

Neutral Citation [2019] EWCOP 68

IN THE COURT OF PROTECTION
(Sitting at North Shields)

No. 13236134

Tuesday, 18th June 2019

Before:

HER HONOUR JUDGE MOIR

(In Private)

B E T W E E N :

THE LOCAL AUTHORITY

Applicant

-and-

(1) A

(by her litigation friend, the Official Solicitor)

(2) B

(3) THE HOSPITAL TRUST

Respondents

REPORTING RESTRICTIONS: Court of Protection Rules 2007

MISS JODIE JAMES-STADDEN (instructed by Legal Services, the Local Authority) appeared on behalf of the Applicant.

MR KARIM QC (instructed by David Auld & Co.) appeared on behalf of the Official Solicitor for the First Respondent.

MR BARKER (instructed by B) appeared on behalf of the Second Respondent.

MR O'BRIEN (instructed by Sintons LLP) appeared on behalf of the Third Respondent.

J U D G M E N T

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 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.

Note: This judgment was delivered in June 2019 and leave for it to be published was given by the Judge at the same time. However, it was not in fact published at that time. It has subsequently been anonymised in accordance with the anonymisation used in the later judgment of Mr Justice Poole, neutral citation [2022] EWCOP 44. This judgment is being published simultaneously with that later judgment, in October 2022, and should be read in conjunction with that judgment.

HER HONOR JUDGE MOIR:

1. These proceedings concern A who is 20 years of age having been born in 1998. She has a diagnosis of mild learning disability and autistic spectrum disorder, namely Asperger's syndrome. A suffers as well from epilepsy, primary ovarian failure, and a vitamin D deficiency. It is right to say at the outset that B, A's mother, does not agree with all of these various diagnoses.
2. By way of an application dated 6 April 2018, the applicant, the Local Authority, seeks declarations pursuant to s.16 of the Mental Capacity Act 2005 in relation to A's capacity and best interests. Until 9 April 2019, A resided with her mother B, the second respondent in these proceedings. B had at all times been A's primary carer with assistance from A's maternal grandparents. A did not receive any care from the local authority and was home schooled throughout her childhood by her mother. A has not attended any college or education provision.

3. A has been represented through the course of these proceedings by her litigation friend, the official solicitor. The applicant, the Local Authority, is the relevant statutory body who has responsibilities under the Care Act 2014 to meet A's eligible needs. The third respondent is the Hospital Trust, which is the relevant NHS Trust, which has responsibility to meet A's clinical needs pursuant to the National Health Service Act 2006.
4. B held a power of attorney (health and welfare) on behalf of A which power of attorney was executed on 4 January 2018 and is one of the issues within these proceedings. It was the local authority's original intention to work with B to enable A to remain at home whilst treatment was undertaken and services provided to meet A's needs. Its plan changed as a result of information and evidence provided to them. It has been stated within the initial care and support plan dated 11 January 2019 and found at E4 in the bundle that:

“The focus of enabling support will be to assist A in developing a greater experience of opportunities and lifestyle choices available to her. This may be further learning, work related activities, leisure options, and/or developing social network with peers. The aim is to broaden A's experience and independence in doing so, improve her ability to make informed decisions about her life generally and future aspirations.”

5. It was recognised for the plan to be effective, B would need to encourage and promote such support as being helpful and positive to developing A's experience and

development. Further, the view was taken that A would be unlikely to engage if she perceived her mother to be opposed to the arrangements.

6. The care and support plan dated 6 March 2019 expressed the local authority's changed view and at E11 in the bundle, it is set out:

“A residential care placement is proposed as a means to provide a supportive environment which can meet A's social care needs. Timescales for the identification of a suitable placement are proposed to be within the next two weeks to allow sufficient time for assessing the suitability in terms of environment, peer group, and preparing care plans with the service provider. There could be opportunity for A to visit prior to moving if this appropriate. Timescales may need to be revised and urgent action taken should there appear to be a risk to A's safety. The placement will also promote A's understanding of and compliance with treatment plans for epilepsy and endocrinology in cooperation with the relevant hospital health teams and also community team learning disability.”

7. I have heard evidence in this matter over four days in March 2019 and over two days in May 2019. Additionally, I heard an urgent application on 9 April upon the application of the local authority to remove A into residential accommodation which application is subject to a separate judgment. I expressed the view that I was satisfied under s.48 that A lacked capacity.
8. I have heard oral evidence from: Mr M the solicitor who drew up a Lasting Power of Attorney; Dr Ince, consultant psychologist; Dr Y, consultant neurologist (to whom the

judgment will refer as Dr Y); Dr X, consultant endocrinologist (Dr X); Ms V, the social worker who has been A's social worker throughout; (B), i.e. A's mother. I also heard from A's grandmother at the hearing on 9 April and Mr Bourne who is A's solicitor. I have had the benefit of written and oral submissions from each of the parties and the opportunity to meet and talk to A upon two occasions.

9. The issues before the court are far reaching. A's capacity to make relevant decisions on conducting the proceedings in respect of residence, care, and contact are disputed, as is the validity of the Lasting Power of Attorney for health and welfare matters, executed in January 2018, which as I have indicated was revoked until the final hearing by interim order dated 18 October 2019. The first attended hearing was on 18 April 2018 when the official solicitor was appointed to act as litigation friend for A. Interim declarations were made and the NHS trust was joined as a party to the proceedings. Dr Ince was directed to provide an independent psychiatric assessment in respect of A. On 13 August, the court gave permission to Dr Ince to report on A's capacity to execute the Last Power of Attorney dated 4 January 2018 and purportedly executed by A at a time when she had capacity.
10. On 18 October 2018, the court required Dr Ince to answer questions of clarification arising from his report and also direct a s.49 report from Dr X, consultant endocrinologist and Dr Y, consultant neurologist. Further the court revoked the LPA pursuant to the provisions of s.22(4)(b) and s.48 of the Mental Capacity Act 2005 until the determination of the issues at the hearing fixed to commence on 5 March 2019. I am told that the proceedings were issued by reason of the Local Authority's concerns that A was failing to engage with healthcare and other professionals possibly due to B's undue influence in

consequence of which A was not receiving the appropriate or any treatment for her physical health conditions. The consensus opinion of the professionals involved was and remains that without appropriate treatment, A was at serious risk of health complications, including increased seizures, osteoporosis, fracture risk, and cardiovascular disease.

11. In addition, it was and remains a concern of the local authority that A's social care needs remained unmet. The substantive issues for determination can be summarised as follows:

- (a) A's capacity to conduct proceedings to make decisions about residence, care, contact, and medical treatment and to execute a Lasting Power of Attorney;
- (b) Whether the Lasting Power of Attorney, dated 4 January 2018, is valid;
- (c) Whether the handwritten document dated 6 March 2018 and referred to as A's living will and wishes is valid as an ADRT and/or an expression of A's wishes and feelings;
- (d) Whether it is in A's best interests to undergo treatment in accordance with the recommendation of her treating clinicians:
 - (i) Epilepsy;
 - (ii) Primary ovarian failure;
 - (iii) Vitamin D deficiency;
- (e) Where it is in A's best interest to reside;
- (f) Whether it is in A's best interest to receive care and support in accordance with the care plan; and
- (g) What contact it is in A's best interests to have with her family.

12. The local authority, official solicitor, and NHS trust submit that A lacks capacity and that now her best interests are served by undergoing the recommended treatment and

receiving appropriate care within a residential setting. B disputes that A lacks capacity and wishes to have A returned home to live with her. Thus, it follows that B does not accept that the court should be making any decisions on A's behalf or in her best interests. B argues that the Lasting Power of Attorney is valid. B now, I am told, is willing to consider a plan which will enable A to access the support which the adult services have suggested to her but only from her home as opposed to in a residential care home or setting.

13. Within the plan, the local authority sets out at E12:

“The primary reason for A's proposed move to residential care is to address concerns related to her health and wellbeing. A is likely to need a period of sensitive, tailored emotional support to enable her to come to terms with a move to residential care as she is opposed to this plan currently. The move may be experienced as traumatic and distressing. A referral to health agencies who can provide psychological support will be considered as needed. A has significant health needs associated with epilepsy and primary-ovarian failure. She has been resistant to treatment plans, particularly in relation to the latter diagnosis. The aim of the plan is to provide a supportive, engaging environment where A's understanding of the benefits of treatment and her compliance can be promoted more effectively.”

14. It was also noted that B had not been involved in the development of this plan. B has said that she does not want a social worker or support services and it was said that a

discussion with B at this time in respect of these matters had not proved beneficial. A advised the social worker that she did not want Social Services' involvement or to receive any support. The plan of 22 March 2019 followed upon the Court of Protection proceedings going part heard and it proposed a move for A on 9 April 2019:

“...to reduce the risk of her absconding or coming to harm given the evident and expected level of resistance to this plan.”

