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Case No. 11822229

IN THE COURT OF PROTECTION

Royal Courts of Justice, Strand, London, WC2A 2LL.

Date: Monday 11th August, 2014

Before:

THE HONOURABLE MR JUSTICE BAKER

IN THE MATTER OF THE MENTAL CAPACITY ACT 2005 AND IN THE MATTER OF M

A LOCAL AUTHORITY

Applicant

- and -

(1) M (By his litigation friend via the Official Solicitor)

(2) E

Respondents

(3) A

Transcribed by:

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Kerry Bretherton (instructed by the **local authority legal department**) for the **applicant local authority**.

Andrew Bagchi (instructed by Mackintosh Law) for the first respondent by his litigation friend, the Official Solicitor

The second and third respondents appeared in person

JUDGMENT

IMPORTANT NOTICE

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 no person other than the advocates or the solicitors instructing them and other persons named in this version of the judgment may be identified by name or location and that in particular the anonymity of the 1st Respondent and members of his 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.

MR JUSTICE BAKER:

INTRODUCTION

- 1. M is a 24-year-old man who has been diagnosed with autism and a learning disability, although, as discussed below, that diagnosis is a matter of controversy. For the first 18 years of his life he lived at home with his parents his mother, hereafter referred to as E, and father, A where he was by all accounts generally looked after very well. His parents were and are devoted to him and have devoted much of their lives to his care. He attended local special schools and enjoyed a wide range of activities.
- 2. Until his late teens the family had no contact with the local authority. At that point, however, social services became involved because his parents were looking for a residential placement where he could continue his education. There is no evidence up to that point of any conflict between members of his family and those professionals with whom they came into contact. From that point, however, the picture changed and there has been almost continuous conflict, in particular between M's mother, E, and the local authority. M's parents assert that they have been subjected to a malicious campaign aimed at removing M from their care. The local authority asserts that M has been subjected to a regime characterised by excessive control exercised by E over every aspect of M's life. More seriously, the local authority alleges that E has fabricated accounts of M's health problems and subjected him to unnecessary assessments and treatments, as well as imposing on him an unnecessarily restrictive diet, with a range of unnecessary supplements. There have been several court proceedings concerning the family, culminating in this case, brought by the local authority in the Court of Protection, seeking orders as to M's future residence and care. The local authority makes a series of allegations on which it asks the court to make findings. All those allegations are hotly disputed by the parents

and this has necessitated a lengthy fact finding hearing. This judgment is delivered at the conclusion of that hearing.

BACKGROUND

3. The following summary of the background to this case does not include every aspect of the very long and complex history as set out in the thousands of pages of documents which I have read before, during and after the hearing. I did not have the benefit of a comprehensive chronology and, in fairness to counsel, such a document would probably have been impossible to compile, let alone agree. In preparing this summary I have drawn on the local authority's chronology in section L of the bundle, an outline chronology filed on behalf of the Official Solicitor, the documents filed by E and A, including their 45-page document headed "chronology of health issues", the chronology of medical records and treatments prepared by Dr Peter Carpenter, a psychiatrist instructed as an expert witness in these proceedings, and my own reading of the voluminous papers.

1989 to 1998

- 4. M was born on 25th July 1989 by caesarean section after what is described as a normal pregnancy. He has one older sister, S, born in 1987. Dr Carpenter was unable to find any record of family history of any mental disorder, including learning difficulties or autism. His mother, E, worked for many years in the National Health Service in a number of jobs involving management responsibility, including responsibility for catering. Her curriculum vitae discloses, inter alia, that she has diplomas in public health and hygiene and in institutional housekeeping and catering. She has also, amongst other things, served as a governor for one of the schools attended by M and as a trained mediator, as well as serving in other roles in various organisations concerned with autism. Since 2004 she has taken a career break to devote herself to caring for M. M's father, A, has worked for many years in the fire service.
- 5. On four dates between September 1989 (when he was aged six weeks) and March 1990 (aged eight months) M received the normal range of inoculations, with no recorded reactions. In May 1990 M was unwell, with a fever and vomiting diagnosed at the time as a full upper respiratory tract infection. When seen by Dr Baird, a consultant paediatrician at Guys Hospital two and a half years later, in October 1992, M's parents described how during this illness on three occasions during one night they had felt that he "nearly stopped breathing" and turned blue. They told Dr Baird thereafter that his health gave rise to great concern because he always seemed to have a problem breathing through his nose and difficulty with swallowing. In another account, contained in an undated education report, his parents later reported that:

"A clear indication of the trauma his body experienced from this illness was from that time onwards he could

not bear his head to be anything other than upright. If it was moved lower than his shoulders his whole body would go completely rigid. For a time he lacked control over his tongue, until we managed to teach him how to keep it in his mouth."

- 6. Between July and December 1990 there were eight further visits to the GP noted in M's medical records in which he was reported as suffering from a variety of infections. There is no record of any developmental delay in these notes.
- 7. On 12th January 1991, aged just under 18 months, M was given the measles, mumps and rubella ("MMR") vaccination. There is no record in his GP notes of any adverse reaction. In fact, there is no report of any adverse reaction to the MMR in any record relating to M for the next nine years. From 2000 onwards, however, M's parents, and in particular his mother, have given increasingly vivid accounts of an extreme reaction to the injection experienced by M. There are descriptions of M screaming after having the injection, followed by six hours of convulsions, screaming and projectile vomiting. It is the parents' case that the mother told their GP that he had had a bad reaction to the MMR but was told by him that she was an over-anxious mother and must be imagining it. When E called the GP a second time and said she was calling the emergency services, she was told not to do this, but went ahead because M was going in and out of consciousness. The paramedics and the GP had arrived at the same time, at which point M's temperature was 104. The GP had told the paramedics to leave. Before going, they had told her that this was a case of meningeal encephalitis. The GP had been verbally abusive to E. The above account, given to Dr. Beck, a psychologist instructed as an expert witness in these proceedings, is similar to that given by the mother to a variety of professionals. She also gave a detailed description of M's reaction to the MMR in the course of her oral evidence. One note in an "auditory processing assessment report" dated 31st October 2002 records E alleging that, following the MMR, M had remained in, "A persistent vegetative state for six months."
- The parents' "chronology of health issues" prepared for these proceedings 8. states that between January and June 1991 M was prescribed antiinflammatories, antibiotics, antihistamines, decongestants and pain relief. There is no medical record of any such prescription, save for the decongestant. It is the parents' case that the medical records have been tampered with in some way to conceal the true picture. They produced two copies of the medical records which purported to show a gap of some eight months between December 1990 and August 1991. In fact, the original records show that the next consultation after the MMR took place on 26th April 1991. It is the parents' case that a page of the medical records was missing from the copies with which they had been supplied previously. The GP note of the consultation on 26th April 1991 records that E was concerned that M was a nasal breather and had thick mucous. He was prescribed a decongestant. The note also records that he had been uncooperative at the hearing test that day. According to E, in the summer of 1991 he started to receive homeopathy, reflexology and cranial osteopathy.

- 9. On 14th August 1991, aged just over two years, M was assessed by medical officers at the Audiology Service. The notes record that they were told that M had sat at five months and walked at 16 months. He was now able to feed himself and make attempts at undressing. It was noted that, though very placid and happy, he did not seem to take notice of people. He had little speech, other than "mamma" and "daddy". It was noted that he had bilateral hearing loss. The assessors were able to establish some eye contact and record during testing but concluded that M needed a fuller developmental assessment. There is no reference in these assessment notes to any adverse reaction to the MMR.
- 10. On 23rd August 1991, aged 25 months, M was assessed by a speech and language therapist. He was noted as presenting with delay in all aspects of communication and his development was said to be functioning at a level of approximately sixteen months, and he was said to be suffering from hearing problems. It was noted that he was using stereotyped play routines. Again, there is no record of the assessors having been told of any adverse reaction to the MMR injection. At the end of October 1991 M underwent surgery for the insertion of grommets and the removal of his tonsils and adenoids. After the operation it was recorded that he "has vacant staring and eye rolling? Absence seizure." Again, there is no record of any adverse reaction to the MMR. According to E, it was in December 1991 that M started to receive what she described as "basic natural nutritional supplements." On 22nd January 1992, when M was again seen by the Audiology Service, it was recorded that E felt that he had a much more healthy interest in activities and was actively involved with them. He had regained normal hearing. At about this time, according to E's "chronology of health issues", M was started on a gluten and casein free diet. On 25th March 1992, at a further developmental assessment, E reported that there was little progress in M's language development. She reported that he was producing a lot of sounds but no words, enjoying lining up cars, playing alone and not making eye contact easily. The assessors observed that he seemed to have a basic communication disorder and referred him to Dr Gillian Baird, a consultant paediatrician at Guys.
- 11. Dr Baird assessed M at her clinic on 8th October 1992. In the record of her assessment, there is no suggestion of any link between M's developmental delay and the MMR indeed, no reference to the MMR at all. Instead, Dr. Baird states:

"The parents described M's illness in May 1990 at aged 10 months and how it was clear in retrospect that his behaviour had changed quite abruptly following this illness."

E told Dr Baird that M had seemed inaccessible to them between the ages of 10 months and two years. Dr Baird commented:

"I am struck by the history which the parents gave and it is possible to postulate either that M's illness had nothing to do with his present developmental disorder, and it was merely coincidental in its timing, or one could postulate that M may have had some mild encephalitic illness which may have caused an alteration in his developmental progress. There is no way of proving this one way or the other now."

Dr Baird thought it appropriate to consider his problems under the general heading of "autistic learning difficulties". She suggested that he undergo a range of tests but observed that, if all proved negative, there might well be a substantial genetic component to his developmental problem. I note in passing that Dr Carpenter, in his examination of all the records in this case, found no test results following this assessment and was unclear how far the genetic component to M's autism was explored with the parents.

12. Thereafter, E sought an increasing range of alternative and complimentary treatments for M, in particular homeopathy, cranial osteopathy, reflexology, naturopathy and light and sound therapy. According to her "chronology of health issues", once the complimentary alternative and dietary interventions were established, there were only annual visits to the GP for the purpose of urine tests and checking ears, until November 2009. M's GP notes, however, show that he continued to be seen by the GP several times each year for a variety of illnesses and was also seen by various specialists, including an audiologist, ophthalmologist and speech and language therapist. In none of the records prior to 2000 is there any account of an adverse reaction to the MMR. From 1995 M attended special day schools for children with learning difficulties. He remained living at home with his parents and sister. For most of his childhood he was unknown to social services. There is no suggestion that he suffered any harm during this time. On the contrary, it is the parents' case that through their efforts he achieved a much higher level of attainment than was originally feared.

1998 to the start of these proceedings

14. In February 1998, Dr Andrew Wakefield and others published a paper in The Lancet which suggested a link between the MMR injection and autism and a condition they named "autistic enterocolitis". The subsequent history is well known but summarised briefly by Dr Carpenter in his reports in these proceedings:

"Dr Wakefield claimed that a series of 12 children with autism and bowel disorders had had a unique colitis. In discussions with the press, he linked this to the MMR vaccination. Unfortunately, when later reviewed the histopathology findings in the cases were felt by several experienced pathologists to show no evidence of colitis and the histories that Wakefield gave of the cases deteriorating immediately after the MMR were shown to be erroneous in many of the cases. No independent peer review paper has been

published subsequently to confirm the findings of an unusual colitis in autism."

Subsequently, Dr Wakefield resigned from the Royal Free Hospital. After a series of articles by The Sunday Times' journalist, Brian Deer, the General Medical Council in 2007 brought charges of professional misconduct against Dr Wakefield and two colleagues. In 2010 the charges were found proved and Dr Wakefield was struck off the Medical Register. By then he had moved to the United States, where he still resides.

- 15. The preponderance of medical opinion is that there is no evidence of any link between the MMR vaccine and autism, and that the actions of Dr Wakefield were, at best, misconceived and, at worst, fraudulent. It is said that, as a result of his activities, many parents have decided against permitting the vaccination of their children, with significant adverse consequences for public health. There remains, however, a degree of support for his theories, in particular by a group of parents who are convinced that the autistic traits identified in their children are attributable to the MMR vaccine, in particular, the vaccine administered in the late 1980s and early 1990s that allegedly contained what is called the Urabe strain of the mumps virus. E and A are amongst that group of parents.
- 16. Following the publication of Dr Wakefield's paper, a large number of families came together and started legal proceedings seeking compensation over the MMR vaccine. A claim on behalf of M was included in this litigation. Those proceedings came to an end when the Legal Services Commission withdrew funding following the discrediting of the Wakefield research. There has, therefore, been no definitive ruling on the substantive claim which the group of parents sought to bring, and a number of people still believe that Dr Wakefield was correct. As Dr Carpenter observed, "on some websites he is still talked of as a maligned hero."
- 17. The first reference in M's GP notes to a possible connection between the MMR injection and his autism is dated September 2000. At E's request, the GP referred M to Dr Wakefield at the Royal Free Hospital. The referral letter dated 19th September 2000 records that M:

" ... was apparently developing normally until he had his MMR vaccine. His mother states that after that the autism seemed to occur, as well as food intolerance."

