcomes because of them, but mother denied that, and added that 'I have heard them saying that, but it is not true, and I know what is in the best interests of my daughter'.

Analysis:

57. The mother accepts some factual aspects of this allegation, including the extremely serious matters of interfering with the oxygen supply in hospital.

58. This is an extremely important and grave allegation, and the mother can have been in no doubt of the implications of her response to this.

59. The medical evidence is entirely unequivocal. I accept the evidence of the independent expert paediatrician and the clinical paediatrician that the administration of oxygen during a seizure will not harm any patient and will not harm Y. Further, I accept the evidence of

the clinical paediatrician, that she has on many occasions since her involvement attempted in a variety of different ways to explain to the mother that oxygen administered during a seizure will not harm Y. It is not of course sufficient for these findings to be made simply on the basis that the medical evidence is correct, the importance is that the medical opinion had been explained clearly to the mother, that it had been explored and understood by the clinical paediatrician what the mother was saying in response, and the conclusion still from the clinical paediatrician was that there was no danger to Y. I am quite satisfied that is the situation.

60. Given the absolute clarity of the medical evidence, I had sought greater understanding of what the mother had said to the clinical paediatrician as I set out above. It appeared perhaps understandable that the words 'no oxygen' could cause someone to think that the patient should not have oxygen. I was entirely satisfied however that the clinical paediatrician had on many occasions explained to the mother that it was simply a shorthand to explain that a patient did not need to take oxygen home with them when they were discharged, not that they must not have oxygen.

61. I have also of course considered the mothers explanation why she asserts she is right and the doctors are wrong. She asserts that Y having oxygen whilst in hospital when having a seizure has in the past caused Y to have 'respiratory distress' and a cardiac arrest. The independent expert paediatrician was of course employed by the court to consider the entirety of Y's medical notes and prepared not just his report, but also a chronology. His evidence was that there was no mention at any time of Y suffering from a cardiac arrest, whether from having oxygen during a seizure or otherwise. There is nothing to suggest in the medical notes that anyone has ever told the mother that oxygen could cause a problem with Y's respiration whilst having a seizure. I heard evidence from the clinical paediatrician and the independent expert paediatrician that it was likely to assist Y by raising her oxygen levels which can drop during a seizure.

62. As I have set out above at length, the mother is entirely immovable in relation to this. She was not prepared to consider any possibility that she may be wrong. I am extremely concerned that the mother will not in the future be able to genuinely accept this important element of Y's care. I make that finding based on the evidence as I have set out above, and the medical evidence which I accept, and due to:

i) the length of time during which the clinical paediatrician has tried to persuade the mother to consider another viewpoint,

ii) the length of time that the mother has held this belief, (which certainly dates back to at least January 2015),

iii) the fact that the mother had some time to consider the clinical paediatrician's evidence until she gave her evidence and overnight from the independent expert paediatrician giving his evidence

iv) the fact that even with the assistance of her very experienced and committed legal team and an intermediary to assist in explaining issues to the mother, she persists in her mistaken belief.

63. The importance of this finding will be considered further of course at the welfare stage, but it is an illustration of how the mother struggles to understand, accept and adapt her thinking as the situation develops in relation to Y. There is currently no doubt that any doctor or medic dealing with Y, possibly in an emergency situation, would be told by the mother that Y must not have oxygen, the mother would resist it happening if possible, which could cause great harm to Y, and the mother would say it would place Y at risk of serious harm to the doctors trying to treat Y.

The disputed allegations within the schedule. (Underlined below)

Allegation 5. Mother accepts (as above) that:

a. when she experiences frustration during her interactions with professionals she can, on occasions, be assertive (which is, at times, regarded as aggressive behaviour by the professionals);
b. she may absent herself from meetings if she is feeling overwhelmed
c. on occasions she says things which she does not mean (without it being made clear at the time that she does not mean the things she says)

Each of those accepted matters presents a risk of significant harm to Y, in terms of hampering the treatment which she receives from professionals, and/or creating communication problems over diagnosis and treatment which can lead to misunderstandings over Y's health care needs and the probability that she will have additional and unnecessary medical interventions.

The local authority assert: In relation to mother's behaviour, there are further examples of this during her visits to the Children's Hospice both in general, and in relation to disputes about the catheterisation process, which provide clear evidence of her failure to learn and

follow appropriate techniques. Two further features which arise from the Children's Hospice' records are:

(a) the insistence of mother that she needs to weigh the soiled nappies taken off Y, when medical advice was that there is no necessity to do this; and
(b) her repeated complaints that too many nappies were being used.

64. The mother says overall in response to this allegation: I do not accept that the above has placed Y at risk of significant harm. I am assertive only when I need to be, to advocate on behalf of Y and what I believe is in her best interests. I do not believe the above has caused Y to be hampered in terms of treatment. I do not accept the above has led to communication difficulties and misunderstandings and that this has been caused by matters not being explained sufficiently or me not being listened to. I do not accept that Y has come to significant harm because of me saying things that I do not mean as I would always put Y's needs first. I am of the view that I know when Y needs to go into hospital. I continue to have concerns about the care that has been offered to Y in the Children's Hospice.

65. In her second response she says: I do not accept that I am not able to learn and follow appropriate techniques. When there has been an issue about techniques, I have kept asking to be shown how people want me to do this so that I can do it the way that they want. The difficulty has been the changes. I have always been willing to learn and adopt new techniques. I accept that I have been shown how to do things differently by the hospital staff and the Children's Hospice. This has caused confusion and disputes. I accept that the records show that there have been disputes. I generally expect the Children's Hospice to do their jobs properly when it comes to the care of Y.

66. The mother continues to respond: that with the changes in how things are done, this has caused confusion and I have become frustrated. I would like for decisions to be made and stuck to and not for things to keep changing. In terms of the use of lubricant when changing the catheter, Y is that used to have a catheter I do not feel that she needs this. In respect of the weighing of soiled nappies, I was told that I could do this by urodynamics. The scales I was provided with initially came from them. These were then lost in hospital, so I had to replace them. It may have been the medical advice that this was not necessary, but I was told I could do this. I would weigh wet nappies to keep an

eye on the amount of urine passed as this was often an indicator of UTI's, which Y was prone to getting. When she had a UTI, her kidneys would not work properly and so she would end up retaining a large amount of liquid. I accept that the issue of the use of nappies has been an ongoing issue. The issue is the supply and demand. The suppliers provide 5 nappies a day for Y. The Children's Hospice are using 6-8. Therefore, there is a shortage. The social worker said that she would give the money to the Children's Hospice for more nappies to be purchased but then the Children's Hospice have been asking me to make the purchase. The issue just needs to be resolved properly.

Evidence

67. The clinical paediatrician as the treating paediatrician was obviously asked about aspects of this allegation. She said that she felt a lot of the time there was uncertainty and concern that things were exaggerated by the mother. She accepted that exaggeration was very normal from parents, but it does mean that things that are important could be missed. She said the school had always told her that Y is bright and happy and loves school. She said her biggest fear was that something important would be missed in relation to Y because they are so sceptical about the mother's reporting. She said previously if something was reported, it was often not reported by other people caring for Y or the school, and that could mean something is missed. She said now it was good to feel confident. She said that in the past sometimes they have repeatedly looked for things in case they are wrong, but that even when they had done that it has not resulted in reassurance for the mother, and they just go around in the same loops.

68. The independent expert paediatrician was asked the specific question whether there was any necessity to be weighing Y's nappies. He said that would only be needed in a child where there were concerns about a child's fluid balance, and they needed to know something with a high degree of accuracy. Similarly, it might be necessary if there were concerns that kidney failure might take place, but otherwise he could not see how it was necessary. He said that having a urinary tract infection does not affect your throughput of urine, and also in response to a question which I asked him, that having a urinary tract infection does not impact upon how your kidneys work.

69. Nurse (2) explained that the relationship between the mother and those providing care for Y was difficult and she went as far as to describe it in her view as "coercive". She said the

mother was asking staff to put things in the records that she thought had happened, which they did not agree with. She said that therefore they had gone to the extent of letting staff write a concern sheet was not completed in front of the mother, as the relationship between the carer and the mother needed to be maintained, and that was why carers were adding things in the form afterwards. It was therefore agreed that the carers could complete these emails out of work hours and away from mother. She said that the mother's compliance was variable. She said that there could be periods of up to 6 weeks to 2 months where there were no difficulties, and then matters would escalate quite quickly over a short period of time. She was very clear this was a pattern and said that towards the end of their time helping to care for Y the cycles were escalating in her view. She said that at times there would be some form of verbal conflict, which in her view would affect Y at times. She gave as an example that the mother considered a carer being in Y's room was disturbing the mother, and that therefore the only way this could be managed was for the carer to be downstairs, and watching Y on a monitor. She said in her view that placed Y at risk, but as the mother was not allowing carers upstairs then they evaluated the risk was greater if they were not there than if they were monitoring at a distance.

70. In relation to the potential for the care package to be reduced, Nurse (2) explained that the mother suggested that Y was often struggling more after school when she was tired, and they therefore did a week where there were carers present 24 hours a day. She said that in fact nothing unusual or difficult was reported, although the mother thought that Y had had a good week and that was why no problems had been picked up.

71. Care Worker (1) denied that she considered mother to be controlling or coercive, although she expressed significant concern about the mother suctioning Y.

72. Nurse (3) said that the mother could be very changeable in her dealings with her, she could be polite and pleasant, but if she didn't agree with something, she could be aggressive and confrontational, she might shout and raise her voice. Nurse (3) said the mother would sometimes contradict herself and agree something one day and a different thing the next day. She said that on one occasion they had to take Y away from the room because the mother was shouting. She accepted that the 'temperature often rose' when the mother was told something different to what she expected, and said that in her view when the mother visited she would find something she wanted to discuss which would end in disagreements.

73. Nurse (3) was asked specifically in relation to the weighing of nappies, as this was a particular point of conflict with the mother. She said that she had telephoned the urology department herself to try and understand the situation. They had told her that there was no need to be weighing the nappies, and they had not recommended that.

74. In her evidence the mother accepted that there was a plan from the commissioning group to reduce the amount of supportive care, as Y was making so much progress. She said that she did not agree with that, and she was frustrated and upset by that decision.

Analysis:

75. I remind myself of the allegation I am considering which is whether the behaviours that the mother accepted in Allegation 4 present a risk of significant harm to Y, in terms of hampering the treatment which she receives from professionals, and/or creating communication problems over diagnoses and treatment which can lead to misunderstandings over Y's health care needs and the probability that she will have additional and unnecessary medical interventions. I have set out above what she accepts.

76. The local authority have added to this allegation by saying there are further examples which illustrate this from the time when Y is at the Children's Hospice, including disputes about the catheterisation process, and disputes about the weighing of nappies and the number of nappies used.

77. I am mindful that it is obvious that the mother will at times have been shown different techniques. Different medical professionals may have different ways of undertaking certain elements of care. I am careful not to criticise the mother for that. It must be right as well that things will change as Y gets older.

78. However, in my view there is ample evidence to show that allegation 5 is correct, and I make that finding against the mother. It is concerning that given what the mother accepts at allegation 4, that she does not accept the implications of that, spelt out in allegation 5. That is however consistent with much of what the mother says she accepts, and her understanding of the problems in this case. It is, in truth, self evident that significant and long standing conflict and disagreements over diagnoses and treatment can lead to

misunderstandings over Y's health care needs. The evidence is clear that they do create the probability that Y will have additional and unnecessary medical interventions. I accept that for a child with the medical needs of Y, there will inevitably be some areas of disagreement and perhaps lengthy discussion between carers and the medical professionals. The issue is the extent to which the mother's behaviour goes beyond that. In my view the evidence of Nurse (2) shows a typical example of that behaviour. She had to manage carers feeling under pressure from the mother not to write things in front of her, even if they considered it to be factual, as that would cause such conflict that it was not in Y's best interests. Without a proper record from the carers of Y, there is of course a risk of things being missed, and accurate records not being made, as the clinical paediatrician so clearly expressed her worries about.

79. The evidence from a number of the witnesses was that there were periods of calm, but then also real problems which recurred. Nurse (2) gave evidence that there were behaviours of the mother which made carers uncomfortable to record their observations. That was clearly supported by Care Worker (2), who considered she had to take photos clandestinely, instead of confronting the mother. I have borne in mind when considering this allegation that for any parent, having carers in your house for that period of time would be intrusive. It is not surprising that there were flash points and some disagreements. The evidence overall in relation to this however shows a pattern which exceeds what would be expected, where the mother's behaviour did hamper the reliable record keeping and treatment from doctors for Y, and communication problems were created by her mother.

80. Although I heard some evidence about the catheterisation process of Y, it did not seem to me that amounted to clear evidence of the mother failing to undertake that properly in general.

81. I did however hear significant evidence about the issue of the nappies being weighed which in my view did support this finding. In another example where the mother clearly disagreed with the medics, significant conflict was caused by the mother insisting that Y's nappies needed to be weighed. Indeed, the mother sets out in some detail in her response to this why she was of that view that the nappies needed to be weighed. The medical evidence however was clear as I set out above, that was not necessary, and again,

the mother's insistent assertion of why this was necessary medically made no sense, and was incorrect. This was a very typical piece of evidence from the mother, which does exemplify many of the problems in the case, that the mother set out in her response in writing, saying that it was necessary to keep an eye on the amount of urine passed as this was often an indication of UTI's, when that is not correct. Similarly, the mother asserted that when Y had a UTI, her kidneys would not work properly and so she would end up retaining a large amount of liquid. Again, that is not correct. The mother's stance about this issue of weighing nappies however was unable to be changed despite the number of times this was discussed with her. Nurse (3) was clear that this was such an issue she called the urology department herself, and then tried to discuss with the mother to reassure her, which would have the impact then of reducing conflict and problems, but the mother would not change her belief. This then is another example where the mother's behaviour does illustrate this allegation, which I find to be made out.