15. The law which I must apply in relation to reaching any decision in this matter is set out within the Mental Capacity Act 2005. The principles which I must apply are set out at s.1 of the Act, namely:

“(2) A person must be assumed to have capacity unless it is established that he lacks capacity.

(3) A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.

(4) A person is not to be treated as unable to make a decision merely because he makes an unwise decision.

(5) An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.

(6) Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.”

16. In addition, I have to consider s.4(6) and (7) of the Mental Capacity Act 2005, namely:

“(6) [I must determine] ...so far as is reasonably ascertainable-

(a) the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),

(b) the beliefs and values that would be likely to influence his decision if he had capacity, and

(c) the other factors that he would be likely to consider if he were able to do so.

(7) [I must also] ...take into account, if it is practicable and appropriate to consult them, the views of-

(a) anyone named by the person as someone to be consulted on the matter in question or on matters of that kind,

(b) anyone engaged in caring for the person or interested in his welfare,

(c) any donee of a lasting power of attorney granted by the person, and

(d) any deputy appointed for the person by the court...”

17. A’s wishes and feelings are clearly relevant. A wishes to remain in the care of her mother without the interference of the local authority. She wishes for the “mess”, as she referred to it when speaking to Dr Ince, to be finished. She told Dr Ince that she just wants her life back to normal because, “I was very, very happy before September 2017.”

18. The fundamental issue which the court must determine is A’s capacity to make the relevant decisions to which reference has already been made. Dr Christopher Ince was appointed as the joint independent expert and filed his report on 24 September 2018 and answered questions of clarification in an addendum dated 3 January 2019. He gave oral

evidence to the court on 5 and 6 March 2019. Dr Ince is a consultant psychiatrist working in forensic learning disability and specialist autism services. He saw A for the purposes of preparing the report on 10 August 2018 and upon 4 September 2018 when he said he was aware of the additional questions that were subsequently formulated within the secondary letter of instruction. In addition to the other documents, he had available to him to prepare his assessment: the report of Dr Y dated 21 September 2017; the record of mental capacity assessment prepared by Ms H who was the Hospital social worker dated 28 September 2017; the IMCA's report prepared by Ms J dated 6 April 2018; the NHS Trust medical records to June 2018; the GP practice records to 28 June 2018; as well as the social work statements and position statements of each of the parties for the hearing on 18 April 2018.

19. Dr Ince outlines the recordings with regards to events leading up to the commencement of the Court of Protection proceedings. I recite some of these details as background only. He sets out that on 13 September 2017, A was admitted to the Hospital assessment suite following reportedly experiencing more than ten generalized clonic seizures at home over the last 24 hours. This had been reported to the GP. B previously routinely reported seizure activity experience to the GP as a matter of course. On this occasion, the doctor insisted on seeing A despite B saying A did not want to see a doctor. The GP had not seen A since 2011. The doctor visited A and advised that an ambulance be called. B was very reluctant to let the crew take A to hospital. The GP had also written a letter for the crew to take to the hospital outlining her concerns. This letter included details of A's apparent decision not to transfer to adult neurology for follow up reviews of epilepsy and medication and that she had not been seen since discharge to adult services in 2016. B is

reported to have advised that A made the decision, though whether A had capacity to make the decision is unclear.

20. I refer to these details set out by Dr Ince but do take into account that I am aware that B does not agree with all the detail and I have not heard evidence in respect of each of the details. As I hope I made clear, I refer to these details as background only. Dr Ince went on to take from the recordings:

“It was considered that B was very reluctant for A to be admitted due to her own fears about hospital that she believes A shares with her. It was noted that B would not allow A to speak for herself and refused to allow A to provide a urine sample. B requested that A be discharged and follow-up to be arranged at home. The nurse questioned whether A could make this decision herself from her presentation. There was a further question raised about A not having experienced puberty and menstruation. B said that A did not want this to be investigated either.”

21. On 14 September 2017, A became subject to an urgent authorisation pursuant to Schedule A1 of the Mental Capacity Act 2005 as she appeared to lack capacity and her mother wished to take her home. A subsequent cognitive assessment was undertaken by Dr G, clinical psychologist. It noted A: to have a full-scale IQ which equalled 65 which is in the learning disability range; had particular difficulty with processing speed and memory, though these could also be affected by seizure activity or the impact of medication; and is reported to have had difficulty with informed discussion or identification of emotions but seemed more comfortable with structured tests and activities in the assessment.

22. Ms H, hospital social worker, also undertook a capacity assessment around whether A was able to make the decision to go home and concluded that A did not have the capacity to understand the safeguarding concerns due to the difficulties retaining the information needed to make the decision and also being concerned about giving answers that her mother would approve of.

23. Ms H, the social worker to whom I have just referred, carried out a mental capacity assessment on 20 September 2017. She set out at F2:

“A retains that she has met me before, but has not been able to recall discussions held previously. For example, I returned to see A the day after I had spoken to her and her mum, yet she should could not recall what the discussion had been about. When I advised her that we had been talking about the concerns at home, A replied, ‘There are no concerns. I want to go home.’ I explained that one of the concerns was that she isolated. She denied this and said she went out and had family and two friends. I asked A if she could recall talking to the doctor. She said she could. I asked what he had told her. She replied, ‘I think it was something to do with out patients appointments.’ The doctor had actually informed her that she had no ovaries or uterus. When I outlined the concern about her being socially isolated, she said she was not. She said she had her mum and her grand parents. I asked about friends outside of the family. She said she had two friends, one called Hannah. I asked how she knew her. She said her mum had gone to school with her mum. She said they sometimes go to the shopping centre together. The other friend was one she had previously

discussed with the psychologist. She told me that she had been to a party at her house once. I explained that at 18, a lot of young adults were moving on, some went to university and got a flat. She replied, ‘Well, I don’t know about that but I’m okay at home with mum’. She appeared unable to weigh up that she had any option other than to remain at home with mum.”

24. Ms H went on to record:

“It also appears, in my professional opinion, that she, A, says things that she thinks her mum would want her to say, for example, she has said several times that she does not want a social worker but cannot expand as to why that is.”

25. Ms H concluded:

“I do not feel at this time that A has the capacity to make this decision. Whilst she showed some understanding into her epilepsy and the reason for admission, she was unable to retain the information relating to the safeguarding concern for long enough to process it and make an informed decision. In my opinion, this is compounded by A often appearing to say things that she knows her mother would want her to say or being vague in her answers for fear of sharing information that her mother would not want her to. A only knows the life she has led and as such has no concept of life outside of living with her mother, being home schooled, and having little social contact.”

26. A capacity assessment was carried out by Dr Y on 21 September 2017 and she noted:

“Suspected learning disability. No official diagnosis but currently undergoing an assessment. Understands she is in hospital and named the hospital correctly and was able to give the appropriate length of her stay so far. Knew the reason for admission and described it as having more fits.

Told me that her medication would be reviewed to make sure she is on the right treatment. Remembers seeing a psychologist and performing tests. A uses simple language and at times took a long time to answer but she was able to give answers at the end. Was happy to stay in hospital to wait for her discharge. Staff reported that she does not ask to leave the ward. A has capacity to make her own decision about her being accommodated in this hospital to receive care and treatment.”

27. Mr C, the team manager of the learning disabilities autism team with the Local Authority, provided a report dated 6 April 2018 in which he set out:

“A lacks capacity to make decisions in regard to care and treatment and she appears to be unable to understand the consequences of not engaging with relevant health professionals with regard to managing treatment relating to concerns around her epilepsy and potential low levels of oestrogen. She appears unable to retain that there may be long-term effects and risks of current epilepsy medication if this is not monitored and reviewed and long-term effects and risk to her health if her oestrogen levels are not monitored and reviewed. There are concerns about A’s

ability to weigh relevant information relating to her health and social needs and residence to meet those needs.”

28. There is an issue about a Lasting Power of Attorney to which I will return. However, in respect of capacity, I note that the attendance of Mr Miller, the solicitor who was asked to prepare the Lasting Power of Attorney, recorded, “No issue as to capacity.”

29. Dr Ince, within his report, stated at G67 within the bundle:

“Overall, there is clear evidence that A suffers from an impairment or a disturbance in the functioning of the mind or brain, namely, and as the term is used in the International Classification of Diseases 10th edition F70, mild mental retardation also known as mild learning disability.. I am further of the opinion that A suffers from an autism spectrum disorder, namely F84.5, Asperger’s syndrome.”

30. Of note, but outside the ambit of these proceedings, Dr Ince questioned whether there is an underlying genetic phenotype that will provide an explanation for A’s presentation. He states:

“Accordingly, whilst not related directly to the current Court of Protection proceedings, that consultation with specialist genetic services may be warranted.”