It was noted that M was suffering from recurrent bloating and bowel pain. On 22nd September, Dr Wakefield referred M to his colleague, Professor Murch. M was seen at the Royal Free gastroenterology department on 7th March 2001. The medical notes from the hospital state the diagnosis as "progressive [regressive] autism and constipation." The medical records of this consultation quote E as saying that M's development had been normal until the age of eighteen months, at which point he had some six to eighteen words of speech and normal hearing. Following his MMR, however, he became "quite

distressed, with fever, his eyes were fixed and his pupils dilated and was not well for days." It was added that he suffered from a loss of eye contact and was not responding to play and had lost his speech and language. On examination it was found that he had faecal loading on both sides of the bowel, with some impaction in the pelvis. He was put on a gluten and casein free diet and prescribed liquid paraffin and Picolax for his constipation.

- 18. The parents' interpretation of his diagnosis is that he was found to be suffering from "autistic enterocolitis". In subsequent documents, E and A have stated that M displayed signs of a severe gut disorder from the time of the MMR vaccine for 10 years until he was assessed and diagnosed at the Royal Free gastroenterology department. According to Dr Carpenter, however, there is no record in the GP notes or any other contemporaneous complaint that M had suffered a gut disorder during this 10 year period.
- 19. M was reviewed again by the Royal Free gastroenterology clinic in September 2001. The hospital notes record the diagnosis as "autism constipation." All test results were normal. The clinical notes include, inter alia:

"Attempted gluten free and casein free diet two months. No improvement at all in behaviour. Started probiotics. Less congested, general well-being."

He was prescribed liquid paraffin and probiotics. Reviewed again four months later, on 9th January 2002, when the diagnosis was described in the clinical notes as "progressive [regressive] autism - constipation", it was noted:

"Remains on a normal diet as there was no improvement in behaviour or bowel habit on a gluten and dairy free diet. The parents are not keen to try it again."

An abdominal x-ray carried out on this occasion showed some continuing faecal masses. His bowel motions were reported as remaining normal and it was suggested that he should be weaned off the laxatives. I note that, according to Dr Beck, E later stated that the Royal Free gastroenterology department had told her that:

"If we didn't follow these procedures and become rigid about M being gluten free and casein free, then he would get epilepsy."

20. In the following years M continued to receive assessment and treatment from a variety of alternative and complimentary practitioners, including auditory integration and sensory intervention therapy and sound therapy, as well as being treated for routine illnesses by the GP. He was not, however, permitted to undergo any further vaccinations. In 2004, E had refused to give consent for M to receive immunisations for tetanus, diphtheria and polio. In addition, M's diet was increasingly restricted and he was given an increasing number of supplements.

21. In his teenage years M started to demonstrate more difficult behaviour. He started having temper tantrums on a scale with which his parents struggled to cope. In her final statement E described this as "an unavoidable personality change" brought about because he was "dominated by testosterone and mercury." Also in her final statement, E asserted that M became violent towards her at this time and as a result she got quite a "lengthy A&E record" because, in her words, "just about every rib in my body was broken, three with double breaks and my stomach muscle lacerated from my ribcage." In 2007 M was prescribed lorazepam and then resperidone and was referred to the community mental health team. In August 2007 the parents wrote to that team stating that they had decided that it was not in his best interests for them to continue to be assessed by them. They stated:

"The medical profession does little to recognise the chronic medical disease that autism truly is ... It is for this reason that we have consistently adopted a biochemical intervention approach and engaged a variety of privately funded specialists, all of whom have made a tremendous difference to the improvement to M's quality of life and proven that autism is a treatable medical condition. Due to the constant rejection and dismissal of our conviction that we have continually faced, we have chosen only to tap into the NHS for diagnosis of secondary medical complications of a more general nature, local dietary advice and, where specialist expertise was available, in the form of Dr Andrew Wakefield."

22. Meanwhile, E was continuing her campaign about the link between the MMR vaccine and autism. On 6th March 2008 she wrote a long letter to the Lord Chancellor and Secretary of State for Justice, the Right Honourable Jack Straw, MP complaining about the failure of the Legal Services Commission to fund the litigation, and making allegations of a conflict of interest against the judge who had dismissed the application against the Commission, asserting that the legal services and the judiciary had betrayed "our" children, warning that as a result they had been placed on "a permanent collision course with each and every public agency" and stating that they would take a number of measures to address their grievances. On 8th May 2008 she received a lengthy reply from the Head of Civil and Family Legal Aid, which was included in the documents produced by E and A in the course of the hearing, stating, inter alia:

"Due to the severity of these illnesses and that they were of the wider public interest, the Legal Services Commission initially invested £15 million in this case. Despite this investment, medical research has yet to prove a recognised link between the MMR vaccine and autistic spectrum disorder. Additionally, no link has been proved by any other medical body. There remains no acceptance within the worldwide medical

authorities that MMR causes the symptoms seen in these children. Therefore, the litigation was very likely to fail. It was for this reason that the Legal Services Commission decided that it would not be correct to spend a further £10 million of public money funding a trial that is very unlikely to succeed, and withdrew funding for this case."

The author of the letter added that a confidentiality clause surrounding the judicial review prevented him disclosing the exact reasons why funding had been withdrawn, but pointed out that the solicitors acting for the claimants were aware of the reasons and were at liberty to disclose them to the applicants.

- By this point M's parents, who had hitherto managed without any 23. assistance from social services, had contacted the local authority as plans needed to be made for M's future when he left school. E and A identified a college in East Anglia which they thought would be the right option for M. Difficulties arose, however, as to the funding of this placement and M's parents issued proceedings against the local authority, claiming that it was unreasonably refusing to fund the package of education and social care. The local authority's case before me is that the placement could not proceed because the Learning and Skills Council was unable to fund the educational component of the placement because the establishment had not been approved by OFSTED and the local authority was unable to pay for the residential component of the placement because it had not been approved by the Care Quality Commission. In July 2008, M left school and, with the local authority's support, attended a life skills development course locally for a year while the dispute between the local authority and his parents was resolved. The local authority has estimated that the package of care and support offered to M during this year cost the authority around £55,000. Negotiations between the local authority, the Learning and Skills Council and his parents continued and ultimately his parents identified an alternative college in the south of England - hereafter known as X College - which the Learning and Skills Council agreed to fund.
- 24. M started attending X College in September 2009. For the first few weeks he was driven to the college every day. In October he moved into a residential unit nearby with the assistance of the local authority hereafter referred to as Y House. At first this placement went well but problems soon arose. E made a series of complaints about the standard of care given to M, including that he suffered repeated episodes of ringworm, other fungal infections, conjunctivitis and ear infections, including a burst eardrum. As a result, E spent three weeks staying in a nearby hotel to provide support for M. She was also concerned that certain assurances given about Y House prior to M's arrival had not been fulfilled. In particular, having been told that the House, which was a new project, was intended for young people of M's age, she was alarmed to find that older people with more extensive disabilities were

accommodated there. Relations between E and the staff at Y House deteriorated. The staff expressed concern about the level of control over M exercised by his mother. She provided a strict dietary programme for M to be followed by the staff, regular health bulletins on his return to the unit after weekends at home and a list of all the treatments and supplements to be given to him. By this point, according to a list prepared by E and A, the range of biomedical interventions being supplied to M included a probiotic, six vitamin supplements, four mineral supplements, five trace elements, fatty acids, amino acids, enzymes and a range of homeopathic remedies. E and A said that this combination had been arrived at through the advice of the gastroenterology department of the Royal Free Hospital, the Autism Research Unit at Sunderland University, the Autism Treatment Trust in Scotland and a privately funded naturopath. They said that the reason for M taking this combination of supplements was "to address the autistic enterocolitis he suffers from."

- 25. In November 2009, following a reorganisation of the local authority's services in which the team previously responsible for M's case was disbanded, M's case was reallocated to a different team and manager hereafter referred to as MS. The relationship between the parents and MS quickly deteriorated. In February 2010, following a visit by MS to see M at Y House, E gave instructions that no-one was to visit X College or Y House or see M without the prior knowledge or agreement of her and A. It is MS's evidence that she has never experienced a response of this nature from a family and that, as the social worker allocated to the case by the commissioning body, she was expected to visit M on a regular basis. A further dispute arose when MS refused to fund additional support for M when he was on holiday at home, on the grounds that the local authority was already paying for a 52 week placement at Y House. There was also a disagreement when, apparently on MS's instructions, the staff at Y House removed some of the written instructions that E had left for M in his room at the unit. E and A have asserted that MS was motivated against them because her husband (like A) had been employed in the Fire Service and had been passed over for promotion in A's favour. In oral evidence MS stated that her husband had had no dealings with A at work. In the course of the hearing E asserted that MS had continued to exert an influence over the case because she shared an office with an occupational therapist who subsequently carried out an assessment. MS denied that she had ever worked with this individual.
- 26. On 11th March 2010 a consent order was finally approved giving the parents permission to withdraw their claim for judicial review, with no order as to inter partes costs, on the basis that the Learning and Skills Council had agreed to fund M to attend a day place at X College and the local authority had agreed to fund M's accommodation at Y House and to fund M's transport between Y House and/or X College and his parents' home at least eight times a year.

27. On the following day, 12th March 2010, E filed an application in the Court of Protection, applying to be appointed M's deputy. It is her case that she was advised to take this step by staff at X College. She asked in her application that this:

"... include life-long custodian to him. In addition, for the court to decide that life-long advocacy is also included in this role unless otherwise delegated by me."

In the box on the application form asking how the order would benefit M, E stated, inter alia:

"My son would benefit from all decisions being made in his very best interests and without the influence of external pressures or distractions."

On 18th June 2010, District Judge Rogers made an order appointing E as M's deputy for property and affairs and personal welfare decisions. This order was made without notice to the local authority, Y House or any other agency involved in M's care.

In the summer of 2010, E and A made a formal complaint against the 28. local authority comprising of a range of individual complaints about the placement, care provision and care management. According to E and A, the complaints made on this occasion amounted to a total of 236 individual complaints. At the hearing before me the local authority asserted that the total number of complaints made was many times more than those made in any other case. Some of the complaints were directed at MS and as a result she was withdrawn from the case. At the end of June, M's case was transferred to a different locality team within the local authority and allocated to a team manager - JR - and a senior practitioner - LG. Those senior social workers have remained responsible for M's case to the present day. The complaints were investigated by an independent practitioner. Nearly all of these complaints were not upheld. In his conclusion the investigator observed, inter alia:

> "First and foremost, although a few of the complaints have been upheld, they arise from a genuine desire by E and A to do the very best they can for M and obtain the very best services that they can ... They feel that their mission has meant having to fight every inch of the way against health and legal services and more recently social care services. This has no doubt influenced the extent to which they are able to work in partnership with the statutory agencies. As E and A have such clear ideas about all aspects of M's life and believe that the conclusions they have reached about him are correct, it is understandable that they have difficulty in accepting the views of others where those differ from their own. In the current circumstances E and A are required to work alongside professionals in social care, medical services and residential care services. Those professionals will also have M's best

interests at heart, but may hold differing views about what is in his best interests. Where the professionals have wished to pursue their own views and approaches, they have found that they have had to be very clear and assertive. This has brought about an even more assertive approach in response and commonly this has led to communications which border on the unacceptable. Many of the complaints appear to arise from such circumstances."

E and A did not accept the outcome of this investigation and asserted, inter alia, that the investigator had not been truly independent of the local authority and had not investigated the complaint properly.