82. I heard little evidence about the number of nappies used and about conflict relating to that, so I make no findings about that.

Allegation 9. The fact that there have been instances of the admitted behaviours at Paragraphs 4, 6 & 7 above, over a significant time period, demonstrates that Mother either lacks insight into the effects of such behaviours upon the children or is unable to adopt strategies which will minimise them and avoid the risk of over- medicalising the children, which will leave either of the children at risk of suffering further significant harm in the future, if they remain in the care of mother

83. The local authority assert: Although mother accepts the aspects of her interactions with professionals, and her relationship problems and experience of domestic abuse set out in Paragraphs 4, 6, and 7, she does not accept that such repeated occurrences over a significant period of time indicate either a lack of insight; or an inability to adopt strategies to minimise their effect upon her children, which will leave the children at risk of significant harm

84. The Local Authority accepts that mother has undertaken numerous courses for aspects of parenting and dealing with domestic violence. However, the Local Authority invites the Court to make the findings sought in Allegation 9. The Local Authority observes that the historic record demonstrates mother's inability to implement what she has

learned for the benefit of the children. For example:

a. Her personal history has previously followed a pattern of relationships in which there are issues of domestic violence. Her current relationship may have similar features; and
b. Observations of her care of H during contact visits at the Children's Hospice.

85. The mother says: I do not accept that I lack insight. I have engaged in a number of courses to enhance my understanding of and relationships with my children. I do not accept that I cannot implement strategies. I have followed advice.

86. In her second response she says: I do not accept that I have an inability to implement what I have learned for the benefit of the children. In relation to a) and b) she says:

a) I accept there has been a history of abuse within my relationships historically. I do not accept that my relationship within my current relationship has similar features. With reference to the bleach referred to, this was purely accidental. In summary, I had put bleach in the bottom of a cup to get a stain out. I have put my cup next to it. I picked the wrong one up by mistake. I did inform the Children's Hospice about the incident. I do not know why they have not recorded this. It was certainly not because I did not tell them.

b) I accept that H does have challenging and aggressive behaviour at times. I accept that this has been observed at the Children's Hospice. I asked for help with this behaviour before and historically. I have done PPP 3 times. I have done reward charts. I have done colour charts. I have done positive reinforcement. I have also been and brought cards that were recommended by the Freedom Programme which she also enjoys doing with me.

87. The mother was taken in her oral evidence to a recent incident at the Children's Hospice, when she was in the reception and on the telephone and having a discussion with her partners 16 year old son. She said that he kept ringing her, and she swore at him and told him to 'leave her the fuck alone'. She had prepared a document which the Children's Hospice had largely agreed with and that things had been calm since then.

Analysis:

88. This allegation focusses on the length of time that these problems have persisted and seeks a finding that the mother either lacks insight into the effects of her behaviour, or cannot undertake strategies to prevent these issues occurring in the future. In considering the totality of the findings that I make: I am quite satisfied this allegation is made out. H's behaviour, and the mother's reaction to her, and her ability to assist H is concerning. Just as on many occasions doctors have attempted to discuss with the mother some of her erroneous medical beliefs, and she has been unable to make changes to her thought processes, it seems that the courses in themselves are not really assisting the mother in her parenting towards H.

89. I was most concerned by the description of H being present during many altercations between the mother and various people, and the mother needs to be aware that will have a significant impact upon her. It is noticeable that despite the courses the mother has undertaken, when H was present during an extremely unpleasant telephone argument between mother and a 16 year old, the mother asserted that had not impacted on H as she had headphones on. There is no doubt that the mother currently shows an inability to demonstrate what she has learnt.

Allegation 10. Mother has repeatedly alleged abnormal blood sugar levels and has subjected Y to excessive and unnecessary painful testing:

90. The local authority assert: There has been significant disagreement between health professionals and mother about the significance of Y's blood sugar levels. Mother has regularly wished to test the levels and has repeatedly reported low blood sugars when the same measurements have not been replicated when Y has been admitted to hospital using more sophisticated equipment. The method of home testing was a painful procedure requiring a blood sample from finger or heel being taken and it was unreasonable for mother to persist in testing for low blood sugars when she was advised this was not medically necessary. Mother attempted to argue that Y could tolerate such repeated painful testing by claiming that Y had a high pain threshold, but had no justification for making that statement and has herself described examples of Y showing signs of pain. Y has also been observed to flinch as if anticipating pain. The health services eventually had to remove the blood sugar monitor which mother had at home to prevent her from overusing it. Mother contends that she was justified in repeatedly checking Y's blood sugar levels and she did not accept the medical advice that this procedure was not

necessary and caused Y pain. She continues to contend that Y had a high pain threshold. However, the Local Authority points to continued evidence that Y does experience pain and flinches from it. Evidence of her further asking for blood sugar levels to be checked at the Children's Hospice, when Y was otherwise bright and alert, is also relevant.

91. The mother says: As per my initial response, I accept that Y has been admitted to hospital for investigations surrounding her blood sugar levels. I do not accept saying that Y cannot feel it, so it does not matter. I do recall saying that Y has a high pain threshold. I had asked for investigations into Y's blood sugars due to observations that I had made including when Y is shaking and dithering her mouth which is an indication of low blood sugars and when I have checked her blood sugars, they have been abnormal. I have asked for tests to be done in hospital in keeping with the observations and at the times when I have tested at home. I do not dispute that at the times when the hospital has conducted tests what they report however, if they did this at the times when I have reported concerns then they may also see what I have been referring to. The hospital has conducted their tests randomly and not when Y has been dithering and shaking as I had reported. I had reported observations of dithering and shaking at 14:30, 18:30 and 23:30. These observations have continued whilst at the Children's Hospice when I have been in contact. I am concerned that if there is something amiss with Y's blood sugars that this could potentially cause her harm and I did not want this to be overlooked. The clinical paediatrician also reports on E63 'uncertainties relating to Y's blood sugars are: 1) whether the KCNJ11 mutation has any bearing on her blood sugar status now and if not, whether it will in the future; and 2) whether any of the low BM readings that have been reported at home or those recorded by paramedics accurately reflect genuine hypoglycaemia'. Low blood sugars have been observed other than by me. I only tested Y's blood sugars when I considered this to be necessary and there were indications that she might be low. I accept that I was asked to hand the blood sugar monitor over. I felt that I was being bullied to do so. I still have the blood sugar machine as this was not handed over to the GP. This has not been asked for again. I have not used this again either.

92. In her second response she says: Y would not flinch when I did the blood checks. I do not dispute that she feels pain. She just did not display this when I did the blood checks. I have only ever asked for bloods to be checked when Y has presented as lethargic, pale and usually when going to fall asleep. I have also observed her mouth dithering which is

also a symptom of low blood sugars. The care plan was to check if she presented like this. I only ever asked for this to be checked when necessary. There have been occasions when Y's blood sugars have been low, and these have been observed by paramedics before and also when Y has gone unconscious as a result. I understand that this is not within the records.

Evidence:

93. In her written report, the clinical paediatrician explains that blood sugars can be tested by parents at home by taking a skin prick sample called a capillary blood sugar, sometimes referred to as a BM. She states that Y has had only one laboratory confirmed episode of low blood sugar, and that happened in 2015 when she was on a Ketogenic diet. The clinical paediatrician sets out that low blood sugars can occur as a consequence of such a diet.

94. The clinical paediatrician confirms that there are no laboratory blood sugars or any investigations relating to low blood sugars over the 3 years from that point. However there has been a pattern of several attendances in a row of Y at hospital without that being raised, and then another episode of acute illness with low BM at home, often corroborated by ambulance staff, but with any hospital testing being normal on each occasion. The clinical paediatrician states that when she first met the mother in January 2017 the mother said that Y has low blood sugars often associated with a seizure. Mother reported obtaining readings as low as 1, when a normal level is 3.5. There have been no levels that low recorded in hospital at any stage. The clinical paediatrician also reports that the mother has said that Y's low blood sugars do not correct with a strong sugar solution, but suggested they do correct with sugar-free paracetamol which The clinical paediatrician made clear does not make sense. The clinical paediatrician was concerned that the mother was testing Y's blood sugars very frequently and not considering the impact of that on Y, and that the mother reported symptoms and signs of hypoglycaemia that were not reported by the carers or by the school.

95. In her second report, the clinical paediatrician sets out that during Y's admission to hospital from 27 April 2021, Y had 4 hourly blood sugar measurements with a plan to do more detailed blood tests if they were abnormal. All the results were normal. The hospital therefore changed to check her blood sugar only when there were any other symptoms, and she had very few blood sugars done after this and nearly all at times when she had a

very significant drop in her oxygen saturation. There was one occasion when she had a low blood sugar 3.1, but the staff treated it so it is difficult to understand what the cause might have been.

96. The independent expert paediatrician in his written report sets out that Y's genetic mutations do not affect her blood sugars. There was a prolonged controlled fast for 20 hours which did not cause hypoglycaemia. In his view Y needs no care for her blood sugars.

97. In his oral evidence the independent expert paediatrician was asked whether it was necessary for Y's blood sugar to be regularly monitored. He said that it was necessary to try and work out if the other genetic mutation did affect it, and that was why she had the 24-hour fast. He said that Y has had some slightly low levels and that can happen to anyone. He was asked about the heel prick, and was clear that having something stuck in your heel or your finger would be painful. He was asked about the suggestion that Y may have a "high pain threshold", and he said that obviously people's pain responses do vary depending on the circumstances but there is no suggestion that Y does not feel pain. In cross-examination, he elaborated upon his report by stating that it was his understanding the KCNJ11 mutation gave a theoretical risk of developing type 2 diabetes later in life. He said type 2 diabetes only occurs in the older age group, and Y would not have type 2 at her age. He was taken to a low measurement of 2.2, and said that would not be suggestive of diabetes, as your blood sugar would be high for that type of diabetes, not low. It could be a period of starvation, or secretion of insulin, which Y does not have. He said it could be an erroneous measurement.

98. It was suggested to the independent expert paediatrician that if mother was told that the level was 2.2, the mother may think there were concerns about blood sugars. He responded by saying that there is nothing to think that Y has a problem. He said that Y's 'ability to regulate her blood sugars is intact', adding that we store sugar in our liver, so there is no concern of Y coming to harm from low blood sugars. He emphasised several times during his evidence that he could not understand why, even if it had been suggested to the mother that Y could have diabetes that would cause her to test in this way, as diabetes creates high, not low blood sugars.

99. I heard evidence from Nurse (1) who is a staff nurse at the Children's Hospice. This was in relation to a note she had made on 23 January 2018. Her evidence was that the mother had told her that she had checked Y's blood sugars, and they were low at 2.6. Nurse (1)

stated that when she checked them half an hour later after the mother had left to take H to school the blood sugars were 5.2. Nurse (1) had checked the machine she had been given by the mother, and the previous reading said 6.9, and that previous reading had been done the day before. Nurse (1) was clear they do not keep any machines such as that at the Children's Hospice, and that was the only machine which could have been used. She said that a normal range of blood sugars would be between 4 to 6, but 6.9 would be in a normal range. A reading of 2.6 then could have been problematic if it was not dealt with. She stated that in her view it was not an unreasonable request of the mother to ask her to do it, but that it was an invasive treatment and there need to be a clear need as to why she was doing it. It was not in the care plan at the Children's Hospice. She said that the mother did not suggest that she had given Y something to eat after that low reading. She was quite clear that that monitor had not produced a reading of 2.6.

100. I heard from the school assistant headteacher. She was particularly asked in relation to whether the mother had stated that Y did not feel pain. It was suggested to her that the mother had not said that, but had said Y had a high pain threshold. The school assistant headteacher responded that she clearly recollected the mother saying that Y 'did not feel pain', saying 'I would not forget those words'. She made it very clear that the school were extremely concerned about the amount of intervention Y had and whether it is necessary. In cross-examination on behalf of the Guardian the school assistant headteacher said that the school were extremely concerned that not sufficient notice was being given to Y's lived experiences. She told me she worried that as Y was non- verbal, not sufficient notice was taken of her reactions to interventions carried out by her mother. The school assistant headteacher said the school's concerns have been ongoing for years, the issues in her view have been the same, and have got worse.

101. The clinical paediatrician was able to update matters in relation to this. She explained that she had sought further advice in relation to the mutation that Y has in relation to the KCNJ11 gene mutation. Some mutations can cause disease in the form of diabetes, or there can be mutations that do not result in disease. She said there is no evidence that Y's particular mutation causes that disease. She explained that as more and more people have been found with this mutation they have a much better understanding if that mutation is relevant, and in Y's case it is not. In cross-examination she elaborated upon this, saying that she was entirely satisfied the KCNJ11 was not causing diabetes or other problems in Y.

102. The clinical paediatrician was asked about the heel prick machine. She said the mother had it before her involvement, and was clear that the normal range for a child's blood sugars would vary widely, but she would probably expect it to be above 3.4/4 depending on the circumstances. She said that if a child was simply under the weather the levels could drop to below 3.5, but it is about context. If a child ate it would change very quickly, and there was a system in the body which keeps it within normal limits. She said there was no evidence that system did not work with Y.