31. During her interviews with Dr Ince, as in her discussions with me when I saw her, A repeatedly referred to pre-written notes when attempting to frame answers. Dr Ince comments:

“It was not clear as to whether these were in her own handwriting or her mother’s given that these are, based on other paperwork, near identical. A

was secretive and refused to allow the specific content of the notes to be seen.”

32. My experience when talking to A was similar. When asked about the notes, she said that she had written the notes herself but would not allow the notes to be seen. A became agitated when her notes failed to provide a response to questions which were posed to her. I also noted in my discussions with A that she was very suspicious of any ordinary conversational questions. I appreciate, of course, that it was an unusual circumstance for her but she had asked to see me and clearly had things she wished to say to me. However, she seemed reluctant to respond to any questions of her or enter into any general conversation of any kind.

33. Dr Ince expressed his view that A lacked capacity to conduct the proceedings which is set out in detail at G68 in the bundle:

“Whilst A displayed reasonable understanding of the factual aspects of the case, she significantly struggled with the more dynamic areas related to instruction or the arguments that may be put forward, either by herself or others. It was notable that she repeatedly referred to her pink folder of handwritten notes and her responses were concrete in nature with a lack of cognitive plasticity or an inability to extrapolate from one situation to another. It is my opinion that A displays an ability to understand the basic aspects of the current Court of Protection proceedings and that, with the aid of written notes, is similarly able to retain certain information. I believe there are significant deficits within her underpinning knowledge and understanding of terminology such that the responses she gives are, to

a degree, rote learned. I do not believe that she is able to independently appreciate the gravity of the current situation or form a view such that this can be communicated to her legal representative in a manner that demonstrates she is able to appropriately weigh the information with which she has been provided. It is clear that she places universally exclusive weight to the views and opinions of her mother and grandparents and cannot appraise whether these are correct or further accept that there may be an alternative view. It was notable that at points where questions were raised that she did not have a pre-prepared answer for, she appeared particularly stuck and perplexed. Based upon the responses that she has given, the absence of true understanding, and retention of said information, and an inability to independently weigh the information, it is my view that A lacks capacity to litigate within the current Court of Protection proceedings. I would furthermore add that A's lack of capacity to litigate is directly associated with her underlying mental disorders and that these compound her ability to appropriately appraise information given to her such that there is clear evidence that she is subject to undue influence of B. This view is based upon the responses of A at interview and the provided collateral information and general practice records, with the latter documenting the minimal contact between A and her general practitioners, arguably to her broader detriment.”

34. In his oral evidence, Dr Ince confirmed the view which he had provided within his written assessment. Dr Ince went on to state:

“I would additionally note the similarities within the terminology and language between the comments of B and A both within the documentation and during the two assessment interviews. Thus, I do not believe that the views of A can be relied upon in any way or that the court can be confident that the views she articulates are indeed her own. The presence of an underlying pervasive development disability also known as autism spectrum disorder), will further impair A’s ability to understand the wishes and motivations of others and thus the lack of cognitive plasticity or the ability to question the validity of others and their undermining motivations is clearly of extreme significance.”

35. Dr Ince considered in detail the capacity of A to decide where she should live, to decide her care and support needs, and capacity to make decisions as to her medical treatment and as to contact. He concluded that A lacked capacity in each regard.

36. B disagrees with his findings and submits that Dr Ince is wrong. It is submitted on her behalf that the weight of expert evidence from other specialist practitioners is such that the court cannot ignore it or overlook it. In dealing with the aspects of decision-making other than capacity to conduct proceedings, Dr Ince further opined thus:

“A was initially given binary options of residing at home or not residing at home and with the latter, further probes as to with whom she may live. It is evident that she lacks significant life experience and I would suggest that this is, at least in part, due to her up-bringing and home schooling. She does not appear to have any real peer group or social circle and

appears to lack any independence, any independent living skills, or an awareness of her own privacy.”

37. I pause to consider the oral evidence which was before the court. It seemed from the evidence given to me that Dr Ince’s assessment was correct. There was little evidence of any social circle other than friends of her mother and there was little evidence of any independence or independent living skills.

38. Dr Ince further referred to A making:

“...one reference to possibility of having a husband and children, albeit the latter did not take account of the consequences of infertility as a result of a primary ovarian failure and her refusal to take hormone replacement therapy. A gave stock responses to questions as to current and future residence and there was no evidence either of independent views that were her own, frequently misspeaking and then correcting her use of the words ‘we’ and ‘our’. A did not display any evidence that she had incorporated any of the comments from the first assessment into her appraisal of the same matters when asked the questions again in the second assessment. A relied heavily upon the views of her mother and thus again, whilst she is susceptible to the influence of others, this is a manifestation of her underlying Asperger’s syndrome and her inability to critically appraise the information that is presented to her due to her lack of reciprocal social communication, empathy, and ability to view things from a perspective of

others. A cannot truly be deemed to understand, retain, or weigh the information relevant to the decisions.”

39. In making the submission on behalf of B that other specialist practitioners have reached differing conclusions, Mr Barker on behalf of B relies upon the assessments of Dr Y in September 2017, the psychological report of Mr P in December 2017, and Mr K, a clinical psychologist. Dr Y carried out a mental health assessment whilst A was in hospital in relation to a request for a standard authorisation. Her brief clinical descriptions and the main symptoms and signs I have already set out. At C13 within the bundle, Dr Y concluded:

“A has capacity to make her own decisions about being accommodated in this hospital to receive care and treatment. She told me she wanted to go home as soon as possible understood this was depending on completion of her psychology assessment so appropriate help could be arranged according to her needs.”

40. Mr P, a consultant educational psychologist, was asked to prepare an assessment in anticipation by A and B of A executing a Lasting Power of Attorney. His opinion is set out at G128 within the bundle. He states:

“A is somewhat quiet and reticent in her general demeanour. However, in terms of core intellectual functioning, she has the ability at a verbal and non-verbal level to engage with the conceptual content of a variety of environmental experiences and stimuli to learn new ways and develop her adaptive skills in a variety of learning, recreational, and social

environments. In the context of the need for clarification as to her intellectual capacity to understand the rationale and implications of giving Lasting Power of Attorney to a significant adult, in this current context her mother, B, I am of the opinion, therefore, that A does have sufficient core cognitive capacity to make a well enough informed decision in this regard. Notwithstanding this, however, she does have significant and specific weaknesses in working memory and processing speed and there is evidence that her competencies in reading accuracy, spelling, speed, and accuracy of her written expression are not as functional as they might be and certainly well below the level that would be predicted on the basis of her core intellectual abilities. The above evidence suggests a combination of elements consistent with a dyslexic profile, the main implications being that she is likely to benefit from help to achieve a higher level of efficiency and confidence when processing information, and when expressing her ideas in written form.”

41. Mr Barker, the solicitor representing B, received an email from Mr K on 27 March setting out that he had been approached by B and A and asked:

“...to repeat the IQ assessment undertaken by [Mr P] and offer an opinion as to Asperger’s.”

42. I received a copy of the report from Mr K in the post on the morning of the hearing.

Putting aside concerns about how this report was commissioned or what information was imparted to prepare the report, I am satisfied that the report of Mr K adds little to the

overall evidential picture. It considers the report of Mr P, the educational psychologist, which was considered by Dr Ince, in any event, when he gave his oral evidence before me.

43. In his oral evidence, Dr Ince considered the opinion of Mr P and told me that it did not fundamentally change his opinion about the diagnosis of borderline to mild learning disability. He said he found aspects of Mr P's report extremely helpful in respect of the areas of strengths and weaknesses which A exhibited. Dr Ince raised the significance and drawback of repeated tests in a short period of time. He said that it was not recommended and that the test on 20 December 2017, which placed it within three months of the previous administration of the same test, can result in parties showing increased personal scores having practiced the test recently. Dr Ince said there was nothing in Mr P's report to show that he was aware of the previous test. Dr Ince told me his view was that the diagnostic aspects upon which he relied were unchanged.
44. When cross-examined by Mr Barker about Dr Y's assessment, Dr Ince stated but he struggled somewhat professionally with that but his assessment was that her assessment is much more narrow in scope and that he noted that Dr Y was not a learning disability specialist. In considering the expertise of Dr Ince as well as the considerable volume of records and information provided to him, it is clear to me that he was in a far better position to provide a detailed and objective view as to A's capacity than the other medical professionals involved.
45. Dr Ince was questioned about the influence of B. He noted the comment from numerous professionals as to the difficulties in seeing A individually and that on occasion, B was heard in the background prompting A. He stated:

“Obviously, A places great weight on mother’s views. As a child we acknowledge A had a degree of cognitive deficits and because home schooled, had limited exposure to alternative points of view.”