- 29. E continued to search for alternative and complimentary treatments for M. In December 2010, a "neurological assessment" was carried out by a clinic run by an establishment known as Hemispheres Movement for Learning Limited, under the supervision of its Director and clinical lead occupational therapist, Shelley Birkett-Eyles. This assessment was said to have shown "marked primitive reflexes" usually only seen infants. In his analysis for these proceedings, Dr Carpenter was unable to establish what form of testing of the neurological reflexes had been carried out. In addition, an auditory assessment identified certain difficulties that M experienced in speech and language. It was recommended that he was reviewed monthly for one hour, with fifteen minutes of neurodevelopmental movements at home every day. It was also recommended that he underwent therapy known as "the listening programme" to address his problems with sensory and auditory processing. This involved listening to tapes for two sessions of fifteen minutes, five days a week for twenty weeks.
- 30. The statements filed by JR and LG, and the many other documents from social services disclosed in these proceedings, demonstrate the enormous amount of time and resources devoted by social services and the staff at Y House to dealing with the care of M. In particular, professionals were concerned about the degree of control exerted by E over all aspects of M's life; in particular, hygiene, clothing, diet, supplements and social activities. Care staff were supplied by E with a large number of documents pertaining to M support plans, weekly activity timetables, health awareness bulletins, lists of supplements to be provided to him of a degree and intensity which none of them had come across before. The local authority believed, that by exerting this degree of control, E was limiting M's ability to make independent choices and acting contrary to his best interests.
- 31. M continued to experience a number of health problems during 2010. Staff at Y House expressed concern that M was not registered with a local GP nearby and that his medical treatment was being administered by the family GP some distance away. It was alleged that as a result he had not been able to access the local learning disability specialist team. It was also said that, when M was ill, he was removed from Y House

and taken home, resulting in his being away from Y House for long periods of time. E's position has consistently been that it was in M's best interests to remain registered with the family GP - Dr W - who knew M well, and that M was able to access all the support he needed via X College. Further conflict arose when E objected to the fact that the issue over GP registration had been raised by an advocacy service to which M had been referred without her knowledge. In correspondence, E described this as "an unbelievable experience inflicted upon us" and pointed out that as M's deputy she had the right to choose whether M had an advocate. The advocacy service subsequently withdrew from any involvement with M. Further disagreement arose from allegations about E's behaviour when visiting Y House and her attitude to the staff. There were repeated incidents of E challenging the social workers about a range of issues, again to a level unprecedented in the experience of the staff. For their part, E and A say that they were concerned in particular by the conduct of the acting head manager - PL - who had previously been M's key worker, whom they accuse of acting in an unprofessional and threatening manner and against whom they made a series of complaints. It is their case that PL was seeking to exert control over all the residents at the home.

- 32. As a result of all these issues the local authority concluded that the legal controls which E was exercising under the terms of the deputyship were not in M's best interests. In February 2011 the local authority filed an application in the Court of Protection proceedings seeking, inter alia, orders setting aside the appointment of E as M's deputy, authorising M's continuing at Y House, prohibiting E and A from removing M from Y House without the local authority's consent and authorising the staff at Y House to register M at a local GP. On 25th May 2011, District Judge Ralton gave directions, including an order joining M as a party and appointing the Official Solicitor as his litigation friend. On 11th July 2011 the same judge gave further directions, including for the joint instruction of a psychiatrist, to be paid for by the local authority, to advise as to M's capacity. Difficulties arose as to the identification of an appropriate expert. E and A insisted on the appointment of what they called a "neuro-psychiatrist" on the basis that M suffered from a neurological condition as opposed to autism. On 5th September 2011, District Judge Ralton gave permission to the local authority and the Official Solicitor and, if they so wished, E and A to instruct a psychiatrist specialising in learning disabilities - Dr Khouja - together with ancillary directions, including for E to file any statement she wished Dr Khouja to read.
- 33. Meanwhile, in June 2011, E had consulted a nutritional therapist, Juliet Haywood, for the first time. On the basis of their discussion, Ms Haywood prepared a "dietary protocol" for M dated 23rd July 2011, incorporating about fifteen supplements. Thereafter, the relationship between E and Ms Haywood became close. There was very regular communication between them, usually by email, from which it is plain that Miss Haywood was a very strong influence on E and the range of

assessments and treatments given to M. At Miss Haywood's recommendation, E submitted some of M's urine and blood to a number of clinics in other countries. In an updated protocol in September 2011, Miss Haywood recommended over twenty supplements, some taken once a day, others more frequently. She also set out a very detailed dietary programme, specifying exactly what M should and should not eat. Meanwhile, M continued to be seen by a variety of alternative complimentary practitioners, including homeopaths, osteopaths and others. E continued to provide regular medical bulletins to the residential unit setting out updating information as to his various conditions and problems.

- 34. In the second half of 2011 concerns arose about the relationship between M and a female resident at Y House. Staff at the house concluded that he could not continue to reside there without extra support from the community learning disabilities team, which they were unable to access because he was not registered with a local GP. On 22nd September the managers of Y House gave 28 days' notice to terminate the placement. Meanwhile, E had also been investigating alternative placements and, after negotiations, it was arranged that M would move to another unit linked to X College hereafter referred to as "Z House".
- 35. On 17th October 2011, Dr Khouja filed his report having examined M at Y House and at home. He concluded that M had a mild to moderate learning disability, had difficulties in all three domains that characterise an autism spectrum disorder and met the ICD-10 criteria for autism, difficulties communication, having qualitative in impairments in reciprocal social interactions and a range of restricted repetitive stereotype behaviours and interests, together with other features of a pattern associated with the autism spectrum disorder, including high anxiety, rigid thinking, hypersensitivity to noise, poor sensory integration and a unique pattern of deficits. He concluded that M did not have the capacity to litigate or make decisions regarding his residence or care or the full range of potential activities. He found that M did have the ability to express a preference from a limited range of options as to diet and dress, but did not have the capacity to determine what that range should be and, therefore, on balance, lacked capacity with respect to diet and dress. He expressed the preliminary view that M lacked capacity to make decisions as to weekend visits home, although reserved a final opinion on that point as the placement at Y House was being terminated.
- 36. On 27th October 2011, having spent five weeks living at home and being taken to and from X College every weekday, M moved into Z House. Initial reports from the staff there indicated that indicated that he had settled in well. It was not long, however, before the staff began to express similar concerns as those raised by staff at Y House about the degree of control exercised by E over all aspects of M's life and her difficult and challenging attitude to staff.

- 37. Meanwhile, in the Court of Protection proceedings, the parties took part in a round table meeting on 6th December 2011 and agreed a further interim order, subsequently endorsed by the court, including a declaration as to M's lack of capacity and detailed directions in the litigation. Subsequently, E and A asserted that the round table meeting had been "flawed and farcical" and raised a number of challenges at the outcome of the meeting, which were in turn rebutted by the local authority. In a supplemental report, Dr Khouja concluded that M had the capacity to decide whether he wanted to go home on visits but not to make decisions regarding biomedical intervention. Thereafter, the parties engaged in mediation leading to an agreement dated 10th May 2012 which was incorporated in a final court order the following day. The agreement included the following provisions: (1) the local authority agreed that it would not pursue its application for the setting aside of E's deputyship; (2) the deputyship order would be amended to reflect the respects in which Dr Khouja had identified that M lacked capacity; (3) E and A agreed to arrange, in consultation with Z House, for M to be registered with a local GP; (4) in the event that they failed to register him, Z House should be asked to do so; (5) information about M's financial means would be provided by E to the local authority upon request for the purpose of enabling an assessment as to whether he should pay a contribution to the cost of his care. The order made provision for a further hearing as to costs in the event that the parties failed to agree that issue. E subsequently applied for costs and that issue remained unresolved before the start of the current proceedings.
- On 21st June 2012, M was taken by E for an emergency dental appointment at the local dental surgery. The family dentist - DC - was not present and M was examined by another dentist, Ms Malik. What transpired at this examination is a matter of controversy in this case and will be considered later. In short, however, it is Ms Malik's evidence that from an x-ray examination she diagnosed that M had a periapical area behind one upper tooth indicating the possible presence of an abscess. E, on the other hand, denies that she was told anything of this sort and asserts instead that she was told that there appeared to be a problem with M's sinuses. In an email dated the following day, E told Ms Haywood that "nothing has shown up on the x-ray, so I am told it is likely to be sinusitis causing teeth nerves to be on edge." On 25th June an out of hours GP prescribed a course of antibiotics for sinusitis. In a further email to Ms Haywood on 27th June, E recorded that M had been put on antibiotics "as his temperature was in the region of 104, his facial features were all swollen and his brain was inflamed." On 27th July, M, with E present, was examined by another dentist at a surgery near to Z House. Nothing abnormal was detected, although the notes of this examination produced in the course of the hearing indicated that E requested that no x-rays be taken. When seen by the oral hygienist at the family dental surgery on 4th September 2012, no signs of an abscess were detected. It was said in evidence that a hygienist would not be in a position to make such a finding.

39. Thereafter, M continued to have a series of health issues, in particular pain in his head. E continued to seek advice from a range of alternative and complimentary practitioners. Her regular email exchanges with Miss Haywood continued. Further samples were sent for testing abroad. In the parental bulletin given by E to X College dated 11th November 2012, for example, it was reported that, over the weekend,

"M had a cranial osteopathic appointment that focused on the contorted membrane between the two frontal lobes, apparently where both optical and auditory brain stems sit. The twist in his central membrane was significant for most of the treatment to be spent on it and it would appear to have come from M's head overheating, obviously trying to release body heat."

Over the Christmas holiday 2012/13, M displayed difficult behaviour at home. In one incident it was alleged that E had sustained some more broken ribs. Following his return to Z House after Christmas, M continued to suffer headaches and returned to college on high doses of paracetamol and ibuprofen. Staff were concerned at the level of the medication and felt under pressure from E to give M more than was appropriate. It is claimed that on 5th February the staff refused a request by E to give M additional paracetamol as he had already had the maximum dose that day. On the following day, 6th February, E arrived and took M home. It is her case that she did this because M wanted to go home, that she was concerned that he was not receiving proper attention for his worsening health problems at the unit and that her concerns were heightened because of similar experiences of another resident.

40. M did not return to X College or Z House again, save for the graduation ceremony the following July. However, one member of staff - KH - was sufficiently concerned about him that he telephoned E on a regular basis to check on M's progress. The local authority relies on KH's records of these conversations as set out in the local authority records and emails that he sent shortly afterwards to senior colleagues. KH had worked with M during the last few months of his stay at Z House, and it was his evidence that E and A seemed to get on with him, to the extent that they offered him a job helping care for M at home. E and A now maintain, however, that KH has a tendency to elaborate and sensationalise situations and was desperate to become a permanent member of staff, so was plainly keen to please his employers. A meeting took place at X College on 15th February 2013. E and A did not attend the meeting because M had a medical appointment. At the meeting renewed concerns were expressed about M's presentation and E's behaviour. It was reported that other residents had complained about E's presence at the unit late at night. It was also reported that KH had been advised that M was now being sedated up to twelve hours a day following an increase in his pain management medication. It was at this meeting that the chief executive of X College - MH - first suggested that E's behaviour was akin to "Munchausen by proxy". Three days later, on 18th February, a professionals' meeting took place at the local authority's offices. Renewed concerns were expressed about the way that E exercised her powers as a deputy. It was agreed that inquiries would be made as to whether the level of pain relief being administered was appropriate. It was suggested that the concerns may be at a level to justify a safeguarding investigation and, as a result, a welfare visit took place on 20th February at the family home, attended by a community nurse and police officer. M appeared well and alert. Thereafter, LG tried to make contact with E via email but had no response. Offers to meet her were not taken up. It has been E's case before me that these emails were never received because they were sent to the wrong email address.

- 41. On 3rd March, KH informed the local authority that E had told him that she believed that M was suffering from an adverse effect to electromagnetic energies and she was wrapping electronic items in his bedroom in tin foil to protect him. On 12th March, according to KH, E told him that they had taken M to accident and emergency two days earlier because he was in an immense amount of pain. He had been diagnosed with what appeared to be brain seizures. On 19th March, according to KH, E said that M was now on three types of pain relief paracetamol, ibupfofen and codeine - and this seemed to help. She thought he was suffering from either migraine clusters or brain seizures. On 4th April, JR and LG made an unannounced visit to the home. What happened on this visit is disputed. The social workers' evidence is that they spoke to A but that E refused to come down to see them as she was busy upstairs and dealing with M. A told them he would ensure that M came to no harm. The social workers did not see M on this visit.
- 42. Around this time M developed a small wound on his leg. His mother, having read two articles in the newspapers, came to the conclusion that he was suffering from Lyme disease. She consulted her GP, Dr W, who tried to reassure her that this was unlikely to be the case, but at her insistence tests were carried out in this country and subsequently at a clinic in Germany. This analysis revealed that M had one chemical marker consistent with Lyme disease. Dr W continued to reassure the mother, on the basis of his own experience of Lyme disease, that the overall clinical picture did not fit this diagnosis.
- 43. In April 2013, M was seen at a clinic run by an organisation called Breakspear Medical Group Limited, by Dr Peter Julu, who described himself as a specialist autonomic neurophysiologist and consultant physician in what he called an "autonomic" report. He stated:

"He has normal resting control, parasympathetic activity associated with a mild resting tachycardia due to poor sympathetic restraint."

It was recommended that he would benefit from "facilitative oxygen delivery into peripheral tissues." Around the same time, however, M was examined by a neurologist, Dr Delamont, to whom he had been referred by his GP, and who concluded that there was no underlying focal neurological deficit but, rather, that this was a case of a more

pervasive developmental delay with some autistic traits. Subsequently, E wrote to her MP to complain about Dr Delamont's neglect in this assessment.