103. In the mother's oral evidence, she said that the local Children's Hospital gave her the equipment and told her to test. The mother went on to say that this was necessary because Y's "sugars were going to the 40s, and she was hitting her ketones at 40 too". In cross examination, the mother maintained that she had said Y has a high pain threshold, and said that it can be difficult to distinguish if Y was in pain or not. The mother elaborated that what she was trying to say is that Y does not display when she is in pain or not. The mother was asked why she asserted that Y had a high pain threshold. She responded by saying that Y can cope with a lot of pain, saying she does not show distress at catheters, although she accepted Y does in respect of oesophagus suctioning.

104. In cross examination, the mother was challenged about Nurse (1)'s evidence. She suggested that Nurse (1) had used a different machine. She asserted that she had only pressed the Children's Hospice to do the blood sugar level monitoring when it was required, and was asked to explain why she still did it when the clinical paediatrician had said that it was not required. The mother responded, 'well that is contradictory, and why would they give me a monitor'. She accepted that eventually she had to be told not to use it. She went on to say she would still use it if she felt it was necessary.

105. In cross examination on behalf of Y, Mother was taken back to the document she had prepared as a behaviour agreement between her and The Children's Hospice recently, about various problems. She was reminded that within that document, only drafted in June 2022, she still set out that she thought blood sugar monitoring could be necessary. The mother agreed that she still thought there were times when Y may need medical glycerol. She explained that she was given the monitor by the hospital because she had told them she was worried about diabetes. Mr Rogers reminded the mother that there was only one documented episode when Y did have low blood sugars, and that was because they were trialling a ketogenic diet some years ago. The mother disputed this,

saying that there had been episodes before arriving at hospital She said that Y had been taken to hospital unconscious, but that they would treat her blood sugars and they had self-resolved by the time she had got to hospital. The mother added that Y would be unconscious and by the time she got to hospital she would be awake. She was asked where the glycogen had come from and she explained that she had received that from the GP, having told the GP that she had concerns about Y's blood sugars being low and high, and then the GP prescribed the glycogen, which she also referred to as 'rescue meds'.

106. Mr Rogers asked the mother particularly about the incident at the Children's Hospice when the mother reported the very low reading and asked for Y's blood sugars to be checked. He asked her in general about the signs that the mother alleged were shown by Y to suggest she had low blood sugars. The mother asserted again that Y's mouth would 'dither', she said that if Y struggled to 'get her levels up' then she had to keep checking and that was why she may check 6 times in quick succession. Mr Rogers suggested to the mother that other people did not see these signs, but the mother responded that sometimes Y would show signs around 5pm, before a meal. Mr Rogers asked her how it would be that the school did not see that before lunch for example, but the mother did not answer that. Mr Rogers pressed her, asking her if she still felt that the levels needed to be checked and she responded that she 'would continue to do that if (Y) was in my care'.

Analysis:

107. I heard, as can be seen above, a great deal of evidence in relation to this important allegation. The picture also became more clear as a result of the careful cross examination of the mother. The difficulties that medics dealing with Y and the mother have faced are amply illustrated by the mother's responses to this allegation.

108. It is quite clear that when Y was initial diagnosed with the KCHJ11 gene disorder there was uncertainty about the implications of that. It is also apparent that at the very least at one stage it was considered that some variants of that disorder could cause problems with blood sugars. It seems clear that was expressed to the mother by way of a letter from the genetics department. What is then apparent is that she requested a blood sugar monitor and from her evidence above was given that. It shows how the facts and realities of Y's problems can be misunderstood. If a parent tells another medic that a hospital has given her a blood sugar monitor, then it sems to me that medic will assume that there was a medical need for that. Similarly, if a parent tells a medic that Y has been in hospital for

investigations into her blood sugar levels, then any professional (or otherwise) may well understand that to be because Y had been showing abnormal blood sugar levels. That will inevitably cause professionals to deal with Y in a certain way.

109. The evidence from the clinical paediatrician however, and confirmed by the independent expert paediatrician was that Y does not show evidence of low blood sugars, and there is no medical reason for that to happen. The only confirmed time was when she was being tried on a low ketone diet many years ago. Although the mother asserted that she saw signs of this, it was not corroborated by school, or staff at the Children's Hospice. Although carers suggest they have seen it, they were accepting the mothers account of Y's mouth 'dithering' as suggesting low blood sugars.

110. I accept of course that it does appear the mother was told this may be a possible effect of that genetic defect, but in fact it is not. I am careful not to look back on the situation and the mother's actions with the benefit of hindsight, but rather in the light of the evidence. There is no evidence that Y has ever had a problem with her blood sugar levels. To the contrary, there is evidence that during detailed testing in hospital she does not. That creates the problem that although the mother has asserted this is an ongoing problem that she can see signs of, she is clearly mistaken, as the medics are quite satisfied now that there is no more uncertainty, and Y does not suffer from problems with her blood sugars. Whatever the mother may believe she was witnessing, was not in fact low blood sugars.

111. The importance of this allegation is that the mother does not accept the medical advice, even with all the assurances being given, and that although for some time the mother was being told she does not need to undertake this testing, and then clearly told that she must not do this, she continued. She is clear even now that she would test if she considered it necessary, despite hearing all the evidence.

112. Again, the mother has had the benefit of the clinical paediatrician saying in her evidence that it is not necessary, and from the independent expert paediatrician that as we all store sugar in any event, it was never necessary. She is still not convinced of that. All that conviction appears to be based on a conversation and letter she had some time ago, and her perception of what low blood sugars may look like in Y. No amount of the clinical paediatrician explaining to the mother that blood sugars do go up and down and is not surprising or to be worried about has convinced her that there is no need for further testing.

113. The mother does assert that Y's blood sugar levels have been shown to be so low that she has been taken to hospital unconscious as a result. There is no medical evidence to support that, and the independent expert paediatrician and the clinical paediatrician say that is simply not right. The independent expert paediatrician did of course accept that there could be an element of error or misreading in relation to a particular blood sugar reading.

114. The mother accepts that she continued to test for a sustained period of time when she was being advised that it was not necessary. The allegation is that she has repeatedly alleged abnormal blood sugar levels. As I have set out, the medical evidence is two- fold, that the gene disorder does not cause that problem, but also that Y in fact, as can be shown as a result of testing, does not struggle to manage her blood sugar levels. I am quite satisfied that the mother has alleged abnormal blood sugars without any basis for fact in relation to that.

115. I then turn to consider the specific allegation that the mother fabricated a low blood sugar reading when Y was in the Children's Hospice in 2018. I heard evidence as I set out above from the mother in relation to this and from Nurse (1). The mother's oral evidence was that this was a misunderstanding and that there were two monitors being used. Nurse (1) had been asked about that however and was absolutely clear that there was no such monitor at the Children's Hospice and there was no possibility that there was another machine.

116. There is always a balance in cases such as this, where specific examples must be considered, but the court must also be mindful to take the evidence as a whole. I am quite satisfied bearing in mind the evidence above that in relation to this example, the mother was not being truthful, and was seeking for testing to be undertaken by medical staff when she had not witnessed the low blood sugars as she suggested. Although the mother also asserted that she had previously taken photos of the blood sugar readings, again, there is no evidence produced by the mother to support that recent suggestion. Nurse (1) was entirely clear that there was no other monitor and given the mother does not give that explanation in her responses to the schedule, and the firm evidence of Nurse (1) in that respect, the mother was untruthful about this aspect.

117. The local authority suggest the mother has a static image of Y's medical needs. I agree

that is a very accurate description in relation to the mothers understanding overall of Y's medical needs. The mother does not appear to be able currently to adjust her thinking to take into account new information. The descriptions of Y have bruising and needles holes in her feet are very concerning.

Allegation 11. Excessive aspiration of the gastrostomy: Mother was repeatedly advised that Y does not require aspiration of her gastrostomy to remove air but despite this advice Mother continued to do so.

118. The local authority assert : No aspiration of the gastrostomy was required between the 27th April and 7th July 2021 while Y was in hospital. This aspiration was reported on repeated occasions with mother specifying the amount of air she claimed was being aspirated (see below at allegation 16) which, in itself, could have led to further unnecessary medical investigations. Mother has accepted some of the concerns about Y being aspirated and states she took on board the advice given, but did not do so promptly

119. The mother says: I do not accept that I have aspirated Y unnecessarily. I wish to comment that I have received conflicting advice about when to aspirate Y. There is one occasion that I recall when Y had been in discomfort and distressed all night. I called Rapid Response and the first thing they told me to do was to aspirate. Y was then settled and no longer in distress. I accept that Y does not need to be aspirated all the time and that there is natural air within the body. When everything was properly explained to me and the different suctions etc I followed the advice, and this was not just because one of the suction machines was removed. I do not dispute that Y did not need to be aspirated between 27 April 2021 and 7 July 2021. I do not accept that the aspiration was done forcefully on 26 January 2021. (The local authority could not call direct evidence for this, and so did not pursue this aspect of this allegation). I had followed advice. I did take on board some of the concerns that had been raised.

120. In her second response in relation to the allegation made when Y was at the Children's Hospice, she says: I did not express a wish for aspiration to be done, I raised concern that if it was required then they were not able to do this.

Evidence

121. The clinical paediatrician sets out in her report for the court that when Y was in hospital between 27th April 2021 and 7th July 2021 she did not need any aspiration of the gastrostomy.

122. The independent expert paediatrician agrees with the clinical paediatrician that there is no need to do so, but no harm in venting the gastrostomy, unless excess force is used which could cause pain. The independent expert paediatrician confirmed that in his oral evidence, accepting that if air was swallowed then it does have to come out in some way. He accepted that air does not normally flow out of Y as it would in an individual without her issues, and that the only choice for it to come out would be downwards not upwards. He was asked whether it was possible that air could be trapped in another part of the stomach, such that it would not evacuate of its own accord. He clearly did not accept that, saying that the stomach is an active bag, therefore unless the peg was temporarily blocked by the wall of the stomach, such that there needed to be some manipulation of the aspiration mechanism, there were not different compartments of the stomach.

123. I heard evidence in relation to this from the Community Nurse. She is a community children's nurse, and has been a paediatric nurse for 18 years. She knew Y from school but first met her within her family in June 2020. She has known Y for about 5 or 6 years. She gave evidence that she had had discussions with the mother about removing air from Y's stomach, and that she advised the mother there was no benefit to Y of the mother doing that. She said that she had agreed with the mother that air would only be removed if Y's stomach was significantly distended and hard, and that Mother agreed to that. She said this had to be repeated on a number of occasions to the mother and there were numerous discussions around this issue.

124. The Community Nurse explained that Y has a gastrostomy, which sits on the outside of her stomach with a bung to keep it closed. The mother would attach a syringe to it to draw air back from the stomach. She said if there was air in the stomach that was not dangerous for the child but could be uncomfortable as if she had trapped wind. She was asked why it would be wrong if the mother was doing that, and said that she was aware of reports that force was being used for this, that would cause trauma to Y. She had recommended to mother it should not happen again unless there were visible signs that there was air in the stomach. As this continued, she had visited and told the mother not to remove the air unless there was distension of the stomach, and warned the mother she

would have to report it if it continued. She said that she had had a number of discussions with the mother in relation to this, and that after they then together spoke to the paediatrician, it did stop.

125. It was suggested to the Community Nurse that she had trained the mother to do this, and aspirate the gastrostomy, but she said that was not right. She had trained the mother how to change the gastrostomy button, and you then needed to aspirate a small amount of stomach contents and test it, but that was not her showing the mother how to aspirate stomach air. The Community Nurse said that she had never seen Y with a bloated or distended stomach that required aspiration. She denied suggesting to the mother that she might be taking air from Y's lungs, but said that she had a discussion with the mother given the quantities of air the mother said she was aspirating, about where that could have come from. She did not recall having any discussion about the movement of organs, and said she could not see how aspirating could move any organs. She said this was of course just a conversation, not any form of diagnosis.

126. Nurse (2) was also asked about this. She said she raised it with the clinical paediatrician and was told that it was not required. She was told Y should be able to pass swallowed her naturally and there was no reason for her to have accumulated over a litre of air. She said she had raised it when it was reported to her that it was not just air that was being aspirated but actual stomach contents.

127. In her oral evidence, the mother said that she would use a 20ml syringe and would pull the air out very slowly. She said if some food came out at the same time, she would put it back into Ys stomach, with water, 'so that her blood sugars did not drop'. In examination in chief, the mother was asked who had told her to do that? She responded that it was a natural procedure with a gastrostomy, and that when she was trained she needed to make sure there was no air in Y's stomach. The mother said she was trained about eight years ago. She agreed that she was told she needed to stop doing that at the very end of last year before Y was removed from her care. The mother was asked what the clinical paediatrician had said as to why she needed to stop, but the mother responded, 'she said I needed to just stop'. The mother accepted that from about February 2021 she was encouraged to stop this practice, but said that she could still do it when Y had an extended stomach. She added that she still had to follow the advice in relation to when Y 'had her meds'.

128. The mother was taken to F1891, where in October 2021 at the Children's Hospice she

was still telling a nurse that Y needed to have this done to stop her waking in the night. It was put to her that she was talking to someone who did not know the history, and she was encouraging the nurse to arrange for aspiration which other medical professionals had said did not need to be done. The mother's response was that she still felt that Y needed to have it done. She suggested that it was necessary as Y was waking up in the night, but she was reminded that Y was in the Children's Hospice at this time of course and they were not reporting that Y was waking in the night.