46. He said, greater than that, the expression of mother’s views by A are such, “...that I believe they profoundly impact upon A’s ability to weigh information with which she is provided, including validity and alternatives” and he gave examples of “doctors in the NHS lie”. He went on to say, “I don’t believe A came to this conclusion on her own.”

47. It was put to Dr Ince that he was not able to determine what A’s views are because they are so closely aligned with B’s views and that it affected A’s ability to weigh information. He agreed with both propositions. Dr Ince said that there were clear signs of influence which, in his view, significantly impacts upon A’s ability to weigh decisions because the decisions are not effectively appraised. Dr Ince stated that it was very hard to predict what may occur in the future given the degree of influence because of the proximity and likely degree of influence because of the relationship between A and B. Dr Ince cautioned that account must be taken of the diagnosis and whether A can develop skills to critically appraise information given to her. At the moment, he did not believe it could occur but he stated:

“in my report, and [Mr P]’s report, whether that is the case in two or three years’ time, I don’t know, if you took out the undue influence.”

48. However, Dr Ince was of the view that at the present time, there was a significant degree of influence from B albeit insufficient to impede the causal link between the diagnostic and fundamental tests. He concluded that A’s removal from home would be the only

option if B was refusing to accept the proposed treatment for A. Dr Ince concluded that A is:

“...profoundly lacking in life skills and naïve regarding accommodation, care, and support required.”

49. At G70, at 16.93, Dr Ince states:

“A has led a socially isolated life to date. She has not had the opportunity to engage in usual peer interactions and it is not clear as to the precipitant for the decision for her to be home-schooled. As a consequence, it is my view that she is profoundly lacking in life skills and thus naïve regarding both accommodation, care, and support and her broader future options. Indeed, she does not really entertain the possibility of any alternative options for accommodation, care and support, education, employment, or a host of other areas, and she unquestioningly accepts that she will live at home with her mother.”

50. A articulated the view to Dr Ince that she did not need any care or support outside of the significant care and support provided to A by her mother. Dr Ince further went on to say:

“As noted above, A’s inability to appraise the information and form an independent view is a manifestation of her underlying Asperger’s syndrome and her inability to critically appraise the information that is

presented to her due to her lack of reciprocal social communication, empathy, and ability to view things from the perspective of others.”

51. In respect of capacity to make decisions as to medical treatment, Dr Ince states at

16.10.2:

“I have significant concerns as to the current issues relating to A’s physical health monitoring, her seizure control, and her refusal to comply with hormone replacement therapy. I believe that the undue influence of her mother, perhaps as a direct consequence of B’s reported dislike of hospitals *et cetera*, wholly prevents A from entering any discussion as to the merits of treatment or otherwise and that her underlying diagnoses prevent her from being aware that this process is occurring. I also note that her views are based upon the presumption that NHS staff lie and her reliance upon the stock phrase of “that’s private”. I further note the longstanding barriers that have been put in place between A and any health professionals by B. Overall, the evidence clearly shows that A does not truly understand the information relating to her health conditions or the longer-term implications of non-compliance. I do not believe that she understands the risk of SUDEP. I would also note that the one view that she has articulated, although I do not believe that it is her own, as to wanting to change her antiepileptic medication, was contradicted by B at a point wherein A was presumed to lack capacity and thus was either not in her best interests or did not take her views into account.”

52. I have considered very carefully all the evidence before me in relation to capacity as set out including, of course, the evidence given by B and the maternal grandmother. B is of the view that A has a mild form of dyslexia and does not accept A lacks capacity in any regard. She told me she accepted that A does not understand about the endocrinology issue because she has not had the information to help her understand. However, in respect to epilepsy, the Lasting Power of Attorney, and all other issues, B was very clear that A had capacity to make her own decisions.

53. B does not accept A is in any way isolated but I find that B's account of A's day to day life did not include any regular interaction with adults other than her mother and grandparents. I also found it somewhat troubling that B and A speak to each other or have been heard to speak to each other in their own language on occasion when the social worker has been present. B told me that it was Farsi, although particular reason was given apart from interest as to why both mother and daughter would learn and speak Farsi and use it when others were present.

54. B was adamant that all decisions which were made were made by A herself. B told me that A has her own opinions, strong ones, and that she will argue with her. B told me:

“From having an idyllic life in September 2017, A goes into hospital, to this, threats and misery. The last one and a half years has been threats and misery.”

55. The court must presume that A has capacity unless it is proved that she does not. I found Dr Ince's evidence measured, comprehensive, and cogent, and sufficient on the balance

of probability to rebut the presumption of capacity. I repeat the helpful summary provided to by Mr O'Brien in his supplemental submissions:

“Dr Ince concluded:

- (a) In relation to the diagnostic test, A has a learning disability and also Asperger's. In cross-examination, he was clear that, on the balance of probabilities, both impairments were present.
- (b) A lacks capacity to conduct the proceedings. Dr Ince reaffirmed that A did not have the ability to independently appreciate the gravity of her current situation. She continues to place significant weight on the views and opinions of her mother. This inability relates to the absence of A's ability to use and weigh relevant information and is directly associated with her underlying mental disorders.
- (c) A lacks the capacity to make decisions about where she should reside and lacks the capacity to make decisions about her care and support needs. Dr Ince reaffirmed that A does not entertain the possibility of any alternative options for accommodation, care, support, education, or employment. A's ability to understand her are needs is impaired.
- (d) A did not have capacity to make decisions as to her medical treatment. She did not truly understand the information related to her health conditions or the longer-term implication. A does not have the ability

to understand, retain, or weigh the information relevant to the decisions on medical treatment that she has to make; and

(e) A lacks the capacity to make decisions about contact with others.

There was an inability to understand information relevant to the decision. She had impairments on retention of information.”

56. I make those findings. Dr Ince has the expertise, experience, and knowledge of A to reach the conclusions outlined. The assessments of capacity provided by the other professionals have not exhibited the depth of comprehensive knowledge and expertise provided within the written assessments and oral evidence of Dr Ince. I find his evidence compelling and I find, upon the balance of probabilities, that the evidence before me is sufficient to rebut the presumption of capacity.

57. The Lasting Power of Attorney for Health and Welfare was executed in January 2018. On the balance of probability, Dr Ince concluded that A did not have the requisite capacity to independently make decisions regarding the preparation of a Lasting Power of Attorney at the point of execution in January 2018. He sets out:

“With regard to the responses of A at assessment, there are clear deficits with regard to her understanding of the nature and purpose of the Lasting Power of Attorney. The responses that she gave were confused and contradictory and she particularly struggled with regard to life-sustaining treatment, the allocation of individuals to act in her best interests, and the definition of the term, of future changes to the allocated attorneys,

particularly were her personal circumstances to change. It was notable that she continued to believe that her mother would be the best individual to make decisions on her behalf even if she was, at some point, to be married.”

58. He further went on to state:

“A displayed limited understanding as to the possible revocations at a future point and further could provide no explanation as to the rationale for the preparation of such a document in an individual aged 19 years, who is broadly fit and well, particularly given that the preparation appeared a direct response to poor treatment by hospital staff.”

59. I heard evidence from Nigel Miller the solicitor who drafted the LPA. He identified his understanding of A’s motivation, namely so that B could speak to staff at the hospital when A was unwell and unable to communicate. No mental health problem or learning disability was raised with him. Mr Miller said that the lack of communication at hospital and families being excluded from meetings was an issue he frequently came across. It was not unusual. He accepted it was unusual for a 19-year-old to want to appoint an attorney. He saw A and B together and said it was quite usual to see the donor and donee together. The focus was on medical issues. He told me that he was satisfied that A knew exactly what she wanted and that the presence of B did not influence her negatively. He viewed it as unnecessary to speak to A in private to clarify any matters.

60. Mr Miller did not see the report of Mr P. He told me, if he had done so he would have sent the certificate over to him to sign. The appointment was the 30 minute appointment and no further appointment was offered. Mr Miller said he did not probe why B may have been excluded or any detail as to the hospital admission as he did not see it as relevant to capacity. Mr Miller said he was not told about any autism, Asperger's, or learning disability. I comment that I suppose that this is not surprising bearing in mind that B does not accept those diagnoses. He said that if he had been, he would still have told A that a Lasting Power of Attorney was sensible but would have sought a medical opinion and got a consultant to sign the certificate.
61. Dr Ince, in his own interview with A, noted there were clear deficits with regard to A's understanding of the nature and purpose of the LPA. The responses she gave were confused and contradictory and she struggled particularly with regard to lifesaving treatment, allocation of individuals to act in her best interests, including a definition of the term and future changes to the allocated attorneys particularly when her own personal circumstances change. Mr O'Brien highlighted the position with regard to A still taking the view that the best person to take decisions on her behalf would be B even if A was married.
62. Mr Miller did not discuss with A the many issues upon which an LPA could impact, namely, residence, contact, or future changes in A's circumstances. He said it was about medical issues. Mr Miller provided two written statements and gave oral evidence. He was of the view, and continued to be of the view, that at the relevant time A did have capacity to execute the LPA.