On 4th April, E and A sent a further lengthy formal complaint to the 44. local authority's Director of Families and Social Care. On 6th April, according to KH, E said that M remained in a great deal of pain and it was a very complex situation in terms of his health. When KH asked to speak to M, he was told he was asleep, although it was 2.30 in the afternoon. KH also states that, on 23rd April, E told him that M's urinary system had shut down. When this was passed on to JR, she spoke to the family GP, Dr W. He told her that he had seen M recently with E, who had shown him video footage of M apparently in pain, and as a result he had prescribed codeine. He said that M had seemed in good health and no different from any other time when he had seen him. On 26th April, JR and LG made another unannounced home visit. Their account on this occasion was that they saw M, who seemed in good health. E seemed agitated and told the social workers that she had been giving M a hand and foot massage, although the social workers saw no signs of this on M. E told them that they should not have visited; they should have made an appointment. On 1st May when KH rang again to check on M's progress, E allegedly told him that M had lost sensation in both his hands and feet, so she was massaging them for two hours each Meanwhile, E, with the support of some of the day and night. alternative practitioners she had consulted, had requested a blood test to establish the presence of measles and rubella. Neither was detected, but E remained concerned that the viruses were present in M and quoted one of the alternative practitioners with whom she had consulted, Professor Puri, as supporting her concern. In May 2013, E sent an email to the Breakspear Unit stating that M was now finding it difficult to walk very far at all. She said they were "enabling M to have deep tissue massage every other week ..." and added:

> "He is also benefiting from reflexology twice a week at the moment, as his hands and feet are so pale, freezing cold, rigid and painful. We are giving sips of water in between mouthfuls to help it go down and we are ensuring his bite size is far smaller, but he does seem to be suffering with trapped wind."

Breakspear replied, recommending that M should continue to use the oxygen concentrated therapy for four to six hours a day.

45. On 23rd May 2013, M was taken to another dental surgery, known as the Tooth Fairy Holistic Centre. Further x-rays revealed the presence of a cyst, consistent with what had been allegedly seen by Ms Malik some 11 months earlier. M was referred to an oral surgeon, Mr Norris, who on 6th June informed the Tooth Fairy Surgery that it was quite clear that one or possibly two of M's upper teeth had got periapical areas, suggesting pulpetic and abscessed teeth. Mr Norris indicated that surgery under general anaesthetic would be required. On 7th

June, E emailed Ms Haywood and recounted the meeting with the oral surgeon, Mr Norris, stating, inter alia:

"Although this was not picked up on the x-ray M had last summer, it was clearly there and appears to have grown at least twice the size that we can now see and is just that and not a swelling of the sinuses as interpreted last summer. It is likely to have killed one if not two tooth nerves and, whilst doing so, would have given M intolerable pain over a period of months, reaching a crescendo which would have been excruciating for him."

E continued in her email to Miss Haywood:

"The consultant also advised that, being a surgeon for cancer of brain, head and neck, more important than this, he was not at all happy with a black shadow the left hand sinus is sitting on and the closeness of the auditory nerve to this. Apparently, this is the least of his problems."

46. On 12th June, KH spoke again to E, who told him, he says, that the doctors had found what appeared to be an abscess in a complicated place on M's brain and that she and the family were keeping positive that it was not cancer. On 26th June, KH rang again to check on M's progress. On this occasion he was able to speak to M, who told him that he was feeling better. It is KH's evidence that E told him that M was extremely weak as he was suffering from autonomic failure. On 1st July, in a conversation with the senior practitioner at X College, E was said to have recorded that M's immune and nervous systems were down and that the tumours needed operating on and that he had also been diagnosed with chronic blood poisoning. She mentioned Lyme disease and said that M was now on oxygen for six hours a day. On 4th July, after M had attended for a pre-operative assessment, KH spoke to E again. According to his note of the conversation, E said that M had Lyme disease and had tumours in his gum sockets, but the main thing the surgeon was worried about was "the black shadow sitting on the left sinuses". E had said that the surgeon had said that he was a cancer and facial reconstruction surgeon and would be able to do facial reconstruction if necessary. E said that she was concerned that M might not survive the operation, adding "with what has happened in the last five months, it will be a miracle if he pulls through." She said she would ask MH to arrange an autograph book for M for everyone at X College and Z House to sign, adding "so, if he doesn't pull through, it's something for him to take to the grave."

History after the start of these proceedings.

47. On 18th July 2013 the local authority started these proceedings in the Court of Protection seeking orders (1) permitting the authority to remove M from his parents' home and either return him to Z House or place him in independent or supported living; (2) that he should not

take supplements or medication unless prescribed by a doctor or considered necessary by his carers; (3) that professionals and care staff were not required to follow E's instructions regarding M's care and (4) removing E as his deputy. In the application the authority identified concerns about M being isolated from professionals, his apparent distress at his mother's behaviour, the fact that he had been removed from Z House without agreement, the degree of control exercised by E over his life, the difficulties in E's relationship with professionals and the allegation that had been made that E "may have Munchausen by proxy."

48. On 23rd July, M attended the graduation ceremony at X College. On 25th July, District Judge Mort gave directions, including the reappointment of the Official Solicitor as litigation friend. subsequently applied for the summary dismissal of the local authority's applications, contending, inter alia, in a lengthy exposition of her case, that it was "a shameful and reckless attempt [at] retribution by persecution of us as a family" and made with the purpose of "sabotaging" the costs application outstanding from the previous court proceedings, and to detract from the complaints and other litigation which she and A had brought against the authority. Attached to E's application for summary dismissal was a further document described as an "overview of M's health", listing the background of dental attention, including a reference to the x-ray of July 2012, which "indicated the swelling above UL6, advised to be sinuses", a list of twenty illnesses and symptoms that M was said to have suffered since October 2012 and a further list of thirty-one illnesses, symptoms and treatments that he was said to have suffered, exhibited or taken in the past four months, including: "on movement body temperature drops/hands and feet freeze and become rigid", "swelling of joints, hands and feet", "projectile vomiting", "excruciating pain and in intensity and frequency likened to headaches/migraines", "uncontrollable temperatures", "stabbing pain in the groin, "difficulty in urinating", "uncontrollable sneezing", "unable to have any volume/sounds on", "simplest of movement causes exhaustion", "on constant pain relief", "now on concentrated oxygen for up to six hours a day", "biomedical natural supplements have become life supporting.". It was said that in the previous four months M had seen

> "our GP on a weekly basis, an ENT specialist, a neuroautonomic diagnostic specialist, a neuro-psychologist, a neuro-physicist, his neuropsychiatrist and his biomedical nutritionist."

It was further said that M

"underwent an MRI brain scan and an EEG on the 2nd of May 2013, referred by neuro-physicist, and as a result of possible brain stem dysfunction, suspected internal destruction of his nerve endings and heightened/over-exaggerated reflex response and his

nervous system was so obviously trapped in flight mode."

It was said that his immune system had been "chronically compromised" as a result of his infection with bacteria associated with Lyme disease. E added that:

"blood is not interrogated further in this country, unlike the European laboratory in Germany. In this country there is a reliance upon a GP to clinically diagnose and treat this most debilitating disease but that does not allow for the fact that GPs prefer to avoid doing so, for reasons we are now endeavouring to determine. Meanwhile, our son continues to deteriorate at an alarming rate."

It was said that E was having to massage his hands and feet for up to six hours a day. E added:

"the loss of this circulation and sensation has since been diagnosed as rheumatoid arthritis induced by his immune system turning in on itself and known as autoimmune dysfunction."

Amongst other claims made, E also asserted that it had been suggested that M could be suffering from an electro-sensitivity disorder and as a result they had terminated all wireless transmissions in the house. E set out her case in detail as to what she had been told about the problems in M's mouth, referring to a complete breakdown of all life support and systems, a black shadow on which the left sinus was sitting and an intolerable level of pain.

- 49. On 31st July 2013, District Judge Mort dismissed the parents' application for summary dismissal of the local authority's application. On 2nd August, he made a further order inter alia (1) reciting that both sides had raised concern about M's health and that the court required up to date evidence about his capacity to make decisions about medical interventions and treatments; (2) suspending E's appointment as property affairs and personal welfare deputy; (3) ordering E and A to provide all documents relating to M's finances, affairs, health and welfare, including details of all those who had examined him in the last three years to the local authority forthwith; (4) directing the local authority to nominate and instruct, (a) a medical professional to conduct an urgent assessment of M, including what medical conditions he suffered from, what treatment he required, including alternative remedies, supplements and a specialised diet and (b) a professional or professionals to assess whether M had capacity; (5) directing E and A to cooperate with these assessments and to allow the experts access to M, and (6) listing the case for a further hearing seven weeks later.
- 50. On 5th August 2013, M underwent surgery under general anaesthetic in which the two teeth were removed. The hospital notes for this admission reveal that, in summarising M's medical history, E said that he had "tested positive for Lyme disease." The two teeth were subsequently given to E, who stored them in her home freezer with a

view, it is said, to send them for testing in America by Mr (formerly Dr) Wakefield. In a further email to Ms Haywood dated 11th August, E spoke graphically of the implications for M of the delay in treating the abscesses:

"This would not only explain the excruciating pain that [M] has experienced, and possibly on/off since October 2011 ... that would have been horrendous for [M] to have had to cope with over the last year and just unbearable without intravenous pain relief. They also easily explained the neurological and blood poisoning problems that M has been suffering. Left undetected they can be fatal. Hence, they have said they have caught [M] in time but not soon enough to stop the bacteria produced by these abscesses from eating away at the body and affecting all life supporting systems. Apparently, the soft facial tissue is attacked first, along with the soft tissue of the heart and the lungs while they swell the brain and cause abscesses on it. While all this going on, apparently at the same time they eat the bone structure of the body - the knuckles and fingers and toes, the wrists, ankles, elbows, knees, shoulders and hips - as they make their way up the bones. So, all of this was well underway with [M]."

Miss Haywood was continuing to prescribe various protocols for M, and on 6th September she prescribed a general nutritional supplements protocol and a "Lyme disease protocol".

51. Meanwhile, on 8th August, E filed a further notice of application which appears to have been intended as an application for a reconsideration of, or possibly an appeal against, the directions order made by the district judge. This was followed by the filing of supporting applications signed by A, their daughter S, and E's sister, seeking to be joined as parties to the proceedings. Each application complained in strong terms about the actions of the local authority and the treatment of E, using such terms as "vindictive", "malicious", "cruel", "vengeful" and "callous." It is not clear to me what happened to those applications, although the next order, dated 25th September, in which the district judge made further directions, names not only E and A but also S and E's sister as parties (although they have played no part in this hearing save that S was called as a witness). At that hearing the local authority and the Official Solicitor were represented by counsel, whereas E appeared in person, accompanied by two friends, who are, I am told at this hearing, the mothers of two other autistic young persons who have been involved in litigation concerning MMR. The order directed, inter alia, that, pending further order, no medical examination, investigation or treatment of M should be carried out without the knowledge and written approval of his GP, Dr W. The district judge directed that the local authority carry out by 25th October an assessment of M in order to determine whether it was deemed to be in his best interests to reside with his parents, in supported living or in residential care, and that the other parties responded in seven days as to whether they agreed with that assessment. The order recited that the court concluded that it was in M's best interests to remain living with his parents pending completion of this assessment. On 3rd October, E filed a further notice of application asking for a reconsideration of the order of 25th September on the grounds that it conflicted with the directions given at the hearing and complaining about the actions of the local authority and the Official Solicitor in the drafting of the order. The notice was accompanied by a document in which E and A set out, in advance of the local authority assessment, what they would and would not agree to as in M's best interests.

- 52. The local authority's interim assessment concluded that it was not in M's interests to be removed from his parents' home. At the next hearing the district judge dismissed the outstanding application by E that the local authority should pay the costs of the previous Court of Protection proceedings and directed that the case be listed before a High Court judge. Thus the case came before me for the first time on 9th December 2013. At that hearing, at which all parties, including E and A, were then represented by counsel, I made interim declarations that M lacked capacity, which have been renewed at subsequent hearings. I gave directions giving permission to the parties jointly to instruct Dr Alison Beck, a consultant clinical psychologist, and Mr Keith McKinstrie, an independent social worker, the cost to be borne as to one third by M on his public funding certificate and two thirds by the local authority, but giving the authority the right to apply for a contribution from the parents at the conclusion of the proceedings. I further listed the matter for an issues resolution hearing on 20th March and a final hearing over 10 days in June 2014.
- 53. On 3rd March 2014, Dr Beck delivered her report to the solicitor representing the Official Solicitor, Miss Nicola Mackintosh. Dr Beck concluded that E suffers from factitious disorder imposed on others and that M is the victim of that disorder. She added that she could not:

" ... rule out the possibility that E may pose a risk of harm to M in order to prevent her loss of control over him as a source for attention for herself."