129. Mr Rogers asked the mother at the very conclusion of her evidence whether if Y was still in her care, she would undertake this procedure. She responded that she would not do it if she had not been trained, but as she had been trained then if she thought Y's stomach was distended, then she would do it.

Analysis

130. I was concerned that there was an element within this allegation that we needed to be more careful regarding the terminology. There is a difference between air being vented from the gastrostomy, and air being aspirated by a syringe. The mother was clear that in general she was aspirating air.

131. I am careful to treat each allegation separately, but the reality of course is that this is a very similar pattern to allegation 10 above. It is quite apparent that something that has been suggested to the mother as a possible problem/solution then becomes an issue in itself, with the mother repeatedly performing this action, and struggling to accept the updated advice, and failing to be reassured by medical advice. Although the mother had clearly been given instructions and shown how to do this and told that she could do this when necessary, the Community Nurse made it clear that in fact she had not trained the mother to do it in the context that the mother then undertook the procedure, and that she had not suggested it was necessary.

132. The evidence of the clinical paediatrician and the independent expert paediatrician was that there was no reason to think that Y had a particular problem in this regard. Whilst the independent expert paediatrician accepted that Y was unlikely to be able to expel air upwards, there was no reason to think it would not go downwards. When Y was in hospital for a sustained period of time, she had no difficulties at all with this, and did not

need to be aspirated. It has not needed to be done at the Children's Hospice.

133. The evidence of the Community Nurse and Nurse (2) was that this was an ongoing problem for a sustained period of time with the mother continuing to do this, despite all their efforts to persuade her it was not necessary. The problem is neatly illustrated by the mother's response to Mr Rogers, which was that she would continue to do this if she considered it necessary as she had been 'trained to do it'.

134. The evidence was of course that the mother had in fact been told that she could do it, if it was necessary. Once again, the evidence is that this was not medically necessary for Y. Whilst of itself venting the gastrostomy did not cause pain to Y, and neither did aspiration of the gastrostomy, the aspirating is in my view still an intrusive procedure, which would be unpleasant for Y, and I accept the medical evidence that it was unnecessary. The mother was in this example as well, unable to reconsider her views, or accept the medical evidence, as shown in her discussions with the Children's Hospice staff that showed she still considered it may be necessary, and as shown in her oral evidence that she would still undertake this if she viewed it as being necessary.

Allegation 13. The events of 24th April 2021: Mother states that Y had an 8 minute seizure at about 9.00 am on 24th April 2021, but accepts that she failed to administer medical treatment or to call an ambulance or seek urgent medical treatment. This placed Y at risk of significant harm and/or death.

135. The local authority assert: mother called Rapid Response Nurses at 1.00 pm, to check the results of a urine test taken the day before and asked them to visit to check Y. They did so at 4.30 pm and found Y alert and well, however that would have been too late if there had been serious consequences of the seizure at 9.00 am. The Community nurse visited on 25th April 2021 and mother attempted to argue that she did not have a plan which stated she should have called an ambulance in response to such a seizure. Mother has subsequently made a number of inconsistent claims about why she did not administer medication or call an ambulance. For example, she has suggested inaccurately that 'Y was allowed to have 3 myoclonic seizures before she was to go to hospital'; or that she did not call an ambulance because she did not trust the hospital; or that she was justified in denying Y hospitalisation as she had asked to be transferred to a different

hospital.

136. The Local Authority also invites the Court to refuse to accept mother's assertion that: 'I did call Rapid Response following the myoclonic seizure and it was confirmed that Y was okay' given that the evidence shows mother telephoned them at 1.00 pm to check on the results of a urine test and asked them to visit, and that they did not visit until 4.30 pm. The Local Authority further invites the Court to refuse to accept mother's assertion that she had received conflicting information about what she should do in the event of such a seizure, which in some way might excuse her failure to take the action, which she appears to accept she should have taken. It is asserted that she had received very detailed training which allowed her to distinguish between the different types of seizures.

137. The mother says: I accept that Y had a myoclonic seizure which lasted 8 minutes. I accept that I did not call for an ambulance. I accept that I did not administer medical treatment. I did call Rapid Response following the myoclonic seizure and it was confirmed that Y was okay. I did not know that a myoclonic seizure lasted seconds rather than minutes. I had been told that I should time the seizure which is what I did. I had received conflicting information about this. With myoclonic seizures you also did not administer medication. Since this incident, the guidance has been much clearer over expectation. I regret not calling for an ambulance and I am ashamed of that decision. I am being truthful about this incident taking place. There is an error in my statement at paragraph 300, in which I refer to 3 myoclonic seizures, this should read tonic seizures. Y does not need to go into hospital for myoclonic seizures as they are not epileptic seizures. My understand is that they are not the ones that can damage the brain, the tonic ones are. Y has a complex seizure plan and complex epilepsy. I accept that the seizure plan was not clear, and this appears to have been accepted as well by professionals following the event. I accept that I did ask for a transfer to a London Hospital. At one point this was going to take place but then it was decided that Y should stay at the local Hospital. I have held my hands up that I could and should have dealt with things differently.

138. In her second response the mother says: I do not accept that the seizure plan was clear, and this has been acknowledged. I have accepted my failing and my shortcomings and mistakes in respect of this incident.

<u>Evidence</u>

139. The community nurse gave evidence that she contacted the mother on the Sunday after this event as she was working. The mother told her that she wasn't sure what she should have done, as she did not think advice for that event was in the plan that she had. She did have a conversation with the mother feeling anxious about the care package for Y being reduced, and that that was being discussed as there had been a reduction in the seizures. The mother had said that she was so worried it was causing her to lose sleep. The mother felt that if the care package was reduced then she, the mother, would have to sit with Y during the night and that would impact upon her health.

140. In relation to this incident, the Community Nurse was clear that her advice had been to the mother that she should have called an ambulance. It was suggested to her that the mother thought that she should only call an ambulance if it was a tonic/clonic seizure. Her evidence was that what the mother described to her was not a tonic/clonic seizure, but that Y was slumped forwards with her arms pulled in and violently shaking for 8 minutes. She said that the jerking movements were consistent with myoclonic seizures. She said that she found it hard to understand why the mother had not called an ambulance when the mother told her that she had not seen a seizure of this severity before but accepted that perhaps the mother hadn't understood the severity of this seizure. She said the mother told her that once it subsided Y reverted to normal and slept for 45 minutes. She agreed that an ambulance should have been called for. She said that in her view this seizure went on for 'a very, very long time' and it was a long time for someone to watch a seizure. She was very clear that the mother had told her she had not seen that before.

141. The independent expert paediatrician was asked about this. He said that the seizure plan that was in place at this time dated March 2020 was a standard plan. It said that if the seizure continues for more than 5 minutes then you should call an ambulance, and the reason for that was that it was very unlikely that any harm would come to a child if a seizure was 5 minutes long but with the increasing time there could be a risk of there being a lack of oxygen.

142. The independent expert paediatrician clearly considered the seizure plan that was in force to be a sensible one, and a very normal plan. He was also clear that the purpose of the 5

minutes limit until an ambulance was called is a recognition of repeated movements consistent with a seizure going on for that time. That was not about individual jerking movements being repeated.

143. When the mother gave her evidence, she said that she should have called an ambulance. She said however that 'I was indiscretion' but she had not had the information from the hospital. She said she was contemplating whether to give Y the medication. She said that it was a myoclonic seizure and Y tilted her head forwards and jerked. She said that at that time she had 'interpreted it wrong', and she had made a mistake. She said that she was confused. She said that at that time she had lost trust with the hospital as they had neglected Y in her view and sent her home when they should not have done. The mother went onto tell me about the possible diagnosis when Y was a baby that Y had Mitochondrial disease and how she had understood that meant Y would die and she had even picked out Y's coffin.

Analysis:

144. The mother, to her credit, accepts that she should have called an ambulance for this seizure. The mother does attempt to justify in part why she would not, when that is difficult to understand. In my view the seizure plan was quite clear, that for any seizure lasting over 5 minutes, an ambulance should have been called. I do not accept that any confusion about what type of seizure it was would impact upon that. Ultimately, I was unable to understand why the mother did not call an ambulance, but there is no doubt that if it is true and this seizure took place as the mother described it, she placed Y at great risk of harm in not calling an ambulance.

145. I have considered the mother's explanation of how she had at that time lost faith with the medical professionals. I do bear in mind throughout this hearing what evidence the mother gave about the impact of Y's diagnosis on her. She expressed clearly the dreadful suggestion of how she understood Y was going to die as a baby and spoke movingly about her understanding and actions at that time. Although clearly there were a number of disputes between her and the medics, as set out in the allegations I have already considered, it is hard to understand how that would impact on her decision not to call an ambulance or how events when Y was far younger could still impact on her in a practical way during that event. Ultimately, given I was unable to ascertain exactly why she took

the decisions she took, it is a significant concern in the future that the mother could take such a decision again if she were caring for Y. It is certainly true that the mother has given various and quite different reasons for her decision made on that day.

146. In relation to this, it is noticeable that the mother clearly used the wrong word in trying to express herself. She said that her decision was an 'indiscretion', when she clearly did not mean that, but was trying to express that it was a unintentional mistake. I set that out not to distress or upset the mother, or demean what she was trying to express, but only to illustrate that she will often use words and phrases which are not correct in their context, but which to someone who does not understand the mother's cognitive difficulties could be very confusing.

Allegation 15 Jerking episodes: Reports by mother of Y's jerking episodes have been frequently far higher than those observed by health professionals and care providers, which can lead to higher levels of medical intervention than are needed.

147. The local authority assert: mother accepts that her reporting of Y's 'jerking episodes' or vacant episodes is far higher than the reports by professionals, but asserts that her reports are more accurate because she is more attuned to her daughter, and that professionals sometimes miss seeing such events. This is strongly disputed by the Local Authority and a finding is sought that mother has over-reported the seizure episodes and that the over reporting is likely to lead to higher levels of medical intervention than is needed.

148. The mother says overall in relation to this allegation: Accepted. I have said repeatedly that professionals are not always watching Y. Some of the jerking movements are subtle and if you are not watching her, they can be missed. Professionals do not always observe Y in the same way or as consistently as I do. This has been a continual problem. I have on occasions challenged this. I have also pointed out when jerking movements have happened and they have been missed by professionals.

149. In her second response she says: I have said repeatedly that professionals, contact workers are not always watching Y and as some of her presentation is subtle, this is often missed.

Evidence

150. In her report to the court the clinical paediatrician sets out that when Y was in hospital between 27 April and 7 July Y had a seizure on her 1st night in the hospital. She had around 7 other episodes during the course of the admission where her oxygen saturations dropped very low, and the clinical paediatrician believes they were seizures. She had 3 other episodes where her oxygen saturations dropped but recovered almost immediately, and again the clinical paediatrician considers these are likely to have been brief seizures. the clinical paediatrician says that clinical staff who are unfamiliar with Y seizures could fail to recognise them. There have been no concerns about myoclonic seizures apart from on the 1st night. the clinical paediatrician accepted that as these are often very brief it is likely Y had some others while she was in hospital, but she does not believe these were a frequent occurrence as they were not reported by any staff member or visitor over several weeks of admission.

151. The clinical paediatrician explained in evidence that Y has myoclonic seizures which look like an electric shock, and said that some of her other movements are 'a bit funny' but that Y is unusual and some of her jerking movements probably are seizures. She accepted that Y has the most unusual seizure plan of any child she has ever looked after. She accepted Y's seizures would be very worrying and need an immediate response, and that was to be expected in relation to Y's pattern of very unusual epilepsy. She accepted these are difficult for a parent to manage, and that the mother has managed seizures very well. She also accepted that sometimes there would be seizures which were not necessarily very obvious, and they could in fact be very subtle, although the effects on Y could be very dramatic. She accepted that people can miss them. She was clear that at times they would cause Y to drop her oxygen levels, and that is likely to be due to a seizure. She said that it would be abnormal for a seizure to continue for many minutes.

152. The independent expert paediatrician agreed with the clinical paediatrician that it is difficult to categorise the fits and seizures suffered by Y. He accepted that management of them is quite difficult.

153. Nurse (2) accepted from her involvement that Y's seizures were difficult for a parent to manage. She said the carers were trained to observe and describe, not to allocate a condition. Her concern was that their recollection did not always match the mother's. She said they would describe a jerk as being a movement, purposive, and that Y was interacting, whereas the mother said that these were seizures, and that Y had a blank

expression, which the carers did not agree with.

154. Nurse (3) said that when Y first came to the Children's Hospice she had a substantial overnight care package, and they were told she had multiple seizures, but at the Children's Hospice she had hardly any overnight.

155. The following specific allegations (a) to(e)are made by the local authority in support of this allegation:
Allegation 15(a) The very clear evidence from the Children's Hospice' carer at F1545 (25th July 2021) of an event where mother was having video contact with Y and claimed to see evidence of Y's eye rolling which the carer, who had Y on her lap and her own eyes on the screen the entire time, did not experience or see.