63. Pursuant to s.9(2) of the Mental Capacity Act 2005, an LPA is not created unless “P” has capacity to execute it at the time it is executed. Section 9(3) of the Act provides that an instrument which does not comply with s.9 and s.10 or Schedule 1 of the Mental Capacity Act 2005 accordingly confers no authority and is not valid. In *Re Collis*, an unreported decision of Senior Judge Lush on 27 October 2019, and referred to by Mr O’Brien, Senior Judge Lush considered the information specifically relevant to the execution of an LPA.

64. I have considered all the evidence in relation to the lasting power of Lasting Power of Attorney, and particularly the evidence of Mr Miller and Dr Ince, and I am satisfied that A lacked capacity to execute the LPA at the time she purported to validly execute the document. The oral evidence of Mr Miller does raise concern as to just how vigorously, if at all, he investigated the position. He saw B and A together. He did not enquire into A’s medical history although aware of her hospital admission and diagnosis of epilepsy, and bearing in mind the appointment was only of 30 minutes’ duration and he says within it he discussed it being unwise to have only one attorney and also discussed revoking it, it is questionable whether Mr Miller was able to consider the necessary salient factors in respect of capacity. It is, of course, easy to be critical with hindsight and with the information now available to the court. However, I find Mr Miller did not sufficiently question whether or not A had capacity or attempt to avail himself of the necessary information to conduct an adequate assessment of A’s capacity to understand, retain, and weigh the information relevant to the decision to execute the LPA. There is cogent evidence to suggest A did not have capacity to execute the LPA at the relevant time and thus, the LPA is not valid and I make a declaration under s.15 to that effect.

65. There is a handwritten document at I3 in the bundle which A calls her living will and wishes, dated 6 March 2018. It sets out A's wishes. She says:

“I want to live with my mother and my other attorneys at our home. I want my attorneys to get me out of hospital. I do not want to be at hospital. I do not want to go to any outpatient's hospital appointments. I do not want to do any psychometric IQ or other IQ tests. I do not want Social Services in my life. I do not want a social worker. I do not want to go to any [something] appointments. I want my attorneys to give me my medicines. I want my attorneys to access all my medical and welfare records. Some of my hobbies and interests are, ballroom dancing, reading, listening to radio, outings to favourite places, for example, the beach, countryside shopping, [the shopping centre], going for walks. I like to eat with my attorneys and I like home cooked meals, and home baked treats. [Signed] A.”

66. It is useful as a document which expresses A's wishes and feelings as at 6 March 2018 but it is not valid as an advanced decision to refuse treatment or as any other formal document. Section 24 requires that “P” has capacity to make such advanced decision. On the basis of the evidence before me, A did not have capacity at the time she completed this document and therefore, it is not valid.

67. The applicant also raises whether the document is invalid as an expression of A's true wishes and feelings for the purposes of s.4(6) of the Mental Capacity Act 2005 due to there being good reason to doubt it is an accurate reflection of her own and entirely independent wishes and feelings. Upon the basis of the evidence before me, it is unlikely that the wishes and feelings expressed by A within this document or any other expression

of wishes and feelings are indeed her uninfluenced views. However, she has consistently articulated clearly that she wants to stay with her mother with no outside interference by social workers or the court. These are her views which she has expressed.

68. A has refused to meet her solicitor in order to allow the official solicitor to ascertain her wishes and feelings which is fundamentally required pursuant to s.4(6)(a) of the Act. A's wishes and feelings were formally ascertained during the course of the court hearings and recorded in the attendance notes of Mr Bourne, her solicitor. She was asked by Mr Karim about the proposed hormone treatment and at D119, her responses are reduced to writing:

“SK: What are your thoughts on proposed hormone treatment?

A: I don't want to take at the moment.. Want to wait and see. I want an opinion from a private endocrinologist . First wrong answer. Otherwise, no.

SK: What about proposed changes to your epilepsy treatment?

A: I don't want it changed. Current medication is controlling my epilepsy. Has been a few years. I can't understand why they want to change. I've spoken to a pharmacist and the epilepsy helpline. They say treatments are similar.

SK: What about the risks with the current medication?

A: I have been taking vitamin D. Want to stay on the same medication unless it doesn't work. All I want is the truth.

SK: Why do you think the current doctors are untruthful?

A: I have had a couple of different diagnoses which have been different and therefore I want a second opinion.”

69. The responses are disjointed and do not seem to follow any specific line of thought. The proceedings were originally initiated because of the concerns expressed by the treating clinicians and medical personnel about A's and B's engagement in respect of treatment for A. This court is required to consider A's best interests. Section 1(5) of the Act requires that any decision taken on behalf of a person must be in his or her best interests, and s.4 provides a detailed framework for the assessment of those best interests. Best interests include medical, emotional, and all other welfare issues.

70. In *SL (Adult Patient) (Medical Treatment)* [2001] FLR 389 Thorpe LJ Encapsulated it as:

“In deciding what is best for the disabled patient, the judge must have regard to the patient's welfare as the paramount consideration. that embraces issues that are far wider than medical. Indeed, it would be undesirable and probably impossible to set bounds to what is relevant to a welfare determination.”

71. Further, Lady Hale in *Aintree University Hospitals NHS Trust v James* [2013] UKSC 67 said that:

“The most that can be said, therefore, is that in considering the best interests of this particular patient at this particular time, decision-makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves and its prospects of success; they must consider what the outcome of the treatment for the patient is likely to be; they must try and put themselves in the place of the individual patient and ask what his attitude to the treatment is or would be likely to be; and they

must consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be.”

72. The first issue which I consider in looking at best interests is the primary ovarian failure in respect of which I heard evidence from Dr X. During her admission with epilepsy in September 2017, various tests confirmed primary ovarian failure. A scan was reported showing that neither the uterus or ovaries could be delineated within the pelvic cavity. Dr X said that this finding was not unexpected as the ovaries and gonadal dysgenesis are often invisible on a standard scan and the prepubertal uterus can be so small as to be invisible on a standard transabdominal scan. Unfortunately, B and thus A perceive that they have been lied to by the medical personnel and have been reluctant to accept Dr X’s expertise in regard to these matters and thus have continued to express the view that they must seek further opinion.

73. Dr X, in his report and oral evidence, told me that there is no range of medical opinion regarding the management of primary ovarian failure. Treatment is invariably sex hormone replacement therapy. He said there are no long-term associated health risks to the treatment provided the condition is properly monitored and treated. He set out that usually, a girl with primary amenorrhea who had not imitated puberty would be seeking medical attention by her mid-teens or depending on the circumstances of the individual, her parents would be doing so on her behalf. B told me that Dr D had told them that it need not be investigated until A was 20 or 21. I have not heard from Dr D, but if she expressed that view, it is outside the advice which would be given by an endocrinologist specialist within the field. Dr X told me it was exceptionally unusual for a girl absent

period not to be brought to the attention of the medical professionals and that he had never come across a parent who had left it so long to have the situation investigated.

74. In the GP notes, it is recorded that on 13 September 2017, B said that Dr D had said to them that fits might get worse at menarche, so A does not want them to start, and when the GP suggested that it should be investigated, it is recorded that B stated:

“A doesn’t want to see a GP and now is of an age to make her own decisions.”

75. Dr X was clear that he did not foresee any adverse impact of inducing puberty upon A’s epilepsy. Dr Y concurred with his view. He said they take patients through puberty, menopause, and everything.

76. An appointment in the endocrine transition clinic was arranged for A on 19 October 2017. She failed to attend. A further appointment was arranged for 21 December 2017 but a phone call shortly before the appointment said that A would be unable to attend because her mother, who had LPA, had an upset stomach. A eventually attended an appointment on 19 April, some six months late, accompanied by her grandmother. The hospital note reads at G13:

“Explained to them this difficult and distressing diagnosis. Ovaries have not developed properly and are so tiny as to be barely visible on ultrasound scans. Same for the uterus although, unlike the ovaries, this will grow with treatment. Neither A, nor apparently mum, were bothered by her lack of periods and being home schooled A does not have a peer group of class-mates with whom to compare physical development. She declined pubertal (inaudible) today by Sister Jackie. Reassured that she is

at no major excess risk of fracture now. However, in order to develop into a mature woman and, crucially, to avoid getting premature osteoporosis (brittle bone disease) in her 30s and 40s rather than her 70s or 80s, she will need to start oestrogen replacement and continue for four decades. Understandably, she is not delighted by the prospect but we explained the lack of any viable alternative. She elected for oral over patch oestrogen replacement with progesterone deferred until after she has begun to experience vaginal spotting.”