These conclusions led the Official Solicitor and the local authority to be concerned, first, that M might be at risk of harm remaining in E's care and, secondly, and immediately, that he might be at heightened risk of harm when the report of Dr Beck was disclosed to the mother. The Official Solicitor made an application to me for directions in relation to the disclosure of the report to E and A. By the time the application came on for a hearing the local authority had applied for the immediate removal of M from the care of E and A and this was supported by the Official Solicitor. At the conclusion of that hearing on 6th March, I authorised M's removal the following day, into an emergency placement at an establishment - hereafter referred to as "N House" - run by an organisation - hereafter referred to as "C Limited"

- some sixty miles from the family home and in a different County, and ordered that he should reside there until further order. I listed the matter for a hearing on notice before me on 11th March and I gave supplementary directions.
- 54. On 11th March, E and A were represented by Miss Alison Ball, Q.C. I directed, inter alia, that the hearing previously listed on 28th March should be used to determine M's interim placement prior to the hearing in June and gave further directions as to that hearing. I made a detailed order as to interim contact arrangements and an order preventing the mother from removing M from his placement, attending at or visiting the accommodation or communicating with him by any other means other than those specified in the contact order. I further ordered that E and A should not, whether by themselves or by encouraging any other person to do so, disclose or publish any information relating to the proceedings to any person, including any media organisation, save for their legal representatives. permission to E to instruct a consultant forensic psychiatrist to report on whether she suffered from any mental illness or disorder and her relationship with M. Subsequently, Dr Gwen Adshead was instructed pursuant to this direction, and met E on two occasions.
- 55. At the hearing on 28th March, when E and A were still represented by Miss Ball, oral evidence was given by Dr Beck, Mr McKinstrie and E. I reserved judgment over the weekend and gave judgment on 31st March, concluding that it was in M's best interests to continue to reside at N House in the interim pending conclusion of the final hearing listed in June 2014. I recorded in a recital that there should be supervised contact between M and his parents at N House on three occasions every week for two hours on each occasion, subject to this being in M's best interests and that the length of the contact sessions and the need for supervision would be reviewed regularly. I renewed the orders preventing the removal of M from N House and against any unauthorised disclosure of information relating to the proceedings. At the hearing Miss Ball had argued for the instruction of a suitable physician to prepare a chronology of medical and complimentary medical involvement. I adjourned that issue to a further directions hearing on 10th April.
- At that adjourned hearing on 10th April, the issue of interim contact was revisited but I concluded that the court was in no position to amend the current arrangements in the absence of evidence. I declared that it was in M's best interests to have contact in accordance with the terms set out in a schedule as to the dates, times, provisions for reviews and E's behaviour. Following the course advocated by Miss Ball on behalf of E and A, I gave permission to the parties jointly to instruct a consultant psychiatrist with a specialism in autism and learning disabilities to prepare a medical chronology, to include a chronology of complimentary medical therapies in relation to M and, if possible, to provide an opinion as to whether past medical and other

investigations/assessments of him had been in his best interests. I further gave permission to the parties jointly to instruct a consultant gastroenterologist to provide an opinion as to M's dietary needs and the need for biomedical supplements. I directed that the cost of these instructions be borne in the proportions of one half by the local authority, one third by M and one sixth by E on the basis that the local authority should provide an indemnity to E in relation to her share of the costs which E should discharge by payment to them at or before the conclusion of the proceedings, adding that there would be permission to any party to apply for a different allocation of the costs of the reports at the conclusion of the hearing in June. I gave directions that, if the parties were unable to agree the identity of these two experts, the matter should be referred back to me for a decision on paper. In the event, (with hindsight, unsurprisingly), the parties were unable to agree on the choice of experts and the matter was, indeed, referred back to me. On 25th April, I approved the experts identified by the local authority and the Official Solicitor, namely the psychiatrist, Dr Carpenter, and the gastric surgeon, Professor Williamson. As the parents objected to this choice, I amended the previous order so as to exclude them from the instruction and reallocate the funding so that the costs of instruction would be borne by the local authority and M equally. I added that, if E and A wished to apply for the instruction of a further expert or experts, as had been intimated, such application should be made in the appropriate form and on notice to the other parties by 5th May 2014 and, if opposed, should be listed for hearing before me. No application was pursued prior to 5th May, but subsequently E and A applied for permission to call a psychologist, Dr Kenneth Aitkin, as their expert.

57. On 18th May, E and A filed a notice that thereafter they would be acting in person. Asked to prepare a witness schedule, E filed a document which appeared to indicate that she wished to call, or at least rely on the evidence of, 91 witnesses at the hearing, including Keith J, who had heard part of the litigation involving MMR, and their MP, the Right Honourable Mr Michael Fallon, and for 48 witnesses to be required to attend for cross-examination. A further case management hearing was convened on 4th June, at which E reduced the number of witnesses required. Having heard the application by E to adduce expert evidence, notwithstanding that the application was being pursued some weeks after the expiry of the time limit for such an application and only two weeks prior to the start of the final hearing, I made an order permitting E and A to instruct either Dr Aitkin or another expert, Mr Paul Shattock, on condition that. (1) whichever expert was instructed would confirm that they would produce a report by 9th June, (2) the expert's costs would be borne by E and A, (3) the expert instructed would receive copies of certain identified court documents and (4) the scope of the report would be limited to advice as to the appropriateness of medical and other treatment for autistic people generally and M in particular. I further ordered E to produce by 6th June a list of all relevant documents which she maintained were missing from the court bundles, which had by then been prepared for the final hearing, running to over 30 lever arch files. I directed that M's solicitors should use their best endeavours to identify those documents which were not in the bundles, whereupon E would provide copies of all such documents to the solicitors for onward distribution as appropriate. The purpose of these directions was to ensure that all relevant documents were available at the start of the hearing. In the event, this direction was not properly complied with and E and A proceeded to produce a steady stream of documents throughout the hearing, amounting in the end to over 700 pages. I extended the time for E and A to file all statements from all witnesses from whom they intended to adduce evidence to 9th June, indicating that such statements would stand as their evidence-in-chief, subject to any supplemental questions that might be allowed by the court.

- 58. The final hearing started with a preliminary hearing on 10th June in order for the court to take the oral evidence of Dr Carpenter, who was due to be away for the fortnight starting 16th June scheduled for the At that hearing it emerged that, contrary to my clear direction, E and A had sought and obtained reports from both Dr Aitkin and Mr Shattock. Nonetheless, I allowed both reports to be filed and relied upon. E and A had not filed all the statements from witnesses as directed by the court. I extended the time for filing to 13th June - the last working day before the start of the hearing. Dr Carpenter's evidence was started at the hearing on 10th June but not completed. It became clear that the 10 days allocated for the case were insufficient and a further three days were identified, with Dr Carpenter to return on one of those days. I gave a number of further miscellaneous directions, several devoted to the disclosure of further medical records, as it was alleged by E that some of M's records were missing.
- 59. In addition, M's parents had expressed concern at the suitability of the current placement at N House. They were concerned as to the quality of care he was receiving there, pointing in particular to an increase in his weight and an alleged deterioration in his condition which they attributed to the fact that he was no longer following the prescribed diet. Subsequently, a report from a GP local to N House indicated that M was in good health. E and A urged the court to consider authorising his move to another home run by C Limited hereafter referred to as "W House" which was much closer to the family home and, furthermore, was known to M and the family as by this stage some of the contact sessions had been relocated there. I directed that Mr McKinstrie be asked to consider the suitability of such a move in the event that the court was unable to deliver its judgment for some weeks.

FINDINGS SOUGHT BY THE LOCAL AUTHORITY.

- 60. The findings sought by the local authority are set out in a lengthy Scott schedule. As E and A point out, there is considerable repetition in that document. In summary, the local authority asserts as follows:
 - (1) E has stated that M is suffering from numerous conditions, the overwhelming majority of which are not true, and has subjected M to unnecessary tests and intervention and/or lied about his tests. This is not in his best interests. Relying on the evidence of Dr Beck and Dr Adshead, the local authority asserts that, if the court makes the findings as to E's behaviour, it amounts to a factitious disorder imposed on others.
 - (2) E controls all aspects of M's life and does not allow him to develop his independence. This includes control over supplements, diet, privacy and sexual development, personal care activities and socialisation with his peers.
 - (3) E restricts access to M and to information about M and in so doing is acting against the principles of the Mental Capacity Act 2005 and her duty as a deputy. By so doing, she has reduced the possibility of challenging her decisions and has undermined M's ability to have a voice and his independence and coaches M.
 - (4) E is unable to work with professionals and regards the local authority with suspicion and mistrust. She regards the local authority as conspiring against her, despite numerous attempts to meet E's numerous concerns and complaints, which include allegations which are personal and offensive. This has drained resources and diverted attention away from M.

In the schedule the local authority gives particulars of these allegations. I have already alluded to many of the issues raised in my background summary set out above.

- 61. In reply, E and A have inserted lengthy responses to the allegations in the Scott schedule, some already referred to earlier in this judgment, others considered later. It would be impractical, without making this judgment impossibly long, to recite all of those responses in detail, but I confirm that I have read and taken into account all that they have written. As with most of their evidence, the response of E and A in the Scott schedule contains a large amount of repetition. In summary, however, their position is as follows. (I say "their" position, but plainly it is E who has taken the lead on all matters.)
 - 62. First, they refute the suggestion that E has been misleading about M's health or caused him to undergo unnecessary assessments and treatments. They say that they have accurately reported his symptoms, which are difficult to interpret because of M's autism and communication difficulties. As for their use of alternative and complimentary treatments, they say that they

have done nothing wrong. They assert that, in addition to what they describe as the standard approach of cranial osteopathy and homeopathy, along with what they consider a responsible dietary intake and natural supplements, they have kept ahead of research and used appropriate alternative therapies to avoid the need for medication and further complications. They point out that many people, including conventional doctors, accept and in some cases recommend the use of such treatments for autism. It is their case that these treatments and the adherence to a careful diet has worked well for M, including the use of a gluten and casein free regime. They deny that taking the supplements has caused him any harm. E and A point out that they have acted on the advice of a specialist, Ms Haywood, and that thousands of people follow such regimes, including leading sportsmen and women. They say that they "fail to see why different standards should be applied in the management of optimum health and performance for someone merely because they happen to be disabled."

- 63. Until 2012, M's health was generally good and the fact that it declined thereafter was due, they submit, to the lack of proper care he received at Y House and Z House. When M became ill in 2012/13 and suffered from high levels of pain, the steps they took to establish what was wrong were reasonable. Since they were unable to establish what was wrong, they kept an open mind to ensure that nothing was missed, including, for example, Lyme disease, hypersensitivity to electromagnetic radiation and undetected brain tumours. E's concerns about the inadequacy of the NHS test practices led her to send samples abroad for further testing. E asserts that she knows her son best and intuition and maternal instinct told her there was something wrong.
- 64. As for the allegation that E's behaviours amount to factitious disorder imposed on others, they argued that the diagnosis is very subjective and intangible and that it "gives permission to pathologise the most innocent interaction". They submit that:

"The person labelled with this diagnosis is fair game for anything that anyone wants to impose on them or do to them, such as abuse and violation of normal family relationships and the treatment of their loved one."

65. So far as the MMR issue is concerned, E reiterates that she was present when M underwent the vaccination and is speaking the truth about his reaction. E and A deny that E was subjecting M to control over all aspects of his life. In the response to the Scott schedule, E asserts:

"There are no issues of control, only enablement and empowerment for independency and self-sufficiency, to access every possible opportunity to reach full potential and fulfilment."

Had control been their aim, they would never have pursued an out of county placement. Theirs was a normal functioning family characterised by unconditional love. Guidance on diet and other

matters were merely at the request of the college and care provider and were not prescriptive, but rather a basis which could be built upon. They were helping the staff to get to know M's likes and dislikes without having to discover the hard way. E stated that she is a very precise individual and passed on the information in a way that ensured clarity. They refute the suggestion that the staff at the homes found the amount of information provided excessive. On the contrary, the staff told them that it was helpful and in some respects, for example diet, adopted the guidance for other residents in the home. They accepted that the documents were lengthy but stated that this was justified because of the range of staff that had to use them, including agency and bank staff, and the difficulty that M has in communicating his own needs. They drew attention to a comment by Dr Khouja in his report during the first Court of Protection litigation that it was in M's best interests to have a set of appropriate guidelines for staff in order for them to deliver high quality care because people on the autistic spectrum respond well to consistency and predictability. They point out that the staff at X College did not have a problem with this approach. In the Scott schedule, in response, however, E adds that the guidance "developed into measures to counteract the failings and neglect of others". It quickly became apparent that the care home environment did not suit M but it was unavoidable if he was going to attend the college. Such an environment had to meet the needs of a range of users with different needs. In the case of Y House, there were residents of a much wider age range than had been anticipated at the time that M was first placed there. The guidance was the way to ensure that M's needs were met. So far as bowel movement management was concerned, they assert that in childhood, due to his gut problems, he had required the use of an aggressive bowel clearance treatment and that the monitoring of his bowel habits was designed to guard against repetition of these problems.