156. The mother in her second response stated in response that: Y was eye rolling.

157. Nurse (3) gave evidence about the incident above, on an occasion when she was caring for Y when she had virtual contact with her mother. Nurse (3) said that professionals did see jerks when they were caring for Y. On this occasion Nurse (3) said Y was sat on her lap with her back to Nurse (3)'s chest, and she had one hand holding the phone pointing towards her and Y. She said that she could see Y's face because her head was to the side of Y's head, and she could see Y's face on the screen. She said that she was paying attention to Y as she was asked to record how Y reacted in contact and therefore she was taking notice of her face. She said Y did not roll her eyes and did not jerk. Nurse (3) explained that she has worked at the Children's Hospice for almost 20 years, and that about 80% of their clients have seizures, which are often small and discreet. She said she would simply have made a note if it had taken place, and that of course it was of no consequence to her whether it took place or not. She said that the mother and H then encouraged Y to breathe, but that Y was breathing regularly. She said she could feel her chest movement and that had Y not been breathing or had she changed colour or if her breathing pattern had changed she would have recorded that. In her statement about this event Nurse (3) said that mother had suggested at the time that Y did jerk.

158. In her oral evidence the mother was asked about this incident. She insisted that Y's eyes had rolled upwards for about 6 seconds or so. When it was suggested to her that that would have been quite noticeable for anyone looking at Y, she responded that she was very observant with Y, but the professionals are not really aware of what she does.

She denied saying that Y had jerked, but said that Y had held her breath, 'after the eye rolling'.

Analysis:

159. Once again, the local authority, appropriately in my view, plead a specific incident to illustrate what they say is general occurrence. Nurse (3) gave her evidence in straightforward fashion. She had clearly been concerned at the time about events, as she recorded that as such in the notes. Her evidence was that she was watching Y as she held her, on the phone. The mother was watching on a phone, so their views were similar. The mother's assertion is that Y rolled her eyes upwards for approximately 6 seconds. In my view that is a lengthy period of time for anyone watching the face of a child. Nurse (3) was absolutely clear that Y did not roll her eyes upwards at all, let alone for that period. As Nurse (3) pointed out, had that happened she would simply have recorded it. She said that Y often did have small episodes.

160. The other aspect of this was the other matters that the mother complained about at the time. Nurse (3) said that the mother asserted that Y jerked. The mother said that was not right in her oral evidence, it was only that Y rolled her eyes and was not breathing.

161. In relation to Y holding her breath, there is a wealth of evidence that Y did do that at times. Once again however, the mother says that she could see that Y was holding her breath and Nurse (3) was clear that she was holding Y around her chest, and Y was breathing as normal.

162. I have considered all the evidence relating to this allegation. I am quite satisfied that Nurse (3) was accurate in what she says, and that Y did not have any form of seizure during that phone call, and her eyes did not roll upwards. I am quite sure that Nurse (3) would have seen if Y had indeed rolled her eyes upwards for six seconds and would simply have reported and recorded that. I also accept her clear recollection that the mother did suggest that Y jerked and in my view the mother has resiled from that suggestion given the way in which Nurse (3) illustrated that she was holding Y. Nurse (3) would clearly be able to have felt that. I am particularly concerned not only that the mother asserted Y was breath holding but that she involved H in relation to that, when clearly that was not taking place. I accept the local authority's submissions in relation to this matter, that it did appear the mother was adjusting her evidence in relation to this.

Allegation 15(b) The frequency with which mother claimed to have seen episodes which were not observed by staff in the same room at the same time, also gives rise to doubt that such episodes actually occurred.

163. The mother in her second response stated in response that: When I have been attending contact with Y since she has been removed from my care and whilst she has been at the Children's Hospice, the Children's Hospice staff have not been permanently present, there has been a contact worker. They are not always watching. They do not know the presentations of Y and therefore how can they comment?

164. In making my finding above, I do make it clear that I also have no doubt that there are times when Y has very minor movements or possible small seizures which at times the mother has noticed when others have not. That does not detract however from the seriousness of the mother asserting that incident above took place when clearly it did not. In my view the very significant disparity between the number of seizures that the mother reported and the number that everyone else, including the hospital, carers at home and the Children's Hospice reported is too large to be explained by the mother being more observant. I make this finding as I set out below in more detail that the mother reported seizures that were not taking place.

Allegation 15(c)The frequency with which mother claimed to predict that a seizure was about to occur, when it did not.

165. The mother in her second response stated in response that: I would only report when I thought a seizure was going to happen when Y presented in that manner. For example, when she would hold her breath. Her presentation at times can be very subtle.

166. The independent expert paediatrician was asked in relation to the jerky movements, and whether they were definitely seizures. He said it is not absolutely possible to say that a particular jerky movement is or is not a seizure, the only way you would know is if a child had a brain monitor attached at that time.

167. I asked the independent expert paediatrician whether breath holding to be an indication of someone being about to have a seizure, or whether that could cause a seizure. He did

not consider that to be possible.

168. I shall deal with this allegation together with d) below.
Allegation 15(d) mother told an orthopaedic consultant on 3rd September 2021 (F1596) that Y was having around 50 seizures a day. There is no evidence that was happening at the first the Children's Hospice' site. On 14th December 2021, the mother told the paediatric consultant that Y still had seizures and breath holding episodes, but this was contradicted by the the Children's Hospice worker (Y having moved to the second Children's Hospice' site on 3rd November 2021) who attended and who added that they had not needed to use her rescue medication. Mother went on to say that Y had had cardiac arrests in the past and that at home her seizures were up to 70 to 80 a day. However, on 16th December 2021, Mother accepted that Y's seizures have reduced, and said this may be why the school felt she no longer needed 1:1 support at school.

169. The mother in her second response stated that: I was reporting what happened when Y was in my care. I have never reported 70-80 seizures a day. Y also only needs rescue medication for certain seizures and not all the time. I am pleased about this. That is not to say that what I was reporting before is inaccurate or incorrect. I do feel that Y needs 1:1 support for her safety.

170. In her oral evidence the mother said that she has never said Y had 70 seizures a day, but she has said that Y has 50. She said for some of these Y would drop her head and shake her arms.

171. At F1931 the mother is recorded as saying on 14th December 2021 that Y had up to 70-80 seizures a day when she was at home.

Analysis:

172. It seems to me overall and as I have set out above, that the mother is quite sure that she can see seizures that others miss. Whilst that may be the case occasionally, the mother is also convinced of certain 'signs' that there is no medical support for. In my view it is established on the balance of probabilities that the mother does overestimate the number of seizures that Y suffers from, and states that seizures have taken place when they have not and she does not accept that can have serious consequences for Y, and is not careful of her assertions about seizures, and will not accept she may be mistaken at times. I am conscious of the mother's numerical difficulties, but I am satisfied that the mother has told professionals that Y has had up to 70 seizures a day, despite her denials of that.

Allegation 15(e)There has also been at least one clear example of the misreporting of a seizure, which could have led to different intervention being required. Y was seen by staff to have a 3-4 second self resolving seizure on 2nd October 2021 which mother subsequently described as being a 4 minute seizure, when she asked about treatment on 6th October 2021.

173. The mother in her second response stated in response that: I was called by the Children's Hospice to inform me about this seizure. Why would they have called me for a 3-4 second self- resolving seizure because they didn't normally. I was told it was a 4 minute seizure on the telephone. I remember it clearly as I was very concerned.

174. In cross examination in relation to this incident, the mother repeated that she was told it was a 4 minute seizure and that the Children's Hospice had rung her to tell her about this. She in fact elaborated on this, saying that she had asked if Y was blue, and was told she was, and that she had asked if Y was given buccal midazolam and was told she had, but was not given a bag and a mask. The mother said that in her view it was frustrating that the Children's Hospice had not followed the seizure plan. She was challenged that the note from the Children's Hospice was that it was in fact only a 3 or 4 second seizure, and the mother responded that they would not have rung her if that was the case.

175. The mother was then taken the Children's Hospice notes, F1712, F1708, F1908, which showed that in fact the mother had phoned the Children's Hospice, and had been told that there was a 3 or 4 second seizure, however, in oral evidence the mother maintained her version of what had happened.

Analysis:

176. This is another relevant allegation that became far more clear in oral evidence. Whilst the mother again claimed that the Children's Hospice had called her, and used that fact to illustrate why she was right about this report, as they would not call her about a shorter seizure, it was shown that there was no evidence that such a phone call had been made. I have no doubt that the Children's Hospice would not only have documented such a seizure, but would have documented the phone call following it. That is not at all what the documents show, in fact quite the contrary, they show that no such call was made, and the mother is either mistaken in her recollection of this, or it is an example of her exaggerating a seizure taking place. The local authority assert this demonstrates the mother making up something to vindicate her position, rather than admitting she was

mistaken. In my view that is correct. The mother's evidence was characterised by an inability to accept she may be mistaken, and a dogmatic insistence that she was correct even when taken to other evidence which clearly disproved her stance. I accept of course that at least partly this is out of the mother's lack of capacity to change her thinking, it is not simply that she chooses to behave in this way, and that is illustrated by a number of the conclusions of the psychological assessment.

Overall Analysis of this allegation:

177. The mother accepts that her reporting is higher than others. In my view this is only to a limited extent due to the mother being more attuned to Y. In large part it is also due to the fact that she is prone to interpreting every movement as a seizure. I accept that for parents of children with life threatening seizures, that every seizure or suspicion of one is stressful and that becomes cumulative over the years.

178. The difficulty in relation to this is the mother's lack of ability to analyse and rationalise and accept when she is wrong. Overreporting from the mother does create a risk of harm from the mother towards Y as the local authority plead.

Allegation 16. The alleged quantity of air being aspirated rather than vented: The medical possibility of mother aspirating as much air as she has claimed from the gastrostomy is challenged by medical professionals who are concerned that reports of significant amounts of air will lead to further medical treatment and investigation by professionals unaware of the history.

179. The local authority assert: In relation to the allegation of excessive aspiration of the gastrostomy, mother has suggested that this needs to be aspirated because Y 'constantly breath holds' and that pain in her stomach results. The Local Authority disputes mother's claim that air collects in this way, requiring aspiration. The Local Authority also disputes the extent to which Y genuinely holds her breath. Since the start of proceedings, with Y being cared for at the Children's Hospice, there have been a number of occasions where mother has claimed to observe 'breath holding' which have not been seen by others.

180. The mother says: I accept that professionals have challenged some of my reporting, that does not mean that I am not accurate with it and that I have been misreporting. Y constantly has air in her stomach. She constantly breath holds. This needs to be aspirated and you can tell when she is in pain with this. I have previously asked for a valve bag for Y which would remove the air automatically but that would also remove her food. After consideration I did not accept this course of action.

181. In her second response the mother says: I remind the court that during contact, there are contact workers present, not Hospice workers. They are not constantly watching me. I asked at the beginning of the case if a Children's Hospice worker would be present, and they are not.

Evidence

182. The clinical paediatrician in her report for the court states that the first time she saw this being mentioned as an issue was at a gastroenterology appointment in October 2018. She said although the mother reported she was undertaking this procedure, Y did not need that intervention at school, and it was not needed when Y was in hospital for a two-week period in October 2018. It has never been needed during subsequent admissions to hospital. The clinical paediatrician sets out her concern that the mother's reporting she was aspirating up to 1 litre of air from Y's stomach, and that in her view that was unlikely to be accurate unless it was referring to repeated aspirations over many hours. The clinical paediatrician set out that if there was air in Y's stomach which was under pressure it should come out by just venting the gastrostomy. A carer had reported that the mother had aspirated with such force that her knuckles turned white. Whilst the clinical paediatrician accepted there was a possibility that Y may swallow more air than most children, there was no reason why that would only happen when in her mother's care. She stated that there was no reason therefore for Y to have aspiration of her gastrostomy to remove air as opposed to simply venting. The clinical paediatrician stated that the mother had been told not to aspirate Y's gastrostomy, but she continued to do so.

183. It was suggested to the clinical paediatrician when she gave her evidence that the hospital had originally given the mother guidance and training on how to aspirate Y's gastrostomy. The clinical paediatrician said she was not sure about that, but accepted

the mother would have been given training on how to use the gastrostomy. The clinical paediatrician was of the view that if this was vented gently then there was no harm, but it was still not necessary. She accepted that Y does swallow air, and that she has a funny breathing pattern, but the issue was the mother doing it with a degree of force which was not appropriate.

184. The independent expert paediatrician was asked about this quantity of air, and said that it would be quite common to aspirate 40/50/60 mls of air, in a 60ml syringe, but in his experience it would be very uncommon to aspirate another full syringe. In cross-examination on behalf of the children, he accepted that he would probably view anything over 100mls to be excessive. It was suggested to him that 1400mls of air, would be 1.4 L of volume, which he likened to 3 pints of fluid, saying that would be a very tall order. He said that is therefore an unlikely amount, not impossible but it seemed to him very unlikely. It was suggested to him that if the mother was using a 60ml syringe, that would be around 23 syringes worth of air, which he agreed appeared to be implausible.

185. The community nurse was asked about this. She was able to explain that 1400ml is a very large amount. The syringe would only be 60mls. She said she never saw the mother doing this, but was aware carers had reported the mother doing it.

186. Nurse (2) told the court that she was concerned in relation to the issue of air being removed from the stomach, as she had never heard of such a thing. She was so concerned she had emailed the consultant, as mother was reporting removing over a litre of air, and that did not seem physically to be able to be possible to her. She said she was concerned both the practice and the accuracy of the reports. She said she was told that the mother had been told to stop doing it, but she was then told that it was still continuing.

187. The mother confirmed her written evidence in relation to this when she gave her oral evidence. She said that she was using the same 20ml syringe, (rather than the 60ml syringe described by earlier witnesses) and would draw out the air, - counting 20, and 20 and 20. She said that she would remove lots of air. Sometimes it would be 60ml, sometimes 150ml, and sometimes 1000ml, it could be very variable. She denied that she had been trained or told to only do this when Y's stomach was bloated, and said she had been trained to do this before each feed, and that she had to make sure Y's stomach was clear of all air before she gave a gastro feed or medicine.