It is noted that with encouragement from her grandmother, A agreed to take the vitamin D capsules and oestrogen tablets.

77. A attended the RVI admissions suite on 21 June 2018. The tests undertaken on that occasion show that A had not taken any of the oestrogen tablets or the vitamin D supplement. B told the registrar who saw them on that occasion that if A does not want to take the tablets, she should be supported in this decision whatever the consequences. It was in contrast to the grandmother’s encouragement of A.
78. Dr X spoke to A on 11 July. He formed the strong impression A was being prompted by someone beside her, presumably her mother. B denies that this occurred. A said that they were going to pursue a private bone scan and ultrasound. Dr X advised that both scans would be a waste of time and money and that the ultrasound scan may cause unnecessary concern because a uterus that has never been exposed to oestrogen is often too small to be seen on ultrasound. Dr X told me that it would be useful to do the scans after treatment had been underway for a few years. Dr X did say that he had arranged for A to have a second opinion from Dr M which appointment A attended with her grandmother.

Everything was again explained but A refused to have the treatment saying that she did not want to even have periods despite Dr M explaining that it would be possible to treat her without necessarily causing periods. A declined that option without giving reasons.

79. Dr X became quite emotional when he was giving evidence before me. He told me that the likely success of the treatment was 100 percent. There is no failure rate. He told me it transforms a child into a woman. He said it is the basic human right of every girl to blossom into a woman and he found it inconceivable that it should be blocked. He said failure to treat it was unthinkable and it should have been done five years ago.

80. Dr X dealt with the risks and consequences of not treating A's ovarian failure:

“If this condition remains untreated, the long-term prognosis for A is extremely bleak with outcomes becoming correspondingly less good the longer she goes untreated.

Psychological and social impact – we should first try to imagine ourselves as individuals of adult age still trapped inside prepubertal bodies, and with our minds, thought processes, and imagination not fully matured by exposure to sex hormones. There are fortunately just too few individuals with congenital hypogonadism coming to expert medical attention late in life who have never gone through puberty for there to be any kind of systemic study. However, experts across the world do talk to each other and discuss their more difficult cases and there is universal expert consensus that these individuals are deeply unhappy, have not led fulfilling lives, are socially isolated, have major issues of body image and self-esteem, and have a marked degree of alienation from the rest of

society. They have great difficulty in forming physical relationships and, indeed, penetrative sexual intercourse, is extremely uncomfortable for any untreated hypogonadal woman. In my own clinical experience, I have taken a male or female patient aged over 40 through puberty around once every one or two years. None of them have expressed any regrets about going through this process. All were extremely pleased to have undergone puberty and all had significant regret at not having done so earlier. Neither I nor any colleagues has hitherto encountered an individual who truly, of their own free will, did not wish to go through puberty or whose parents did not wish them to go through puberty.”

In relation to health perceptions and quality of life in late-treated women with a form of congenital hypogonadism, that is less severe than A's. A recent study found major physical, psychological, and social effects on their well-being. Psychosexual issues were particularly common with 87 percent having major concerns about body image and being ashamed of their own bodies; 66 percent continued to have difficulty with intimate relationships; and 30 percent had significant (moderate or severe) depressive symptoms.; 7 percent of them had never been in any kind of physical relationship; and 6 percent of them had never been sexually active at any time. There was a greater symptom severity associated with later diagnosis and treatment.

Osteoporosis and fracture risk – A will not achieve adequate peak bone density, otherwise typically attained in one's late 20s /early 30s resulting in her developing premature osteoporosis (brittle bone disease), which greatly increases risk of spine, wrist, and vertebral fractures from her 30s to 40s onwards. These types of fracture rarely occur in normal women under the age of 60 and their peak instance is in old age, 80-plus. Whereas wrist and hip fractures only occur with trauma, e.g. falls, osteoporotic vertebral stress fractures typically occur spontaneously, leading to chronic backpain and progressive spinal deformity, potentially even with impairment of lung volumes should a pronounced kyphosis develop. Hence, vertebral fractures are associated with increased mortality from respiratory disease, among other things. Statistics show that a third of men and women who undergo fracture neck or femur, which is one of the more severe osteoporotic fractures, are dead within a year and one third never return to their pre-fracture physical and social function. Spine crush fractures are around 10 percent more common than fractured neck or femur in patients with osteoporosis. A is therefore at a significant risk of sustaining at least one spinal crush fracture before aged 50 - 60. These are not only painful in themselves, they lead to secondary arthritis, with further increasing pain and the resulting spinal deformity results in loss of lung volume. The nearly 50 percent increased relative risk of death associated with vertebral fractures largely seems to arise from an excess of

respiratory diseases which may arise from impaired lung function to thoracic deformity.

Appearance – if A does not undergo treatment, in terms of appearance we can be certain that for the next 10 - 20 years or so, she will continue to look much younger than her age and this will also affect the manner of which she is considered by society around her with the inherent negative effects of that on her. However, thereafter she will then begin to look much older than her age, because oestrogen-deprived skin is much thinner and therefore, she will get a more wrinkled appearance much faster, much earlier than would normally be the case in a healthy woman or a woman taking sex hormone replacement.

Cardiovascular – regarding cardiovascular implications and not going through puberty, the only evidence we have relates to women who did not go through normal puberty but then had a relatively early menopause. In a study of some 2,500 older women, 28 percent reported early menopause before the age of 46 years, either one that occurred naturally or as a result of surgical removal of their ovaries. These women had significantly worse coronary heart disease and stroke free survival. This effect was independent of additional cardiovascular risk factors. So it is clear that having premature loss of sex hormones predisposed to increased rate of death through stroke and cardiovascular disease. What cannot be known

for sure because the studies are simply impossible is whether lack of exposure to oestrogen whatsoever during one's lifespan will make this situation even worse. However, in my view, and that of other international experts in the field, that is a pretty safe assumption."

81. I have read out in full Dr X's report in relation to the effects of not undergoing the treatment and the effect of delaying treatment because of the very significant physical and emotional effects which, in his view, will be sustained by A if she fails to undertake the treatment. B's continuing approach is to question Dr X's view and expertise. B and A have continued to press for an independent assessment of endocrinological issues and possible treatment for that. It is a perverse position given all the detail provided by Dr X and the level of his expertise. B and A's expressed reason is that they have been told different things and have been lied to. Dr X explained the findings of the scan and the reasons for the recording but A and B have determined not accept Dr X's views.

82. B in her evidence on 7 March repeatedly said that they had not been provided with information. I do not accept that. B told me that because of the way this was dealt with in the hospital, A wants to go to someone privately with whom she is comfortable. She wants it delivered in a more understandable way. She was highly critical of Dr X. She said she was there when they were told by a doctor that there was no uterus but was not there when Dr X explained the reasons why the uterus may not show up on the scan. B said in evidence to me that the further information she wanted was a private consultation with someone away from the influence of Dr X. She went on to say she accepted what he said but wanted it explained in the best possible way. However, B reverted within her evidence to, "I don't know who lies but we have been given different information." Her

response to the question, “Do you accept that there is a huge advantage in oestrogen treatment?”, B responded, “Hopefully, yes, but I haven’t heard other information.” She was asked, “Can you accept the view that not to proceed is unthinkable?” and responded, “Yes” but she went on to say, “My daughter said, ‘I still want a second opinion’ and I agree.” B admitted that she continued to have difficulty accepting the advice of Dr X and, indeed, I find that that is the position. I found the evidence of Dr X compelling, his explanations easy to follow, and his approach empathetic.

83. I accept that the first doctor following the scan may have said no ovaries or uterus could be seen but this was explained on 19 April 2018. The benefits of the treatment have been outlined and significant consequences of not having the treatment highlighted. A is more than a year on since Dr X explained the necessity for treatment and no treatment has commenced. Although B articulates that she accepts what Dr X says, she has continued to press for a second opinion even to the extent of seeking an endocrinologist in York without the court’s permission as referred to in the previous judgment. B told me that she now believes in the plan in respect of the delayed puberty because A is now 20 to 21, which is the age she wanted it done. B expressed no conviction or decided view that it was necessary or beneficial to A to have the treatment. B’s approach when giving evidence in May was that someone else, another medical person, should tell A so that the information is given in a more humane way. She told me:

“It was what we were aiming to do in York. I think it does need it so it is given in a more comfortable way, away from Dr X and his team.”

84. I have listened very carefully to B. Whilst I accept that she is now saying that she accepts that treatment should be undertaken, I have no confidence that she will encourage or

support A to take medication or keep hospital appointments. B continues to assert A has capacity, that it is A's distrust of medical professionals arising from her admission to hospital in September 2017, which has prompted B's own approach. B continues to reiterate that the doctors have lied to them and that a second opinion was required because she had no trust in Dr X or his team. B continues to say A can make up her own mind and her decisions should be respected.