- 66. On the particular issue of the GP registration, E and A state that a number of the residents at Y House remained registered with their family GPs. Dr W was familiar with M, and M knew him well. They do not accept that M missed out on support from the learning disability team in the locality of Y House since he received a wide range of support via X College. E and A do not accept that M's life was restricted, and point to the large number of activities that they enabled him to access when he was living at home, both before he went to X College and after he returned in 2013. They want his life to be as full as possible, hence their pursuit of a further education place, initially in East Anglia and then at X College. One of their main complaints about Y House was the paucity of activities available to M in contrast to what he had been used to at home.
- 67. As for the allegation about restricting access, E denies that she inappropriately used her deputyship as a way of causing professionals to abide by her instructions. She asserts that she has been fully aware of her obligations as a deputy and acted in accordance with the Mental

Capacity Act and all relevant guidance at all times. She points to the positive comments about her made by the Office of the Public Guardian. She asserts that generally she has worked in a collaborative way with professionals. The reasons for asking that any information to be passed on to the local authority should be requested from them, rather than given by the care staff at the home, was to ensure clarity of information. They objected to the referral to an advocacy service because they were not consulted and because they believed it was made as a ruse to get M to say that he wanted to transfer to a GP local to Y House. In any event, it is their case that M did not need an advocate as E was acting as his deputy and as his "support and collaborator". E and A refute the allegation that they denied the social workers access to M after he left Z House. It is asserted that the series of emails which LG claimed to have sent to them was never received. They also dispute the local authority's assertion that they have withheld information about M's finances.

68. As for working with professionals, E and A point to their good relations with other professionals involved in M's care, including the alternative and complimentary medical practitioners and many of the mainstream doctors who have treated M over the years, in particular his GP, Dr W. They say that tensions only arose in 2008 when the local authority forced them to start litigation to secure funding for the specialist education they sought for M. E and A say that their many criticisms of professionals who have been involved in this case since 2008 are all justified. They stand by the criticisms that they have made of the social workers - MS, LG and JR, the Head of Adult Services, MW, the staff at Y House, Z House and N House and the experts who have been involved in the case, in particular Dr Carpenter, Dr Beck and Mr McKinstrie. In oral evidence E agreed that it was her case that no fewer than 13 of these professionals had lied in their evidence to this court. E accepted that she may have appeared angry at times but said this was not surprising given the extent of her frustration at the actions of the local authority. She maintains that the local authority was motivated against them from the outset of the placement at Y House because MW had chaired the funding panel at the time of the judicial review application and would have taken it as a personal slight that they had successfully litigated over that issue. E and A say that they were concerned at the poor quality of staff at Y House throughout M's time at the home. In their response they described it as a failing care provider and assert that the care manager, PL, "had a desperate need for control over the residents." It was to address these concerns and on the advice of X College that E had applied for deputyship. At Z House the staff had been better at the outset but things had deteriorated when a new home manager, CH, took over. E and A deny the charge levelled by the local authority that E is a vexatious complainant who uses the threats of complaints as a method of bullying.

- 69. Underlying the parents' case is their conviction that there are two parallel approaches to the treatment and management of autism one which E calls "mainstream medical" and the other "mainstream autism" which she asserts is widely recognised and followed "within the autism community". It is their case that each approach is equally valid and should be given equal respect. They assert, however, that many members of the "mainstream medical" lobby do not treat the "mainstream autism" approach with proper respect, but rather have pursued a campaign to undermine the use of alternatives to mainstream medicine.
- 70. In the course of the hearing it became clear that E, and perhaps also A, see themselves as the victims of a network of three conspiracies. First, they assert that there has been a systematic conspiracy by the medical profession to conceal the truth about the effects of the MMR vaccine and its links with autism. Secondly, they assert that the employees of this local authority have fabricated a case against them with the aim of removing M from their care for financial reasons, to acquire control of his benefits and limit the amount of money the authority has to spend on him and, furthermore, has drawn into this conspiracy all the other professionals involved in this case - the staff at Y House, X College and N House and some of the doctors - all of whom they say are financially dependent on the renewal of future contracts with the local authority. Thirdly, they assert that the Official Solicitor, far from representing M properly in these proceedings, has used them as an opportunity to pursue an agenda of undermining the prospects of future litigation about the MMR vaccination and to that end has deliberately chosen experts (Dr Carpenter and Professor Williamson) whose views are known and who have been involved in similar cases in the past. They assert that the Official Solicitor and the local authority have attempted to attract political favour by bringing the MMR issue into this litigation.
- 71. I will return to this issue at the end of this judgment at this stage, I merely observe that, if the parents' assertion about conspiracies is correct, it would amount to gross misfeasance in public office and the biggest scandal in public care and social care in modern times.

THE HEARING

72. The hearing was originally listed for 10 days. In the event, it took twice as long. With hindsight, the time estimate was plainly too short, but the case was undoubtedly extended by the fact that E and A were representing themselves. At the hearing E acted as advocate and A as note-taker and supporter. In some respects this arrangement worked well. At the outset I was told by E that she had problems with communications attributable to a long-standing neurological condition. In closing submissions I pointed out to her that, having listened to her for 20 days, I had detected no problems with communication whatsoever. I found it difficult during the hearing to keep E on the

point when she was cross-examining witnesses. This problem arises of course, with many litigants in person and, indeed, some professional advocates.

- 73. The fact that the parents were acting in person in what was undoubtedly a complex hearing necessitated the court relaxing a number of its usual procedural rules. In his closing submissions Mr Bagchi, on behalf of the Official Solicitor, helpfully summarised the steps that the court has taken, and I have reproduced, with some amendment, his summary here:
 - (1) I tried to avoid harrying or rushing E in her questioning of any witness, which meant that some witnesses were much longer than forecast and had to be rescheduled.
 - On occasions I assisted E in formulating her questions and was not overly critical of her style, which sometimes involved long statements without a question and serial repetition of previous points.
 - (3) I re-ordered the normal sequencing of questions so that E generally had the opportunity to put her questions after the other parties had put theirs.
 - (4) I tried to avoid sitting for overly lengthy hours taking evidence. Generally, the court took oral evidence between about 10.45 a.m. and 4.45 p.m., save when the court occasionally sat early at 10 a.m., although "housekeeping" regularly took up time before and after the oral evidence.
 - (5) I ensured that E had at least one break during each session of the hearing, morning and afternoon.
 - (6) The court has been much more accommodating than might usually be the case, in permitting E and A to give further notice of further witness requirements many days into the hearing.
 - (7) I allowed E to ask leading questions of her own witnesses and, in the case of one of her witnesses, Dr W, to cross-examine him at length in re-examination.
 - (8) As explained above, I allowed E and A to call both Dr Aitkin and Mr Shattock as additional experts, even though permission had only been sought and granted for one of them on an either/or basis, and permitted them to have sight of further documents when ordinarily the court might have refused such a request.
 - (9) I admitted statements and over 700 additional pages of documents, in section N, from E and A long after the trial had started and, in the case of E, her main statement running to some 55 pages was finally not provided until almost the end of the hearing, albeit the first 25 pages had been provided a few days earlier. Exceptionally, I then permitted E and A to file further documents, in bundle O, after the conclusion of the

oral evidence. These documents included summaries of transcripts of secret recordings made by E of their sessions with Dr Beck and Mr McKinstrie and also of Mr McKinstrie's sessions with M.

- (10) The court was careful to ensure that E and A were not placed at any disadvantage by new contentions in the court room by the other advocates and had notice of relevant page references in advance of questioning from the other parties, while being tolerant of E's sustained practice of referring to undisclosed documents when cross-examining the witnesses.
- (11)Having excused E from what I thought would have been the onerous task of submitting written final submissions and setting aside several hours of court time for her oral submissions, it was perhaps predictable that E would not complete her submissions in the time allotted. Some judges might have imposed a guillotine at that point. Instead, I allowed her a short extension of time to file the remainder of her submissions in writing. In the event, E chose to file the whole of her submissions in writing (including much of what she had already said orally) in several instalments over the next few weeks, including a further 24 pages (single spaced) this morning on the day set aside for judgment. In a series of emails to my clerk, she explained that she had sustained an injury to her torso and ribs which restricted her movement for several days and also that she and A had suffered difficulties with their computer equipment. I make it clear that I have read all the documents supplied by E and A, including the documents supplied since the conclusion of the hearing, including their comments on the transcript of the hearing of 6th March and the material supplied today.
- Mr Bagchi expressed the view that the court could not conceivably have done any more to counterbalance any inherent procedural disadvantage brought about by E and A's status as litigants in person. In the circumstances, it was gratifying to read the opening words of E's final submissions, drafted, I note, originally in her name only:

"As we are a family, we have very much appreciated the very kind consideration, understanding and leniency shown to us by his Lordship throughout the proceedings of the trial we have faced. His Lordship has undoubtedly made the court process as bearable as possible for us, in such unknown territory, with scant resources and the enormous pressure we have felt whilst under the utmost scrutiny that anyone is likely to ever have to withstand."

Having said that, however, E proceeded to describe the whole process in extreme terms, saying, for example:

"Having had the expectation of such litigation hanging over us and blighting our lives for so many years has in itself been insufferable and very destructive to our family."

E and A complained that, notwithstanding the efforts of the court, they have been unable to compete with the "limitless public funding and resources" at the disposal of the local authority and the Official Solicitor. Mr Bagchi, on behalf of the Official Solicitor, stated that other parties have recognised that the litigation would be an arduous process and have afforded E and A substantial assistance with the storage and transportation of the court bundles, with copying facilities for the papers and with a daily opportunity to identify in advance the documents relevant to the witnesses to be called; that the Official Solicitor's representatives have, additionally, assisted with securing the attendance of E and A's witnesses and seeking disclosure of documentation from third parties for their use and that E and A were given an early sight of the final submissions and have been provided with a neutral overview of the law and supporting materials. E does not wholly share this view of the degree of cooperation provided by the other legal teams, asserting that they "wanted to appear to assist us throughout the trial" and asserting that the cooperation tailed off as the trial progressed. My firm impression, however, is that E and A were afforded a high degree of assistance by the other legal teams throughout the hearing.

- 75. Overall, I cannot recall a case in which litigants in person have been assisted by the court and the other lawyers to the extent provided in this case. I am satisfied that as a result E and A, and indeed M, have received a fair hearing, but this was only achieved at the cost of a significant lengthening of the proceedings. One lesson of this case is that, if parties such as E and A are to be unrepresented in hearings of this kind, be it in the Court of Protection or in the Family Court, the hearings will often take very considerably longer than if they were represented. Denying legal aid in such cases is, thus, a false economy.
- 76. In total, the court papers filled some 33 lever arch files (court documents and file records) plus two further lever arch files of documents produced by E and A during the hearing. No doubt if the parents had been represented, it might have been possible to reduce this material into a core bundle, as I did myself at the conclusion of the hearing. Even those 35 files may not represent the totality of the disclosable documents that might have been produced. For example, no health visitor records were produced for the period of M's early years. At a very late stage E alluded to the possibility that she may have copies of these records somewhere in the loft at her home. Furthermore, and despite my explaining the rules about disclosure on more than one occasion, I am not entirely satisfied that E and A have complied with their obligation to disclose all relevant documents,

including those that do not support their case. At one point E's medical records were produced and, when E objected to their disclosure on grounds of confidentiality, I conducted a public interest immunity examination to determine which pages of the records were relevant. In the event, I concluded that only 16 pages fell into that category, but E insisted on challenging the disclosure of some of those pages on the grounds that they would assist the other parties. This illustrates another consequence of parties appearing without representation in these cases, namely that the courts may have to devise new rules as to disclosure.