188. Given the questions asked of the independent expert paediatrician, the mother was asked about breath holding and reminded that was not the same as breath swallowing. The mother's response was that 'Y does breath hold, and you can get that out of her, but she does air swallow as well'. When the mother was pressed about this, that she has previously said that Y was breath holding and that therefore she needed to be aspirated, the mother then said that if she felt that Y was breath holding and her stomach was extended she would vent her.

Analysis:

189. This allegation of course is connected to number 11 above. This part relates to the mother's suggestion that she has aspirated up to 1.4 litres of air, and on a number of occasions has vented over 1 litre of air. Every professional involved in this matter expressed significant doubt over the alleged quantity, but the mother maintained her stance in her written and oral evidence.

190. Once again, the oral evidence assisted in relation to this. The mother explained that she was using a 20ml syringe, and when asked about how she measured the amount of air that she was removing, she said she counted 20, and 20 and 20 to reach her overall figure.

191. The independent expert paediatrician, as I have set out above, made it clear that he would consider it unusual for there to be 100ml removed, and that he would consider anything over that to be excessive - that is, not necessary. The mother is stating of course that she removed 14 times that amount. I am conscious of the mother's difficulty with accuracy in mathematics, and do not wish to simply assume that she is wrong, but the combination of the evidence from all the witnesses means that I am quite satisfied that the mother has not aspirated 1,400ml of air from Y's stomach. It appears to be far more likely that the mother has become muddled with the sums she has added up. To withdraw 1,400mls of air using a 20ml syringe would take 70 syringe fulls. Whilst no medic suggested that was impossible, and it would be open to me to make a finding that did take place, (which for the avoidance of I would view as an entirely unpleasant and unnecessary procedure to be performed over a lengthy period of time on Y on a large number of occasions according

to the mother), my finding is that did not take place, and the mother is simply mistaken in relation the quantity of air.

192. The relevance of that of course is that the mother does not accept she is mistaken, and refuses to accept that possibility. Again, even after hearing the evidence of The clinical paediatrician, the independent expert paediatrician and the community nurse in relation to that, the mother was quite certain that she was right. This finding is clearly made out that the mothers continued incorrect assertions may well lead to future investigations into Y which are unnecessary and inappropriate.

193. The other worrying aspect of this allegation, is that the mother asserted both in her written evidence and in her oral evidence that this was in some way connected to Y breath holding. To ensure I was not misunderstanding this, I asked the independent expert paediatrician about that. He of course confirmed that Y breath holding cannot be linked to air in her stomach. The mother quite clearly however believes that it is. It is a very typical example of the difficulties in this case, and the many things that the mother holds strong but incorrect views about. Without of course wishing to distress the mother, as a result of difficulties with understanding, she has clearly for many years believed that Y breath holding puts air into Y's stomach which needs to be removed. She is entirely wrong about that.

Allegation 17. Reports of choking: Mother reports Y choking when she is feeding, but these events are not observed by the carers, school or hospital staff. Whilst choking is one of the concerns due to Y's condition, mother's over-concern has led to her suggesting Y should be fed via her gastrostomy which would have the detriment to Y's quality of life of removing the pleasure she gains from eating food.

194. The LA say: Mother claims that Y chokes when feeding but she accepts that this is not observed as much by others. The evidence is rather more nuanced than that, in that mother has invited professionals to watch while she feeds Y, asserting that she has just choked and will do so again, and the observation is not made.

195. The mother says: I accept that I have reported choking incidents. I accept that this has not been observed as much by carers, school or hospital staff. They are not present with Y all the time. It had been queried that Y may have more issues when she is tired or due to a change in medication for her epilepsy. I do think it is safe for Y to be fed by gastrostomy

tube. Feeding needs to be done in a safe way. However, Y enjoys eating and this should be promoted.

196. In her second response the mother says: When Y is coughing and spluttering, I will give her a break from her food. That is what I refer to as choking.

Evidence

197. In the clinical paediatrician's written report for the court, she sets out her concerns that what the mother describes as Y having over aspiration, that is, coughing, going red in the face, has not been witnessed by school hospital staff or carers. She says that as Y has not had episodes frequently of chest infection, that also does not suggest recurrent aspiration. Whilst the clinical paediatrician accepted that it may be that Y does this more frequently after school when she was tired, she states that if there were truly difficulties with feeding she would expect that to happen at more random times.

198. In her second report, the clinical paediatrician states that during Y's admission to hospital 27th April to 7th July 2021 she was fed orally and there were no concerns about her choking or any other adverse events during meals. Y did not require any airway suction except in association with seizures, and there was no evidence of a deterioration in Y's feeding skills or a variability in her skills depending on her tiredness level.

Analysis:

199. This allegation is clearly made out on a factual basis that Mother has suggested Y could be fed by tube to avoid choking. Once again, the evidence from a wide variety of sources is that the mother has over reported this issue.

Allegation 18 Over use of suction in clearing airways:

200. The local authority assert: mother regularly reports Y to need suctioning of the air ways when Y is at home, but this is not required in hospital, at school or when the carers are attending. The procedure is invasive and is distressing for Y, which will therefore cause her trauma, and over use of suctioning can reduce and compromise Y's safe swallowing ability. This is particularly a risk when mother has acquired additional equipment from professionals unaware of the history and has used deep suction techniques and at a pressure above the normal 150, and up to 300, as evidenced by blood being seen in the catheter tubing. Mother accepts that she has used suction to clear Y's airways, but claims

only to have done so when needed, and only to the extent that she has been advised to do so.

201. The Local Authority invites the Court to make the finding, including that suctioning has been over used, that it is invasive and distressing, as well a potentially compromising Y's safe swallowing ability. The fact that blood was suctioned in the catheter tubing by this technique should have made mother appreciate she was over using the technique. It is significant that suctioning is no longer used to clear the airways at all. It should only ever have been used in the event of an emergency.

202. The mother says: I do not accept that I have over used suction to clear Y's airways, and I have only done so when needed. I have followed advice received in terms of the levels of suctioning that I administered to Y. I had received advice from Rapid Response to suction at 300 in an emergency.

Evidence

203. The clinical paediatrician in her report for the court sets out that the mother says that Y needs regular suction of her airways. The clinical paediatrician however states that Y has an effective cough and was able to clear her airway secretions by coughing. She is clear that the only reason Y has suction at home is because following a seizure and the emergency medication Y is likely to have difficulty clearing her secretions. That is why she has a Yankauer at home. Y has no medical need for suction facilities at home for any other reason. Y does not need suction at school and it is not delivered by her carers. During her two-week hospital admission in 2018 she did not need any suction.

204. The clinical paediatrician reported that a new member of the community team in 2020 responded to the mother suggestions that Y found it difficult to clear secretions by providing suction catheters. The clinical paediatrician was concerned at the reports that the mother was suctioning Y frequently, and that this would cause trauma which she suggested was shown by the blood in the tubing. The clinical paediatrician stated that as Y has strong gag and cough reflexes, being suctioned like that would be uncomfortable and distressing for her. The clinical paediatrician stated that once that intervention was

withdrawn Y had remained well since then. The clinical paediatrician was also unclear on what basis the mother was using the high pressure of 300 for the suctioning, and said normal pressure should be 150.

205. The clinical paediatrician sets out all of her concerns in relation to this in her written report for the court. She said that the mother was reporting symptoms of choking that were not witnessed by other carers and it was not clear whether this was fabrication or misinterpretation. Mother has stated that she thinks Y should be fed by gastrostomy, and mother was suctioning Y's upper airway unnecessarily which is invasive and distressing. The clinical paediatrician said that due to the mother's description of Y's management of the airway secretions, a more invasive suction was put in place that was then used frequently by the mother, which caused trauma to Y's airway, and the mother was using a higher suction pressure which the clinical paediatrician viewed as excessive.

206. In another part of her report for the court, the clinical paediatrician sets out that she had suggested trying saline nebulisers in 2017 during her 1st meeting with the mother as it was reported that Y had secretions that she found it difficult to cough up. She states that the idea was that the nebulisers would make secretions more watery, and that was instead of more invasive suction which was the mother's suggestion. The clinical paediatrician states that there was no evidence that Y needed the nebulisers.

207. The independent expert paediatrician in his expert report sets out that if it is true that the mother had undertaken suction on Y frequently then in his view the mother was causing harm and thus inducing illness. The suctioning is uncomfortable and can cause localised oral trauma. In his oral evidence the independent expert paediatrician said that it is not normal for a deep catheter to bring up blood, and it would be very unusual to see blood as part of the mucus that has been aspirated. He said that he would expect someone to be alarmed and make enquiries if they saw blood. He was asked whether there was a need for deep catheter suctioning, and he said that clearly Y had changed over her lifetime, but Y is now fully fed. He said that implied to him that the speech and language assessment was that she had a safe swallow, and therefore secretions would be swallowed. He said there will be no need to suction air from her lungs as her secretions would be swallowed, and said that in his view there appears to be no difference now between Y's oropharyngeal skills, and a child without her needs. He was very clear that there was no need for suction apart from in a situation where there is a seizure.

208. In his oral evidence, the independent expert paediatrician elaborated further saying that the normal reason that a child may need suctioning is because they had a difficulty in swallowing. He said that problems with coordination increased the risk of inhalation of secretions from the mouth or throat into the lungs, and that may have been the case when Y was younger, and may still be the case when she has limited consciousness. It is used to protect the lungs. He accepted it was possible that a change of medication could increase secretions for Y. He explained that when deep suctioning is used, there is a significant suction pressure. The catheter was quite slim and as the whole of the end is quite small it can attach to the side of the throat and cause a breakage.

209. I asked the independent expert paediatrician about the description given by Care Worker (1) about her having seen the mother suctioning Y on a number of occasions and suctioning through the nose, and then through the mouth. He was clearly surprised by the suggestion of suctioning through the nose, saying that there was no reason why that would take place.

210. The previous social worker said in the child protection meeting in April 2021 that the mother stated she was still suctioning Y.

211. Nurse (2) gave evidence that she was not told by carers or other professionals that Y needed suctioning. In her view Y had an adequate cough and a good sneeze.

212. Care Worker (1) gave evidence that she saw the mother suctioning Y on a number of occasions. She said that when she arrived one time the mother was giving Y suction through the nose. She said that in her view it was uncomfortable and distressing for Y, and she said that you could tell Y was uncomfortable, pulling back and she was uncomfortable with it. She said that she spoke to the mother but mother said that she knew Y better than them and so she simply gave her concerns to the nurse. Care Worker (1) said that she had seen the suction tube which had food in it, it was clearly food contents.

213. Care Worker (2) was taken to the email she had written which is set out her concerns about Y's well-being. Feb 2020. (F429) . That set out that the mother started giving Y suction through her nose, and it was not done in a hygienic fashion. Care Worker (2) said

that Y's heart rate increased from 85 to 130, and that the catheter had blood in it as well as the Yankauer. She said the mother had told her the saline bought up secretions, and mother had been told she needed to get secretions out. She said she was not aware of any secretions building up, and that Y had not sounded wheezy. She said that the mother allowed the catheter to go across the floor, and then was moving it between Y's mouth and nose, and that Y was in distress. She exhibited photos which showed what she viewed to be large amount of blood in the catheters. She said that Y was pushing her mother away, and she would fidget and push with her arms to push mother's arms away shaking her head. She said she had asked the mother about it and the blood, but the mother said that it was fine.

214. In cross-examination, Care Worker (2) accepted that when you started a process of suctioning, there could be some bleeding, and that she was aware it was recommended by the district nurse. It was suggested to her that the mother didn't need to wear gloves, as the mother had been told that she simply needed to wash her hands each time she did a new process. She said she wasn't aware of that.

215. In the mother's oral evidence, she said that the previous community nurse, gave her this device in June 2020 and gave her training at that time. She said there had been a change in Y's medication and it was clogging her chest up, and that the medication changed from Epilen, to Zonisamide.

216. The mother said that she was told to remove the secretions when she could hear Y getting wheezy, and when she could feel that there was a clog in Y's chest. The mother asserted that you could feel a pressure where the clog was when you felt her chest. In cross examination, the mother gave some more detail about the suctioning. She said that sometimes she would undertake oesophagus suctioning, and clarified that that was different from deep suctioning, and that deep suctioning was into the top of the lungs. The mother confirmed that the Yankauer was used to suction in the nose and mouth.

217. In cross examination the mother was asked about the blood seen in the catheter. The mother responded that she had not seen it, suggesting that she may have been busy dealing with her 'other daughter' but then said she had asked the previous community nurse when she was trained what to do if there was blood in the catheter, and she had said that the mother should not be worried unless it entered the suction pot. Miss Collinson in seeking to understand this answer asked the mother if she had made that

enquiry before she had ever seen any blood in the catheter, and the mother confirmed that was the case. She went on to say that she had later seen blood several times, and accepted that the clinical paediatrician was very concerned about this when she told her. The mother said that she had been doing it for 'over a month and then they stopped it'. She was asked in the light of that whether she was sorry that she had carried on suctioning Y, and responded that she was not, saying that 'it needed to be done, she was cloggy, and I had to do that as she was at risk of drowning in her own secretions'. She accepted that the previous community nurse had told her that, although she had only met Y a few times, saying that Y was a 'well known child in the local community'. The mother was therefore challenged again that everyone else said that Y had a good swallow, but the mother said that she did not have that when she was not well, and that was why she had to put the suction pressure on her.