85. It continues to be submitted on B's behalf that an independent assessment from a medical specialist away from Dr X's team would provide additional confidence to A, but I am satisfied that despite the evidence that no other opinion or treatment could be obtained, B continues to press for further medical evidence because she does not, in fact, accept Dr X's views and expertise. Therefore, if A is in the care of her mother, as we know occurred before, the administering of medication will not be supported or, indeed, occur as shown by the tests which were carried out. Dr X states:

“There is universal expert consensus that these individuals are deeply unhappy, have not led fulfilling lives, are socially isolated, and have major issues of body image and self-esteem.”

B seems to accept that position should pertain as far as her daughter is concerned for the future.

86. Article 8 of ECHR protects the rights to personal development and autonomy and Article 6.2 of the United Nations Convention on the Rights of Persons with Disabilities states that all appropriate measures should be taken to:

“...ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them to exercise and enjoyment

of the human rights and fundamental freedoms set out in the present Convention.”

87. The advantages of undertaking the treatment are significant and fundamental. It is 100 percent effective without risk. It ensures a normal life expectancy and no death by a serious fracture or cardiovascular disease by 30 to 40 years of age. The disadvantage is that it is against A’s expressed wishes. However, I am not satisfied that she has been able to form an independent and informed opinion. It is difficult to see how it can be said not to be in A’s best interest for the treatment to be undertaken or any potential disadvantage to it being undertaken even if it is against A’s wishes.
88. In light of Dr X’s evidence, it is also difficult to understand why a parent would not have been encouraging A to undertake the treatment over the past twelve months and before that. Sadly, I find that B has been so obsessed with her own wishes, views, and fears that she is being blinded to the obvious and risk-free advantages to her daughter of encouraging her to undergo the treatment and has, instead, failed to encourage her daughter to engage with the treatment or has actively dissuaded her daughter from doing so. Thus, the prospect that B will in the future support her daughter and positively encourage her to engage with the treatment must be extremely limited. Sadly, it is difficult to reach any conclusion other than B would prefer A not to “grow up” for want of a better description, that she would prefer A to remain the same, dependent upon her mother, and isolated within her mother's sphere without any outside influence or interference.
89. In dealing with the epilepsy, in his report, Dr Y recommends a change to A’s current antiseizure medication. He says her current medication is outdated and is associated with

an increased risk of osteoporosis which, of course, is of particular concern as A already has an increased risk of osteoporosis by reason of her primary ovarian failure. Dr Y also stated that A's current epilepsy medication can lead to lifelong issues. In his oral evidence, Dr Y confirmed that the proposed alternative medication is very stable and in terms of side effects, there was a very small chance of irritability. Undertaking a balance sheet approach as prayed in aid by Mr Karim within his final submissions, the advantages included reduced risk of osteoarthritis, and effectiveness and increased monitoring of seizures. The disadvantages include A's wishes and the one in ten chance of balance problems. The official solicitor is of the view that the treatment is also in A's best interests despite contrary wishes expressed by A and B.

90. I did not really understand the objections raised to the updating of the medication apart from the fact that it would be a change. I do appreciate that living and coping with epilepsy must be demanding and therefore, to stay with what is known must have its temptations, but when faced with the expert view that the medication A takes is an old-fashioned medication which can affect bones and further risk of developing side effects, some of which will be hard to ameliorate once they occur, most persons weighing up the best way forward would be keen to commence the more effective and less riskier medication. I am satisfied that A's best interests are served by following Dr Y's advice as to the epilepsy medication appropriate for A.

91. Ms V, the social worker, has provided a support plan recognising the outcome of the adult needs assessment which she conducted in respect of A and a balance sheet analysis of the options available for meeting A's needs. A has been assessed as having eligible needs in the areas of:

“Making use of the home safely – A needs supervision to ensure that she is using equipment, e.g. cooker, safely because of the risk of absent seizures;

Accessing and engaging in work training, education, and volunteering – A has not had a range of opportunities for further learning or support to consider options for working or training;

Develop or maintain family or other personal relationships - while A does have some family relationships and connections in the local community, there is a degree of social isolation from a peer group and limited opportunity to develop further relationships.

Making use of necessary facilities or services in the local community – A needs support to access the community safely due to risk around her epilepsy.”

92. Ms V went on to set out at paragraph 38:

“I believe that A is experiencing a level of social isolation in relation to contact with peers and society in general. Her life experience has been restricted in relation to her education and social opportunities. A reports being happy with her lifestyle, but it is difficult for her to imagine any other way of living due to lack of concrete experience. It is difficult to judge the extent to which A’s social isolation and ability to maintain

relationships is a result of learning disability and autism spectrum condition; or the impact of her isolated upbringing. The only way to determine this is by supporting A to experience more of the world outside of her current environment.”

93. Ms V, however, identified that there were problems in relation to putting this plan into operation given the apparent distrust of both A and B in respect of services which could assist A in developing independence and interests outside the home and family environment. They have both viewed the local authority as well as the NHS as intrusive and unhelpful. Ms V’s view was expressed at paragraph 50 at D49:

“In order to deliver support effectively in the long term and address A's health and care needs, a period of socialisation and education needs to take place to support A to develop her own views. This would aim to increase her capacity to make decisions in these areas independent of her mother to the extent that this is possible.”

94. The least restrictive option recommended by the local authority was to attempt to provide support to A within her home setting. However, that view changed following the evidence heard in court in March and Ms V questioned the likelihood of any plan to increase socialisation, social network, community activities and greater independence being effective if A remained at home.

95. B has contested the view that A is socially isolated but I am satisfied from the evidence presented to me that apart from her mother and her grandparents, and her dancing, A has very little interaction with anybody else. Certainly, there was no evidence before me that she socialised with anyone of her own age group on anything approaching a regular basis.

There seemed to be a reluctance to recognise the benefit to A of developing independence or recognition of the benefit to A therein. Without such recognition, it is unlikely that A will be supported in this regard by her mother. On the arranged visits between the court hearings, A exhibited reluctance to say anything at all in response to questions from Ms V about her life or future. B has pressed for a change of social worker. A has stated to her solicitor on 8 March that she had no intention of cooperating with the support plan and that her mother had only agreed to it in court in an attempt to prevent A being removed from their home.

96. In fact, the court ordered removal on 9 April and the transcript of judgment of 9 April is, of course available. Ms V comments that the relationship between A and B is unusual and complex. I agree. The result, Ms V says, appears to be a life for A where she has not been able to develop a sense of security and identity separate from her mother. She lacks experience of developing relationships with her peers and the social norms and boundaries that others take for granted. Ms V opined at D136:

“A needs to be supported to develop her ability to live and think for herself, to experience the world around her and make choices based on this. Social care support, underpinned by advice from relevant health professionals, could offer A this opportunity. The absence of this support may not be as immediately life threatening as her relevant physical health issues, but will potentially result in a largely isolated life and significant psychological difficulties in the future.”

97. I find that Ms V accurately identifies the social and care issues concerning A. In addition, I find that B exhibited no intentional motivation to support A to develop a sense of

identity separate from her mother. In fact, quite the contrary, B has by her actions, behaviour, and interaction with A encouraged A's dependence upon her and B has not shown any inclination to assist A to achieve any growing independence, it seems preferring the situation pre-September 2017 which she described as "idyllic with no outside interference". Both B and A have described social workers as interfering and have continued to resist any change. Their relationship is enmeshed and I am concerned that established behaviours from when they resided together would return if A went home.

98. A has made two references to her family not wanting her to change and her mother being fine if A were to stay with her and A did not change. A, on 8 March, said that her family accepted her as she is and would support her decision not to change. There has been evidence that this theme has continued even after A's removal to Placement A with B saying in telephone calls not to change and sending a letter containing the following:

"You're divine, dear, stay near me. Night and day, I pray that you will always stay as sweet as you are. Don't change, dear. Don't let them rearrange you, dear."

99. I do not accept B's contention that it was just a Nat King Cole record playing, and she thought the words were nice and decided to write them down, and they happened to be on a table near her when she decided to write to A. I find B continues to be resistant to the idea that A should progress, cease to be like a young girl, and achieve any independence. I recognise that B has cared for A throughout her life and helped her and coped with her epilepsy and it cannot have been easy for her. New experiences and change may cause B

to be fearful for A's welfare but her attitude, I find, is stifling A's opportunity to widen her experience and life.

100. The least restrictive approach as required by s.1(6) would be to deliver any treatment plans and social care support with A living at home with B. In his oral evidence, Dr Ince stated that in order for a package of care to be effectively delivered at home, he would expect B to demonstrate an appreciation of A's needs, an understanding of A's needs, and actual compliance with any plan.