- 77. The list of 139 witnesses who the parents seemed to suggest should or might have to give evidence was, fortunately, considerably reduced. Even so, 32 witnesses gave oral evidence at the hearing: members of the local authority social services team (LG, the current social worker, JR, the team manager, MS, the former case worker and MW, the head of adult services); MH, the chief executive of X College; staff involved with the running of Y House (CS, the first manager, PL, his successor, and RR, the regional operations manager of the agency); staff involved in running Z House (CH, the manager, and KH); staff involved in running N House (AA, the owner of the agency that runs that home, and AR, a care worker at that property); three friends of E and A with experience of caring for autistic people, one of whom is herself on the autistic spectrum; JB, a carer employed by E and A when M was at home; the family GP, Dr W; the family dentist, DC, and the locum who worked at the surgery, Ms Malik; practitioners who had been consulted by E in connection with M's treatment (Shelley Birkett-Eyles, occupational therapist, Dr Julu and Juliet Haywood, the nutritional therapist); expert witnesses, namely Dr Beck, Mr McKinstrie, Dr Carpenter, Professor Williamson, Dr Adshead, Dr Aitkin and Mr Shattock, all instructed by E and A; M's sister, S, and, finally, his parents, E and A themselves.
- 78. In addition to the evidence, I received a number of position statements, notes and closing submissions in writing from all parties. A this stage, I pay tribute to the work of all the lawyers in the case for the local authority, Miss Kerry Bretherton of counsel and Mr Patel, solicitor, assisted by Miss Taylor, who took responsibility for maintaining and updating the bundles an exceptionally demanding task in this case which she undertook with commendable efficiency, and, for the Official Solicitor, Mr Andrew Bagchi of counsel, who assumed unofficial responsibility for giving informal advice to E at various points, and his instructing solicitor, Miss Macintosh, Q.C. (Hons). I am grateful to all of them and others who assisted them for their hard work and professionalism, often in very trying circumstances.

THE LAW

79. The basic principles to be followed by the Court of Protection in all cases are summarised in s.1 of the Mental Capacity Act 2005.

- "(1) The following principles apply for the purposes of this Act.
- (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 a 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."
- 80. The legal framework in which the Court of Protection works can be summarised as follows. First, the court must establish whether the person lacks capacity. The court's powers are only exercisable in respect of incapacitated adults. Secondly, before deciding what orders, if any, should be made in respect of the incapacitated adult, the court must make findings on any facts in dispute. Thirdly, having determined the facts, the court must then make decisions in the incapacitated adult's best interests.

Capacity

81. The statutory provisions governing capacity are set out in sections 2 and 3 of the Act. I set out the approach to be taken by the court when considering capacity in two reported cases: *CC v. KK* [2012] EWHC 2136 (COP), and *Re TZ No. 2* [2014] EWCOP 973. As capacity is not in issue in this case, I do not propose to make this long judgment even longer by referring to the statutory provisions or those authorities in any further detail. Suffice it to say that I have had them in mind when considering the question of capacity in this case.

Fact-finding

82. The principal focus of this hearing has been to make findings on disputed issues of fact as the basis for future decisions about M's life. In my judgment, the legal principles to be applied at a fact finding hearing in the Court of Protection should be broadly the same as in children's proceedings where a court is investigating allegations that a child has been ill-treated or neglected. I have summarised those principles in a number of children's cases, including *Re JS* [2012] EWHC 1370 Fam. Of those principles, the following seem to me to be of particular importance in this case.

- 83. First, the burden of proof lies with the local authority. It is the local authority that brings these proceedings and identifies the findings that they invite the court to make. Therefore, the burden of proving the allegations rests with them.
- 84. Secondly, the standard of proof is the balance of probabilities: <u>Re B</u> (<u>Children</u>) [2008] UKHR 35. If the local authority proves a fact on the balance of probabilities, this court will treat that fact as established and all future decisions concerning M's future will be based on that finding. Equally, if the local authority fails to prove any allegation, the court will disregard that allegation completely. In her written submissions on behalf of the local authority, Miss Bretherton contended that the court should apply the principle that

"the more serious the allegation the more cogent is the evidence required to overcome the unlikelihood of what is alleged and thus to prove it."

This principle, originally stated by Ungoed-Thomas J in <u>Re Dellows</u> <u>Will Trust</u>[1964] 1 WLR 451, was at one time applied by the courts considering allegations of child abuse in family proceedings under the Children Act 1989. In <u>Re B</u>, however, the House of Lords emphatically rejected that approach. Baroness Hale of Richmond, with whose judgment the other four Law Lords agreed, having analyzed the case law, stated at paragraphs 70 to 72:

"70 I would announce loud and clear that the standard of proof in finding the facts necessary to establish the threshold under s.31(2) or the welfare considerations of the 1989 Act is the simple balance of probabilities - neither more nor less. Neither the seriousness of the allegation nor the seriousness of the consequences should make any difference to the standard of proof to be applied in determining the facts. The inherent probabilities are simply something to be taken into account, where relevant in deciding where the truth lies.

- 71. As to the seriousness of the consequences, they are serious either way. A child may find her relationship with her family seriously disrupted or she may find herself still at risk of suffering serious harm. A parent may find his relationship with his child seriously disrupted or he may find himself still at liberty to maltreat this or other children in the future.
- 72. As to the seriousness of the allegation, there is no logical or necessary connection between seriousness and probability."

In my judgment, the same approach must surely apply in the Court of Protection where the court is carrying out a similar exercise in determining the facts upon which to base decisions as to the best interests of an incapacitated adult.

85. Thirdly, findings of fact in these cases must be based on evidence. As Munby J (as he then was) observed in *Re A (A Child : Fact-finding hearing: speculation)* [2011] EWCA Civ 12:

"It is an elementary proposition that findings of fact must be based on evidence, including inferences that can properly be drawn from the evidence, and not on suspicion or speculation."

86. Fourth, the court must take into account all the evidence and, furthermore, consider each piece of evidence in the context of all the other evidence. As Dame Elizabeth Butler-Sloss, President, observed in *Re T* [2004] EWCA Civ 458, [2005] 2 FLR 838, at paragraph 33:

"Evidence cannot be evaluated and assessed in separate compartments. A judge in these difficult cases must have regard to the relevance of each piece of evidence to the other evidence and to exercise an overview of the totality of the evidence in order to come to the conclusion whether the case put forward by the local authority has been made out to the appropriate standard of proof."

- 87. Fifth, whilst appropriate attention must be paid to the opinion of medical experts, those opinions need to be considered in the context of all the other evidence. The roles of the court and the experts are distinct. It is the court that is in the position to weigh up expert evidence against the other evidence: <u>A County Council v. K, D and L</u> [2005] EWHC 144 Fam, [2005] 1 FLR 851 per Charles J.
- 88. Sixth, in assessing the expert evidence, which involves a multi-disciplinary analysis of the medical information conducted by a group of specialists, each bringing their own expertise to bear on the problem, one important consideration and of particular relevance in this case is that the court must be careful to ensure that each expert keeps within the bounds of their own expertise and defers where appropriate to the expertise of others see the observations of Eleanor King J in *Re S* [2009] EWHC 2115 Fam.
- 89. Seventh, the evidence of the parents is of the utmost importance. It is essential that the court forms a clear assessment of their credibility and reliability. They must have the fullest opportunity to take part in the hearing and the court is likely to place considerable weight on the evidence and impressions it forms of them see *Re W and another* (*Non-accidental injury*) [2003] FCR 346.
- 90. Eighth, it is not uncommon for witnesses in these cases to tell lies, both before and during the hearing. The court must be careful to bear in mind that a witness may lie for many reasons such as shame, misplaced loyalty, panic, fear and distress and the fact that a witness has lied about some matters does not mean that he or she has lied

about everything - see <u>R v. Lucas</u> [1981] QB 720. The assessment of the truthfulness is an important part of my function in this case.

Best interests

- 91. S.4 of the 2005 Act sets out provisions concerning best interests. Again, I do not propose to add to this long judgment by setting out the section in full. Suffice it to say that I have had its provisions in mind at all times. In particular, I bear in mind that, when making a decision as to what is in M's best interests, anyone making the decision, including the court, (a) must not make it merely on the basis of a condition of his, or an aspect of his behaviour which might lead others to make unjustified assumptions about what might be in his best interests (s.4(1)); (b) must, so far as reasonably practicable, permit and encourage the person to participate or to improve his ability to participate as fully as possible in any act done for him and any decision affecting him (s.4(4)); (c) must consider, so far as is reasonably ascertainable, the person's past and present wishes and feelings, the beliefs and values that would be likely to influence his decision if he had capacity and the other factors that he would be likely to consider if he were able to do so (s.4(6)); and (d) must take into account, if it is practicable and appropriate to consult them, the views of, inter alia, anyone engaged in caring for the person or interested in his welfare, and any deputy appointed for the person by the court as to what would be in the person's best interests and, in particular, as to the matters mentioned in subsection (6) (s.4(7)).
- 92. In assessing M's best interests, I also have regard to the following further principles. First, the court must have regard to M's right, under Article 8 of the European Convention on the Protection of Human Rights and Fundamental Freedoms, to respect for private and family life. As the European Court of Human Rights has emphasized on many occasions, there is a positive obligation on every State to take measures to ensure that his private life is respected see, for example, Botta v. Italy [1998] 26 EHRR 241. It is important to note, however, as Black LJ observed in K. V. LBX [2012] EWCA Civ 78, [2012] COPLR 411:

"In its wider form incorporating reference to both private and family life, there is a danger that Article 8 contains within it an inherent conflict, for elements of private life, such as the right to personal development and the right to establish relationships with other human beings and the outside world, may not always be entirely compatible with existing family life and, particularly, not with family life in the sense of continuing to live within the existing family home."

93. Secondly, the court when involved with an incapacitated adult must avoid being over-influenced by the so-called 'protection imperative' (the need to protect a vulnerable adult). This conflict was identified in

the context of children's proceedings by Ryder J, as he then was, in <u>Oldham MBC v. GW and PW</u> [2007] EWHC 136 Fam, [2007] 2 FLR 597. I have alluded to it in a number of cases when considering issues of capacity in the Court of Protection - see, for *example*, <u>PH v. A Local Authority and others</u> [2011] EWHC 1704 (Fam), at paragraph 16(xiii), <u>CC v. KK</u> supra, at paragraph 65 and <u>Re TZ (No. 2)</u> supra, at paragraph 28. In a case involving a vulnerable adult, there is a risk that all professionals involved with treating and helping that person, including, of course, the judge in the Court of Protection, may feel drawn towards an outcome that is more protective of the adult. That risk must be borne in mind, not only when assessing capacity (as in the three cases just cited) but also when making decisions as to best interests. The most celebrated exposition of this principle is in the well known passage in the judgment of Munby J, as he then was, in <u>Re MM (An Adult)</u> [2007] EWHC 2003 Fam, at paragraph 120:

"Just as wise parents resist the temptation to keep their children, metaphorically, wrapped up in cotton wool, so too we must avoid the temptation always to put the physical health and safety of the elderly and vulnerable before everything else. Often it will be appropriate to do so, but not always. Physical health and safety can sometimes be bought at too high a price to happiness and emotional welfare. The emphasis must be on sensible risk appraisal, not striving to avoid all risk whatever the price, but instead seeking a proper balance and being willing to tolerate manageable or acceptable risks as the price appropriately to be paid in order to achieve some other good. In particular, to achieve the vital good of the elderly or vulnerable person's happiness. What good is it making someone safe if it merely makes them miserable?"

94. Thirdly, when a person lacks capacity to make a decision about medical treatment, the decision must be taken in his best interests. In *Aintree University Hospitals NHS Foundation Trust v. James* [2013] UKSC67, Baroness Hale of Richmond observed, at paragraph 39:

"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 that 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 are interested in his welfare, in particular for their view of what his attitude would be."

Although that observation was made in the context of a dispute about life-sustaining treatment, it is equally applicable, in my view, to all decisions about all types of medical treatment proposed for incapacitated adults. We shall see later to what extent it was considered by those involved in making decisions about M's treatment.

Deputyship

- 95. The power to appoint a deputy is set out in s.16 of the Act, which I recite in full:
 - "(1) This section applies if a person (P) lacks capacity in relation to a matter or matters concerning, (a) P's personal welfare, or (b) P's property and affairs.
 - (2) The court may, (a) by making an order, make the decision or decisions on P's behalf in relation to the matter or matters, or (b) appoint a person (a deputy) to make decisions on P's behalf in relation to the matter or matters.
 - (3) The powers of the court under this section are subject to the provisions of the Act and, in particular, to s.1 (the principles of P's best interests).
 - (4) When deciding whether it is in P's best interests to appoint a deputy, the court must have regard, in addition to the matters mentioned in s.4, to the principles that, (a) a decision by the court is to be preferred to the appointment of a deputy to make a decision, and (b) the powers conferred on a deputy should be as limited in scope and duration as is reasonably practicable in the circumstances.
 - (5) The court may make such further orders or give such further directions and confer on a deputy such powers or impose on him such duties as it thinks necessary or expedient for giving effect to or otherwise in connection with an order or appointment made by it under subsection (2).
 - (6) Without prejudice to s.4, the court may make the order, give the directions or make the appointment on such terms as it considers are in P's best interests, even though no application is before the court for an order, directions or an appointment on those terms.
 - (7) An order of the court may be varied or discharged by a subsequent order.
 - (8) The court may, in particular, revoke the appointment of a deputy or vary the powers conferred on him if it is satisfied that the deputy, (a) has behaved or is behaving in as way that contravenes the authority conferred on him by the

court or is not in P's best interests, or (b) proposes to behave in a way that would contravene his authority or would not be in P's best interests."