218. Miss Collinson spent some time exploring this with the mother, given her answers. The mother continued to say that when Y was unwell she was told by the nurses to suction Y and that the pressure of the machine may have to go up in an emergency. She also said that in an emergency she may need to use saline and suction through the nose and mouth. The mother asserted that the clinical paediatrician had said that in an emergency that the machine could go up to 300, and maintained that, although she was challenged that was not correct. She accepted at the end of that part of her evidence again that she was told not to do this. She said that it was necessary when Y had a chest infection, as she does not have a good swallow and she was therefore prone to aspiration when she was poorly. She accepted that since Y has been in hospital and then in the Children's Hospice, she has not needed suction at all, but then added that in her view that was because the professionals looking after her do not recognise when Y needs suctioning, adding that was where some of her disagreements came in.

219. In relation to Care Worker (2) the mother asserted in her evidence that she originally had a good relationship with her, but that she was then unhappy at Care Worker (2) buying her boyfriend gifts. She said that she was very calm when she confronted Care Worker (2), asking her how she would feel if someone bought her boyfriend gifts. She said another worker had come to work wearing inappropriate clothes.

220. At the very end of her evidence the mother told Mr Rogers that she did not think that Y now required suctioning, unless Y was having a seizure.

Analysis:

221. In my view this is an extremely concerning allegation, and it is amply made out on the evidence that the mother was overusing suction to clear Y's airways when this was not medically necessary at any time apart from when she had a seizure. The mother was also suctioning at far too high a pressure, and the clinical paediatrician had not told her that was acceptable. The medical evidence of both the clinical paediatrician and the independent expert paediatrician was that Y did not need this suctioning. Y did not need it at any point in hospital, or whilst she has been at the Children's Hospice. There is no doubt that the mother has been told by the clinical paediatrician that this was not necessary, but that she requested the suction machine from a worker who did not know Y well, and then used it in a most excessive way. The descriptions of Y's reaction to it are very unpleasant and should have alerted any carer.

222. I was also most concerned that the mother suggested she had not noticed when she was suctioning such that she had blood in the tube. The independent expert paediatrician was extremely clear that would only happen if the end of the catheter was used such that it effectively stuck onto the side of the throat or elsewhere and caused a 'breakage'. This must have been extremely unpleasant for Y. I do not accept the mother's suggestion that she did not notice blood in the catheter as she was probably attending to H. Either that happened so frequently that she did not really notice it, or she was so intent on what she was undertaking that she considered that acceptable. Either is extremely worrying. I also do not accept the mother's suggestion that in advance of seeing blood in the catheter she had asked the previous community nurse about that. In my view for any parent to think that suctioning their child could cause them to bleed, would be a frightening and distressing suggestion and not one that would occur to a parent unless it had actually happened. I find that was an untrue assertion by the mother to try and make what happened seem less serious.

223. It is quite apparent that the mother had asked the clinical paediatrician about the possibility of suction in 2017, and the clinical paediatrician has instead suggested saline nebulisers. The chronology also shows that the medication was changed. I have no doubt that the mother was aware had she suggested to the clinical paediatrician instead of the previous community nurse that she needed such a machine to suction Y, then she

knew the clinical paediatrician would have said this was not necessary.

224. Similarly, I accept the evidence of Care Workers (1) and (2) , that they witnessed the mother suctioning Y on a number of occasions when Y did not appear to have any secretions, or be wheezy. The cumulative effect of that was that this took place frequently and was clearly a most distressing and unpleasant experience for Y. It is quite apparent that the mother undertook this on a regular basis, not simply when she considered Y was wheezy. I note that the mother did then fall out with Care Worker (2), but not until 2 months after Care Worker (2) had made the note about her concerns, and so that does not appear to me to be a relevant matter.

Allegation 19. Claims of Y suffering 'cardiac arrest':

225. The local authority assert: Mother makes reports of Y suffering 'cardiac arrest' which are not medically credible. She fails to take on board medical advice that, for example, a reading of zero on a heart rate monitor will often be due to failure of the monitor being used, not cardiac arrest, especially if Y is conscious and babbling at the same time. Repeated reporting of such problems could cause professionals to miss genuine crises in the future. Mother has claimed to have undertaken CPR on Y which has not historically been documented. Mother claims cardiac arrest has occurred at the hospital on 6 occasions, although there are no historical medical records to that effect. The symptoms which mother describes as 'cardiac arrests' would inevitably cause great concern to medical practitioners. Her evidence for suggesting that Y has actually suffered such alleged incidents appears to rely on machine recordings and allegations that proper records are not kept; and it is not credible. This catastrophic description may be similar to mother claiming that if Y sleeps on her back or her front, then she stops breathing. The Local Authority invites the Court to make the findings sought in Paragraph 19. The Court may also wish to conclude that Y's heart has not stopped beating, whether on 56 occasions, or at all, and that mother's persistence in insisting that cardiac arrests took place in the past, serves to emphasise her reluctance to accept medical advice with which she disagrees.

226. The mother says: I have always accurately reported what I have observed in Y. I have not made up her suffering from cardiac arrest. There was one occasion where the sats

machines was on. The oxygen was 92 and the heart rate was 0. If that was a failed reading you would not have a reading at all. The machine was still going up and down. There is information that is missing in the medical records. Some issues, even now, are not put into the notes. Y has ended up on a heart rate monitor as well. There was an occasion she was in the hospital on an ECG. She was in hospital for 6 days. They did not seem to be able to tell me why Y had a cardiac arrest. There must be reasons why she has presented in this way.

227. In her second response the mother says: On one occasion I had to call for an ambulance. CPR was administered. My mother was present at the time as well. No one observed this happen. Hospital have also carried out CPR. Why would that be necessary if she did not have cardiac arrest?

Evidence

228. In her court report, the clinical paediatrician details the history of Y having an oxygen saturation monitor at home, and that at times there have been episodes where Y's oxygen saturation's have dropped below 95%. These have been described very occasionally in hospital, but have not been significant enough for staff to raise concerns or to intervene apart from one occasion in recent years in October 2019. On that occasion Y had a confirmed respiratory tract infection and spent a week in hospital. The school have never raised concerns about drops in Y's oxygen saturation or changes in her heart rate.

229. The mother has described episodes however, and presented Y to hospital with reports of her heart rate dropping to below 50 during sleep, but after 11 days in hospital this was not replicated, there were only brief self-resolving and minor drops in her oxygen saturations. The clinical paediatrician sets out that there were brief period when Y's heart rate dropped below 60 during sleep which is not abnormal during deep sleep. The mother however reported either low saturations or low heart rate episodes on several of her visits to the hospital, that was not replicated when the mother was not present. The mother has also described episodes where she says Y's monitor shows a heart rate of 0, but that Y will either look normal at that time, or could look a bit vacant or 'dithery'. The clinical paediatrician suggests that the most likely cause that would be a problem with the monitor. The clinical paediatrician states that although children could have a short period

of asystole (a long gap in heart activity) during a breath holding episode, that would be associated with a loss of consciousness.

230. The clinical paediatrician sets out that the mother had started reporting that Y had experienced cardiac arrests, such that the heart had stopped beating properly and life support was needed to revive the person. The mother asserted at the meeting on 29th April 2021 where the clinical paediatrician was present that Y had 50 cardiac arrests in her life, and that 6 of those had happened in hospital but were not documented in Y's notes. The mother went on to say that the last episode was about 2 years ago, and clarified that when she referred to cardiac arrests she means that Y has had full cardiopulmonary resuscitation. The clinical paediatrician states that she has found no documented episodes of cardiac arrest in hospital, and that the mother has never reported to her that she has administered CPR at home.

231. The clinical paediatrician states that Y does have an abnormal breathing pattern, and she can have breath holding episodes, which can cause a drop in saturations and a heart rate, and the clinical paediatrician would not consider that surprising if that happened in relation to Y.

232. The clinical paediatrician again sets out the concerns in relation to this that over reporting could lead to professionals dismissing genuine concerns if they arise, and that if the mother describes Y having cardiac arrests that could cause her to be perceived as being more vulnerable than she is. Similarly, the clinical paediatrician sets out her concerns that it is difficult to know when the saturation monitor should be used, and that it is difficult to know what are significant episodes reported by the mother and those which are not.

233. The independent expert paediatrician in his expert report states that mother has reported episodes of cardiac arrest, including at least one claim of a cardiac arrest lasting 40 seconds. He says this is physiologically impossible and is a clear fabrication. Mother has now reported in excess of 50 episodes of Y having suffered a cardiac arrest. He sets out his opinion that this is physiologically impossible and again is a clear fabrication.

234. In his oral evidence the independent expert paediatrician confirmed that he saw no reason how a cardiac arrest would have occurred. He accepted that an oxygen monitor is

sensitive to movement, and if it is showing a reading of 0 that tells you that the monitor is no longer working effectively, it does not indicate that there is no pulse. It was suggested to the independent expert paediatrician that there are reasons why a child could have a cardiac arrest, and he of course accepted that. It was put to him that the mother believes that Y's heartbeat has stopped for a short period as a result of breath holding, and he responded that was not possible if a person were deliberately breath holding. A person cannot do that for long enough to cause sufficient lack of oxygen. He was clear Y suffered from no condition that would cause her to have a cessation of heartbeat. A chest infection would not cause the heart to stop. He said the seizures would not cause her heart to go into cardiac arrest, and he repeated that cardiac arrest is very uncommon, and occurs as a final event. He accepted that we had 3 options in relation to the mother's position in relation to this, the 1st one was that the mother was misrepresenting it, the 2nd was that the equipment was malfunctioning, and the 3rd was that the heart did stop. He made it clear he saw no reason how the 3rd option was possible.

235. The independent expert paediatrician was pressed in relation to how a child would present if their heart had stopped. He said that the child would be lifeless. He said if the heart had stopped secondary to other events then it would be the end stage of the deterioration of the child's health. He said the child would be white, their pupils would be dilated and there would be no movement and no pulse. They would be floppy. He was asked if there was a brief period of cardiac arrest, when would life functioning be affected and suggested that would be in maybe 5 minutes.

236. The previous social worker was very clear that the mother had told her there had been 56 cardiac arrests, and the mother had repeated that even though she was told there was no medical evidence or record of that.

237. Nurse (2) accepted that Y did at times hold her breath, but not that Y stopped breathing. She said that Y gained attention doing that and did it less frequently when she was being cared for 1 to 1. She said staff would tell Y to breathe and she then would.

238. The mother was cross examined in relation to this. It was put to her that she had said that at a meeting she had said that Y had 56 cardiac arrests, and some had been at hospital. She said that in fact she had said in the meeting that Y had had 10 cardiac arrests at

hospital and 46 at home. The mother was asked whether she wanted to reflect upon that having heard the evidence of the independent expert paediatrician. Mother was very clear that she does still state those cardiac arrests took place.

239. The mother was also asked if she had said that Y had suffered a stroke. She said that was a difficult one, but that Y did display symptoms of one. She described Y stopping babbling and turning her head to one side. When asked when this happened the mother accepted that she had not been present and that a carer had described that to her, and she was in a meeting when she was telephoned. She accepted that she was relying on what someone else had said who was not a professional and then went onto say that she was told Y had a TIA. She was again challenged that that is not recorded anywhere in the papers, but insisted that was what she was told.

Analysis:

240. I am afraid that once again the evidence is simply overwhelming in relation to this finding, that not only has Y not suffered from cardiac arrest, but there is no medical reason to believe that is a risk for her.

241. There is not a single medical record or note to suggest that Y has suffered from a cardiac arrest. The mother asserts that has taken place, although there is some dispute as to the exact numbers. I am careful as ever that the mother does struggle with numbers, and it does not appear to me to make any difference to this allegation how many cardiac arrests the mother asserts took place at home or at school. If any medical professional considered that this was a realistic diagnosis then I have no doubt it would be clearly recorded on the medical records.

242. Rather similar to the suggestion that when Y breath holds she needs to have her stomach aspirated, the mother also appears confused between what happens when Y holds her breath and the difference between that and a cardiac arrest, where the heart stops beating. Yet again I remind myself of the mother's cognitive difficulties, but she has been challenged in relation to this aspect on a number of occasions, she has had the benefit of expert legal advice and the assistance of an intermediary, and of hearing the evidence of the clinical paediatrician and the independent expert paediatrician. She is immovable in her belief and will clearly continue to repeat that to medics who may be treating Y in the future. Once again that creates a very real risk of Y not being correctly treated, or of being treated in an incorrect way.

Considering the schedule overall:

243. The clinical paediatrician was asked about Y's overall presentation and what her concerns are in this case. She said that Y has medically explained symptoms, they are not unexplained. She was very clear that the relevant genetic mutation that causes a genetic condition for Y is the HNRNP mutation. There are many aspects of presentation in Y's case that accords with the mutation in that gene. She did not therefore accept that this was a case of perplexing presentations.

244. The clinical paediatrician gave evidence at length saying that sometimes the mother and she work together well, but that at other times there is conflict. She said there had been a barrier about the times of Y being discharged from hospital, and that at times mother is a very concerned and frustrated parent. She accepted that can lead into acrimonious exchanges, but said that although anxiety and concern are expected and normal, she would not expect to be in such conflict as happens at times with the mother.