101. Mr Karim, on behalf of the official solicitor, has identified certain aspects of B's evidence provided on 7 March 2019 which raises questions as to whether B has any appreciation of A's needs, any understanding of her needs, or the willingness or ability to actually comply with the plan.

102. Within his final submissions, Mr Karim underlines B's preoccupation with the purported lies of the trust and need to seek another opinion which engulfs her view, whilst she did say that she agreed with medical treatments, when probed in cross-examination, she said a second opinion is required in relation to the endocrine treatment and she was concerned by the risks with a change of medication; her belief A has capacity and should live subject to her own wishes; she does not believe A has the said diagnosis; and that she never believed or noticed that B had any difficulties despite homes schooling her until the report of Mr P of December 2017. Mr Karim remarks that this is remarkably telling. B stated again in cross-examination that she will struggle to allow people to enter the house because she has a diagnosis of obsessive-compulsive disorder, despite exploring whether steps can be taken to help minimise any distress, B did not entertain the option; and her evidence that A was able to write by herself the

living will, is inconsistent with the view of Mr P and B admitted in evidence that (a) it was a joint document and (b) there was a risk that their views have intertwined into one.

103. B has shown continuing willingness to seek out other opinions, e.g. Mr K commissioned to provide a further report on 26 March, and has throughout preferred to accept from others rather than the experts and professionals caring for A, for example, Epilepsy Action, a pharmacist, and a friend whose son has Asperger's.
104. B's most recent statement queries A's wellbeing within the care home. While I accept that it is difficult for B or any mother to accept A living separately from her, B has raised only negative aspects of A's care and wellbeing since she went into Placement A. B has stated in terms that she never saw anything wrong in the lifestyle A enjoyed. B does say that she would support and welcome A exploring new horizons if there was a way to do so but states that she cannot see that A will develop any trust in Ms V. B would wish for a change in social worker saying they would work with Ms D.
105. I found Ms V to be a competent, sympathetic and empathetic social worker. I anticipate that B would have difficulty and thus A would have difficulty working with any social worker who challenged B's attitude, views, or behaviour. B does not trust Dr X. The evidence of the meetings between the social worker and A before she went into Placement A demonstrated a lack of willingness to engage and B's continuing influence over B. The evidence before me, although disputed by B, is that A has coped remarkably well in her new living situation and has been engaging well with staff and has developed good relationships with them, particularly a staff member called Kelly. A has been sleeping and eating well. In his attendance note of 2 May, A's solicitor Mr B confirmed that while A still expressed a wish to go home, she had no complaints about Care Home

One and found the staff helpful. Kelly, with whom A, it seems, has developed a good relationship, informed Mr B that A had begun to become quite chatty with her. Overall, the evidence from the local authority, albeit disputed by B, is that A is benefitting from the care and support at Placement A and is doing well.

106. If A remains in residential care, the local authority proposes to pursue a longer-term plan. This will include:

- (a) A speech and language therapy assessment to consider A's ability to communicate and understand information;
- (b) Involvement of the learning disability community treatment team to promote A's understanding of and compliance with treatment for her epilepsy and endocrinology issues;
- (c) The gradual introduction of new experiences;
- (d) The development of social networks and peer relationships; and
- (e) The facilitation of contact between A and her family and friends.

107. I can have no confidence upon the evidence I've heard, even with a change of social worker as requested by B, that B would facilitate and support such a plan. Upon the evidence before me, although recognising it is not the least restrictive option, residence in a care home, at the moment Placement A, meets the best interests of A.

108. I have considered whether A could reside with her grandparents with whom she has a very good relationship. They have been encouraging and helpful to A in the past but the difficulties referred to in the earlier judgement at paragraph 21 still exist and, presently, I see no way to ameliorate such difficulties.

109. B's third statement is a catalogue of complaints about her daughter's day to day care in Placement A. I do not underestimate how difficult it must be for B to experience someone else caring for A and B having limited contact to her. I am satisfied, however, that it is in A's interests and the only option presently to promote her best interests for A to be cared for elsewhere than at home with B. There must be continuing review of whether the environment of Placement A is appropriate for A and Ms V states that she retains an open mind about whether Placement A is suitable in the longer term and will research other options.

110. Similarly, the contact must be kept under review. The grandparents' contact seems to have gone well and to have a positive on A's engagement with support. It seems that the grandparents have developed a constructive relationship with the care home staff.

111. B's contact has contained elements of attempts to undermine the social worker's role. There is a written record of the telephone call of 24 April between B and A. B appeared irritated with A for talking to Ms V earlier that day. A explained that she had told Ms V how she really felt, i.e. that she wanted to go home and see her mother. At paragraph 82 of her recent statement, Ms V sets out:

“B replied with comments including, ‘You could have got out of seeing the social worker.’ A replied, ‘Oh, well, I’ve got it wrong’ to which B replied that A would have to pay for the consequences for her actions saying, ‘You’re an adult now. Get on with it’.”

112. Such interaction does not indicate any progress in B's attitude towards supporting A to receive support and care from the local authority nor indeed does it bode well for B's compliance with any care plan or treatment plan. It suggests a continuing negative

influence on A in terms of A's compliance with any care or treatment required. A is now 20 years of age. Her enmeshed relationship with her mother is longstanding and established behaviours will take time to alter and B's influence diminish. A deserves and requires the opportunity to experience life as an independent adult with proper support. Sadly, I find it will not occur if she remains living with her mother at the present time. The circumstances, however, will need to be reviewed at reasonable intervals. Thus, I make the orders and declarations which are sought by the local authority supported by the OS and health trust, namely:

- (a) A lacks capacity in all relevant domains to conduct proceedings to make decisions about residence, care, contact, and medical treatment, and to execute an LPA;
- (b) The LPA dated 4 January 2018 is invalid for want of capacity at the date of its execution;
- (c) The living will dated 6 March 2018 is:
 - i. Invalid as an ADRT for want of capacity at the date of its execution; and
 - ii. Is invalid as an expression of A's wishes and feelings for the purposes of s.4(6) of the MCA 2005 due to there being good reason to doubt it is an accurate reflection of her own entirely independent wishes and feelings
- (d) It is in A's best interest to undergo treatment in accordance with the recommendations of her treating clinicians;
 - i. Epilepsy;
 - ii. Primary ovarian failure; and
 - iii. Vitamin D deficiency

- (e) It is in A's best interests to continue to reside in residential care;
- (f) It is in A's best interests to receive care and support in accordance with care and support plan dated 2 May 2019; and
- (g) It is in A's best interests to have contact with B and with her grandparents in accordance with the best interest declarations dated 25 April exhibited to Ms V's statement.

L A T E R

113. Mr Barker, on behalf of B, seeks permission to appeal the decision and declarations which I have just made. In considering whether or not to grant permission to appeal, I have to consider whether there is a real prospect of success or some other compelling reason why permission should be granted.
114. Mr Barker seeks to appeal in relation to my findings with regard to residence, not the other findings. He seeks to call into question my finding in respect of unlikely compliance by B with the care plans which have been put forward in relation to A. He states that I have failed to take into account the change of attitude that B has expressed and that I have failed to place sufficient weight upon the fact that in discussion with Ms D, the sessions proposed between the two court hearings were more positive and that I only referred to the less successful sessions with Ms V. Mr Barker emphasises that B's attitude in relation to the plans has not been properly tested out and that the court is wrong to find unlikely compliance.
115. He submits that there is good authority to suggest that the court should try every viable option, which would include placement at home with a package of support as

indeed, he emphasises, was the initial plan of the local authority. He submits that what changed was what A said to her solicitor and thus a decision was taken to remove A into a care home.

116. In fact, it is the entirety of the evidence that the court has to take into account. It was reaching a final decision rather than an interim decision. The court has to look at the entirety of the evidence which was detailed and it was not just the compliance with the plan which was put into operation between the hearings which the court considered but the continuing position and attitude of B over the time that A has been within the care home.

117. I referred to established behaviour. There is no good evidence that the established behaviour has actually changed and a better interaction with Ms D rather than Ms V does not, itself, give me confidence that B would change her behaviour, as I said within the judgment. Ms D has not been the social worker who has challenged, or disagreed, or directed B or A and upon the basis of all the evidence, I am not unconvinced that there has been any change in the established behaviour exhibited by B over an extremely lengthy period of time.

118. It is perhaps worth stating that I made it clear that A's plan had to be kept under review as is usual and, indeed, must be the position, but I see no grounds upon which an appeal would be successful and no compelling reason. Therefore, I refuse permission. However, of course, what I will do is say that no significant steps, positive steps, whatever one wants to call it, should be taken until Mr Barker has had the opportunity to take further instructions and, if necessary, take the matter to a different court.

119. So the position will remain as it is without any alteration for the next 21 days.