245. It was suggested to the clinical paediatrician that it may become easier to care for Y, because the more challenging aspects are reducing. The clinical paediatrician was unconvinced in relation to that, although she accepts that Y is now a more straightforward child than she was seen to be in 2021. She set out her view however that there had been no treatment that was making that difference, nothing has changed, but her health was now much more stable, and in her view that could be ascribed to the fact that she was being looked after by carers who were more consistent, doctors were being given more accurate information, and that reflects her true being. The clinical paediatrician said that in her view the improvement in Y is not explained by anything medically that has been done to Y, but that the reality was Y was presenting now as a stable child, which was not the situation before. That was not due to anything that they had done, and that in her mind it showed that what she had been told before was not true.

246. The independent expert paediatrician was also asked generally as to the difficulties in this case. He accepted that the mother's difficulties appeared to be related to her cognition and her psychology. He said however that his responsibility was the welfare of the child, and ensuring the focus of the enquiry was on Y. He accepted that the mother had a perception of Y's needs that differs from medical professionals, and that this was often true of families, but was also clear that Y's needs will evolve, she is not a static being and that is one of the concerns in terms of the mother's ability to meet her needs.

247. At the very last part of the mother's evidence, in response to re-examination from Mr Day, the mother was asked what she had learnt from this experience and the evidence she had heard. She said that she had learnt from her mistakes and she should be able to put her concerns and get along with everyone for the best interests of her children. When Mr Day asked her if she would have done things differently, she said she would have done things differently in relation to the seizure, but when she was asked in relation to anything else, she responded 'no, I think I have done pretty well'.

248. Having considered all the evidence in this matter, and the findings that I have made, I am quite satisfied that this is not a case of perplexing presentations. I therefore agree with the clinical paediatrician that Y has medically explained symptoms, and they are currently well understood. I agree with the clinical paediatrician that Y now presents much better, as a result of accurate information about her needs. I also agree with the independent expert paediatrician, that the problems in this case appear to be from the mother's cognition and her psychology. There are many examples given of how the mother holds strange and inaccurate medical beliefs. The problem is that she makes medical assertions with great certainty, and does not seem to be able to reflect that she is sometimes wrong.

249. A comprehensive reading of this case shows how difficult, stressful and worrying it is and has been to care for Y. I do not underestimate that and pay tribute to the mother for the love she shows to both her daughters. As I set out above, no one suggests she wishes to harm Y, and it is accepted she does want the best for her. The reality is however that her actions and in particular her inability to understand medical advice, to analyse that and apply it to Y's needs, and her inability to change and adapt her thinking has undoubtedly caused Y significant harm.

250. The findings I have made are too extensive to be simply summarised, and I shall ask the local authority to draw up a simplified schedule as they have suggested of the facts that I have found.

Removal of Y into foster care, the current plan of the Local Authority:

251. The local authority seek for the court to approve an amended care plan in relation to Y, that she moves from the Children's Hospice to a specialist foster placement. The local authority have always set out that their plan was for Y to move to foster care, but for a substantial period of time they did not have available carers for them to be able to pursue that

option.

252. Mother has always made it clear that she opposes that option, and would wish Y to return to her care. It is accepted that the Children's Hospice have given notice on Y's placement, and in fact that was some time ago. They have been extremely patient in agreeing to the court process taking place, and are no doubt mindful that the courts need to consider Y's welfare, and what options there were otherwise in relation to Y.

253. The current social worker has filed a statement dated 13th May 2022. That gives details of the proposed foster placement.

254. I heard evidence from the current social worker in relation to this. She told me that whilst she accepted the notice that the Children's Hospice have given does not have an actual date on it, in her view Y does not meet the criteria to remain at the Children's Hospice long term, and she reminded the court of the terms of the notice letter that was written by the unit. She said that this would be a long-term foster placement as far as the local authority were concerned and that she considered it much more appropriate for Y to be in a family placement. She confirmed that Y would remain at the same school, and indeed it appears to be the case that one of the carers works at Y's school and therefore knows her. She accepted that contact would need to be looked at, and confirmed that the prospective foster carers would not agree to there being contact in their home. She confirmed that the other child in placement was also known to Y.

255. The mother told me in answer to questions from Miss Collinson that she did not think that the Children's Hospice was the right place for Y, and she did not think that she was getting the best care there.

256. In re-examination the mother was asked a little more about the Children's Hospice. She was asked if I decided that Y could not come home to her, would she prefer Y to remain in the Children's Hospice, or be moved to somewhere else. She was clearly torn about this, but eventually said she was not sure. She accepted that a move to somewhere else would be a disruption for Y.

The law in relation to this issue:

257. There is some limited dispute between the advocates about the legal test in relation to this matter. In my view is appropriate for me to consider this as a welfare matter. The test of interim threshold has already been met when the interim care order was made in July 2021.

258. I must of course be mindful of the passage of time that has elapsed since that time, but the findings I have made above make it entirely clear that the threshold continues to be satisfied.

259. Given that I am satisfied that the threshold is met, then the second stage is a resolution of the welfare issues. I am seeking to establish a holding position, after weighing all the relevant risks, pending a final hearing. I accept that often of particular relevance in any hearing is the balancing of risks for and against removal, and Y has been apart from her mother and sister for over a year. I am aware that the decision taken by the court on an application of this type must be limited to the issues that cannot await the fixture, and must not extend to issues that are being prepared for determination at that fixture.

260. I have in mind the Court of Appeal authorities in relation to interim care order which are summarised by LJ Thorpe in Re LA [2009] EWCA Civ 822.

a) Separation is only to be ordered if the child's safety demands immediate separation Re H [2002] EWCA Civ 1932
b) A LA in seeking to justify the continuing removal of a child from home necessarily must meet a very high standard - Re M [2005] EWCA Civ 195
c) At an interim stage the removal of children from their parents is not be sanctioned unless the child's safety requires interim protection, - Re k and H [2006] EWCA Civ 1898 'Safety' in this context can be used in a broad sense to include the child's physical and emotional safety. I am conscious also that the words 'an imminent risk of really serious harm' used by the Judge in Re L [2008] 1 FLR 575 did not raise the bar to a new standard or alter the approach as outlined above taken by the Court of Appeal (re L [2009] EWCA Civ 822.
d) In addition, in the case of Re L, [2013] EWCA Civ 489 it was accepted that the test was the same if the question is whether to return a child to a parent's care rather than to remove that child.

261. These cases were set out and expanded upon in Re C (a child) Interim Separation 2019 EWCA Civ 1998 **quoted with approval by LJ Peter Jackson in a case also called** Re C (A Child) Interim Separation) **[2020] EWCA Civ 257,**

1. An interim order is inevitably made at a stage when the evidence is incomplete. It should therefore only be made in order to regulate matters that cannot await the final hearing and it is not intended to place any party to the proceedings at an advantage or a disadvantage.

2. The removal of a child from a parent is an interference with their right to

respect for family life under Art. 8. Removal at an interim stage is a particularly sharp interference, which is compounded in the case of a baby when removal will affect the formation and development of the parent-child bond.

3. Accordingly, in all cases an order for separation under an interim care order will only be justified where it is both necessary and proportionate. The lower ('reasonable grounds') threshold for an interim care order is not an invitation to make an order that does not satisfy these exacting criteria.

4. A plan for immediate separation is therefore only to be sanctioned by the court where the child's physical safety or psychological or emotional welfare demands it and where the length and likely consequences of the separation are a proportionate response to the risks that would arise if it did not occur.

5. The high standard of justification that must be shown by a local authority seeking an order for separation requires it to inform the court of all available resources that might remove the need for separation."

In Re C in 2020 the judge summarised it this way:

"The test is whether the child's safety is at risk and, if so, any removal should be proportionate to the actual risks faced and in the knowledge of alternative arrangements which would not require separation." Which was approved of by LJ Peter Jackson.

262. In reaching my decision, I have considered all the points in the welfare checklist, and looked at the evidence in the light of those points. The welfare of Y when I consider this change to the care plan is my paramount consideration. I have given particular attention to the matters contained in the welfare checklist at **s1 (3) of the Children Act 1989**. I have also considered the no order principle.

a) the ascertainable wishes and feelings of the child concerned, considered in the light of her age and understanding.

263. Y has spent significant periods of her life in hospital, sometimes for sustained periods. Even when she was living at home with her mother and sister, she has had very regular admissions to hospital sometimes just overnight sometimes for longer periods. Y has now been apart from her mother and sister since April 2021, and has had a move between the two Children's Hospice sites. There is a great deal of evidence that Y responds well to her mother, and enjoys her mother's love and affection. It seems to me that Y would wish to be at home with her mother and sister if that were possible, but I must also reflect the findings that I have made above, that the mother has insisted on performing unnecessary and at times painful procedures upon Y, and I have no doubt Y

would not wish that to carry on.

264. Y does have regular contact with her mother and sister and clearly there would need to be a change to that. I have not heard detailed submissions about how contact would need to vary, but I have no doubt that appropriate arrangements can be put into place if I were to conclude that Y should move into foster care.

b) Her physical, emotional and educational needs

265. Y has very specific physical needs. I have made findings that the mother is sadly not able currently to respond appropriately to Y's physical needs, and indeed some of her actions I have no doubt will have caused Y emotional harm as well. Given the mother's responses to some of the matters that the local authority alleges, the court can currently have no confidence that the mother's behaviour would be any different if Y was returned to her care, no matter what package of support was put into place.

c) the likely effect on her of any change in her circumstances

266. Y will be significantly affected by any change, and by a move to people that she does not know very well. Although on behalf of the mother it is asserted that any move is for administrative convenience, in my view that is misconceived. Not only is the Children's Hospice not an appropriate place for Y, but they gave notice on that placement 3 months ago, as they are entitled to do, and have been extremely patient. In my view there is a clear welfare balance to Y being in a family type environment, and with regular carers, not nurses, however well meaning they are.

267. Y does already have a relationship with at least one of the potential foster carers. I bear in mind that their accommodation will be unknown to her, and it will be a strange environment. As I have set out above, Y has sadly become accustomed over her short life to staying in a number of different places, different beds in hospitals, 2 different Children's Hospice sites, and I accept that any moves should be minimised. I must weigh it seems to me whether there is a need for a change at the moment, or whether as the mother asserts Y could remain at the Children's Hospice if she cannot return to her care.

268. I accept of course that would be a change in contact arrangements. As I have set out

above, I have not heard detailed evidence of how that would be managed and have no doubt that careful consideration would be needed to exactly how that would work. It does not appear to me however given the geography involved that it would be impossible to resolve the contact issue such that it meets Y's welfare needs.

d) her age, sex, background, and any characteristics of his which the court considers relevant.

269. There are many aspects of Y's needs that are relevant, and I have set those out above.

e) Any harm which she has suffered or is at risk of suffering.

270. I have made very significant findings in relation to the mother's ability to care safely for Y and meet her needs at the moment. This includes harm she has suffered and is at risk of suffering.

f) How capable each of the parents, and any other person in relation to whom the court considers the question to be relevant is, of meeting her needs.

271. It is suggested on behalf of the mother that there is currently no evidence of what the mother could offer in terms of caring for Y with proper support and monitoring. That has of course been the subject of very significant consideration over most of Y's life. Although I certainly accept that the full extent of the mother's difficulties was not known, I am entirely satisfied that those working with the mother did so sympathetically and trying to assist her for many years, and that medical problems and concepts and solutions were discussed with her in many different ways over a sustained period of time, and in a way that she is able to understand from her evidence. She has not been able to modify her behaviour, or to accept the concepts even when they were explained very simply to her. Her ability to do so in the future must of course again be the subject of proper assessment that will only be possible once a clear understanding of the mother's response to my findings is possible. That further assessment must of course take into account the mother's difficulties.

g) The range of powers available to the court under this act in the proceedings in question.

272. There are in reality 3 options available to the court at the moment. Y could return to the care of her mother, she could remain at the Children's Hospice, or she could move to this foster placement.

273. The aim of the court at this stage is to establish a holding position pending a final hearing. When I conduct the balancing exercise in relation to this matter, I am left in no doubt that Y cannot return home to her mother and sister at the moment. The court will need to understand the mother's responses to the findings I have made, and whether there can be any change to the mother's behaviour in a timescale that meets Y's needs.

274. On any realistic analysis, I do not consider that Y can remain at the Children's Hospice. As I have set out above, whilst they have been extremely patient, they have given legal notice to the local authority that Y cannot remain there. It appears to me to be quite wrong to suggest that the court could simply ignore that and refused to make an order that effectively sanctions Y's removal from placement. For the avoidance of any doubt however, even on a welfare analysis Y should not remain at the Children's Hospice. It is an institution, and however well-meaning the staff are, and however long they may have worked there for, it is not a family environment. It seems to me that it is very much in Y's welfare interests for her to be cared for if possible by consistent carers, and in a family type situation and accommodation.

275. I do not accept that the court would be tempted in the future to leave Y in that placement if her mother was able to safely meet her needs, as is suggested on behalf of the mother.

276. Having conducted the required balancing exercise, I am satisfied that the Local Authority's interim care plan for Y is proportionate and in her best interests, and I sanction a planned move to the proposed foster carers.

Summary:

277. As I have set out above, I cannot in a simple summary set out all the findings that I have made. They will need to be set out in a schedule. I will say for the benefit I hope of the mother that no decisions have yet been made about the possibility of Y returning to her care. I urge her to consider very carefully my findings. I appreciate that will entail a

significant adjustment to many of her beliefs which she will find very challenging. She must attempt to understand that she is not always correct in relation to Y and her needs, and it appears likely to the court that only if she is able to make proper and genuine changes to her beliefs and behaviours that there is any real prospect of Y returning to her care.

END OF JUDGMENT