96. Guidance about deputies is found in the Mental Capacity Act 2005 Code of Practice. Under the heading, "What are the rules for appointing deputies?" the Code states, at paragraph 8.31:

"Sometimes it is not practicable or appropriate for the court to make a single declaration or decision. In such cases, if the court thinks that somebody needs to make future or ongoing decisions for someone whose condition makes it likely that they will lack capacity to make some further decisions in the future, it can appoint a deputy to act for and make decisions for that person. A deputy's authority should be as limited in scope and duration as possible."

97. Guidance as to the appointment of personal welfare deputies is found at paragraphs 8.38 and 8.39 of the Code of Practice.

"8.38 Deputies who have personal welfare decisions will only be required in the most difficult cases where important and necessary actions cannot be carried out without the court's authority or there is no other way of settling the matter in the best interests of the person who lacks capacity to make particular welfare decisions

8.39 Examples include when someone needs to make a series of linked welfare decisions over time and it would not be beneficial or appropriate to require all of the decisions to be made by the court. For example, someone such as a family carer who is close to a person with profound and multiple learning disabilities might apply to be appointed as a deputy with authority to make such decisions. The most appropriate way to act in the person's best interests is to have a deputy who will consult relevant people but have the final authority to make decisions; if there is a history of serious family disputes that could have a detrimental effect on the person's future care unless the deputy is appointed to make decisions; the person who lacks capacity is felt to be at risk of serious harm if left in the care of family members. In these rare cases, welfare decisions may need to be made by someone independent of the family, such as a local authority officer. There may even be a need for an additional court order prohibiting those family members having contact with that person."

98. In *G v E (Deputyship and Litigation Friend)* [2010] EWHC 2512 (COP), Fam [2010], COPLR Con Vol 470, I said, at paragraph 58:

"The Act and Code are, therefore, constructed on the basis that the vast majority of decisions concerning incapacitated adults are taken informally and collaboratively by individuals or groups of people consulting and working together. It is emphatically not part of a scheme underpinning the Act that there should be one individual who as a matter of course is given a special legal status to make decisions about incapacitated persons. Experience has shown that working together is the best policy to ensure that incapacitated adults such as E receive the highest quality of care."

I continued at paragraph 59:

"To my mind, s.16(4) is entirely consistent with this scheme. Manifestly, it will usually be the case that decisions about complex and serious issues are taken by a court rather than any individual. In certain cases, as explained in paragraphs 8.38 and 8.39 of the Code, it will be more appropriate to appoint a deputy or deputies to make these decisions, but because it is important that such decisions should, wherever possible, be taken collaboratively and informally, the appointments must be as limited in scope and duration as is reasonably practicable in the circumstances."

99. As for the identity of the deputy, paragraph 8.33 of the Code provides:

"In the majority of cases, the deputy is likely to be a family member or someone who knows the person well, but in some cases the court may decide to appoint a deputy who is independent of the family; for example, where the person's affairs or care needs are particularly complicated. This could be a professional deputy."

In <u>G v E</u> supra, at paragraph 61, I commented:

"It is axiomatic that the family is the cornerstone of our society and a person who lacks capacity should, wherever possible, be cared for by members of his natural family, provided that such a course is in his best interests and assuming that they are able and willing to take on what is often an enormous and challenging task. That does not, however, justify the appointment of family members as deputies simply because they are able and willing to serve in that capacity. The words of s.16(4) are clear. They do not permit the court to appoint a deputy simply because 'it feels confident it can' but only when satisfied that the circumstances and the decisions which will fall to be taken will be more appropriately taken by a deputy or deputies rather than by a court, bearing in mind the principle that decisions by courts are to be preferred to

decisions by deputies. Even then, the appointment must be as limited in scope and duration as is reasonably practicable in the circumstances. It would be a misreading of the structure and the policy of the statute and a misunderstanding of the concept and role of deputies to think it necessary to appoint family members to that position in order to enable them better to perform their role as carers for P."

KEY WITNESSES

100. Before turning to consider the specific issues arising on this fact finding hearing, I shall record my observations about the main witnesses who gave evidence in this hearing.

E

- 101. I start with M's mother, E. Although she was the penultimate witness, it is appropriate to consider her first. E has dominated this hearing in a way quite unlike any other case in my professional experience. In assessing her, I rely not only on her oral evidence which was given over the last few days of the hearing, but also on her performance as an advocate representing herself and her husband over the preceding 17 days. I use the word "performance" deliberately because that is what it was. E performed the role of advocate throughout the hearing. She has described the experience of these proceedings as being "insufferable" but on many occasions during the hearing I had the clear sense that she was relishing the opportunity to put across her case about which she plainly feels very strongly. In his closing submissions, Mr Bagchi said of E that she:
 - " ... is highly intelligent, articulate and outwardly confident. She has in no way been intimidated by the forensic process and it is not unfair to say that she has in many ways thrived within it. Her energies in representing herself and A during this hearing have in no way diminished as the hearing stretched into its fourth and fifth weeks. She has proved herself to be resolute, determined and to have great stamina."

I agree with this description. I have no doubts that E adores her son and her daughter, and that she has devoted much of her life to her children and, in particular, to getting the most that can be achieved for her son. Her devotion is not, however, selfless. On more than one occasion she said that this was case was about her and, although she was quick to retract that comment, when I pointed out that it was actually about M, there was no doubt that she felt she was the main focus of the inquiry. She was the centre of attention and, in my judgment, at times obviously enjoying the experience.

- 102. It was E's case that she had suffered from a neurological condition vestibular neuritis - that causes problems with communication and This was her excuse for clandestinely recording her interviews with a number of witnesses, including Dr Beck, Dr Adshead and Mr McKinstrie. Plainly, if she has a problem with memory, this is something that the court would have to take into account when considering her evidence, so I deal with it at this point. E suggested at the outset of the hearing that she would provide a report from her treating neurologist, but no report appeared. Her medical records did not support the suggestion that she suffered from problems with memory and her GP, Dr W, confirmed that the key feature of this condition is the onset of dizziness and does not to his knowledge include memory loss. In her oral evidence she had no difficulty apparently recalling detailed events from many years ago. I have already observed that she showed no difficulty in communicating. Mr Bagchi submits that her suggestion that she had a memory problem was just a crude cover story to avoid criticism for her secret recordings. I agree. Her decision to record certain professionals was born out of her intense suspicion of those who she perceived or anticipated would disagree with her rather than any problem with In short, this was an example of E exaggerating or fabricating an account of her own health for her own ends. I shall consider later whether this was a pattern of behaviour that she demonstrated with regard to M.
- 103 Throughout the hearing, E was scrupulously polite and courteous to the court and appreciative of the efforts made to accommodate her as a litigant in person. She never once interrupted inappropriately, preferring to raise her hand whenever she wanted to make a point. At times she came across as a warm and humane person. At other times, however, she was domineering and even on occasions intimidating, in particular when cross-examining some of the witnesses called by the local authority; for example, KH. Dr Beck reported that throughout her meetings with E, she had the impression that she was attempting to control the interview. E used a number of tactics to avoid answering questions and ensure that the interview was focused on materials she considered important, including talking a great deal and without allowing interruption, providing emotive impressions which lacked concrete detail, and jumping from one topic to another. Dr Beck reported that she felt on occasion as if E had embarked on a monologue and she found that she had to be very firm and to interrupt her, and when she did interrupt her, E sometimes apologised and at other times protested, but invariably continued talking about whatever she wanted to talk about, without apparently being influenced by Dr Beck's interruption. Dr Beck had the impression that E was keen to control the interview and that, if she reflected on this with her, E's apologies were not genuine and she did not generally change her behaviour as a result.

- 104. My experience of E was very similar. Despite her respectful attitude to the court, she tried to control the court process. She endeavoured to focus on what she thought was important rather than the issues raised by the other parties. On a number of occasions she embarked on a monologue and it was very difficult to stop her. When interrupted she often apologised but almost invariably went back to the topic that she wanted to talk about. In the end, I concluded that attempts to interrupt her or to try to focus her attention on the issues that were of concern to the court were doomed to fail.
- 105. Dr Beck reported that she found E's account at times to be self-aggrandising and dismissive of the contribution of others. She found that the mother seemed to regard herself as superior and adopting a patronising attitude. The same tendencies were apparent in her oral evidence and at other times in the hearing, particularly towards the staff at the various homes where M has lived. Dr Beck thought that E's manner reflected the fragility of her intra-psychic structures. In Dr Beck's opinion, E relies heavily on M's needs and complaining about them not being met to provide structure and meaning to her life. It is Dr Beck's view that E:

"needs M to be a victim so that she can save him and meet her own needs for attention, to be important and to be cared for."

- 106. In a number of respects E gave a detailed account of events that, as will become apparent, I have found to be untrue. This was also Dr Beck's experience. Dr Beck believed that E lied to her during the clinical interview and that she was aware that she was doing so. Dr Beck did not believe that everything she said was a lie, nor that the mother herself could always recall which of her stories were true and which were not. However, Dr Beck believes that the mother is primarily motivated to recount events in a manner which serves her personal interests rather than that which reflects objectively verifiable events.
- 107. The evidence of E's difficult personality only emerged from her evidence about events since 2007 when the local authority first became involved with the family. There is very little hard evidence about her behaviour prior to that date. E gave a detailed account of her employment history in the NHS, involving a succession of posts in catering, in the course of which she has acquired some qualifications, but the history was somewhat nebulous. The circumstances in which she left her employment were also left unclear, although at one point of the hearing she spoke of difficulties having arisen because she had been a whistleblower. E's GP records include a letter from a solicitor to her former GP in 2006 seeking disclosure of her records for the purposes of a claim against her former employers in the employment tribunal and alluding to a separate claim for personal injury arising out of alleged breach of employer's duties. It would have been interesting

to explore that aspect of her background in more detail, but to do so would have extended the hearing even further.

- 108. In Dr Beck's opinion, E has a narcissistic personality disorder which involves her having (1) an exaggerated sense of her own selfimportance and simultaneously a fear that she may be of no importance whatsoever, and vacillating between these two extremes: and (2) impaired interpersonal functioning whereby she cannot identify with the feelings and needs of others. In her supplemental report, Dr Beck added that the people with narcissistic personality disorder usually lack empathy for others and often think that they are the most important thing in everyone else's life and that the world should be organised around them. Dr Beck advises that this disorder is extremely difficult to treat. The major challenge in the treatment of narcissistic personality disorder is that most people who suffer from it do not accept that they have it and in fact work hard to defend themselves against it. In Dr Beck's opinion, it is not feasible in this case that E's narcissistic personality disorder could be alleviated in a reasonable timescale for M. Dr Adshead agreed with Dr Beck that there are significant features of personality disorder in E's presentation, mainly narcissistic and histrionic features. In addition, she suspects that E may have some features of an emotionally unstable personality disorder.
- 109. Dr Beck also expressed the view that E has factitious disorder imposed on others. In her oral evidence she confirmed that this diagnosis is dependent on the court's findings on the local authority's allegations that she has fabricated or exaggerated M's symptoms. Dr Adshead also stated that any diagnosis would turn on the court's findings of fact. I shall, therefore, return to this aspect of the case towards the end of the judgment.
- 110. In closing submissions, Mr Bagchi submitted of E that:

"Her tendency to exaggerate and dramatise events is just one aspect of her personality disorders ... which render her utterly unreliable as a historian of events unless such accounts can be verified independently. Bound up with her propensity to present a false account is her ever-present instinct to accuse others of lying and conspiring against her in a manner which is either an expression of her paranoia or a device to explain the all too common divergence of account between herself and others."

He continued:

"All of this points to a deeply paranoid and hostile view of any professional who is prepared to challenge her, and it utterly destroys the prospect of forging working relationships with any independent professional carer based on mutual trust and respect."

- 111. A is a completely different character. He sat through the hearing making little comment, taking notes and prompting his wife on occasions with Post-it notes, rather in the manner of a solicitor sitting behind counsel. Prior to giving oral evidence as the last witness, his comments during the hearing were largely confined to raising concerns about M's present predicament, about which he has strong views, being adamant that he should leave N House immediately. It is not surprising that this was a topic on which A wanted to address the court. Manifestly, he is absolutely devoted to his son and desperate to do whatever he can to help him. I accept that this is A's principal motivation.
- 112. In addition, however, he came across as somebody completely devoted to his wife, whose views he appeared to accept without challenge. Although at times it seemed as though E was "fighting" and I use that word deliberately this case on her own, I am in no doubt that A has been at her side in every sense. According to Dr Beck, he told her that his role was "to support her [meaning his wife] to the hilt." In closing submissions, Mr Bagchi submitted that it was clear from A's oral evidence that:

"he and E are very much together in their approach and, whilst he may have a more relaxed and different style to the professional staff, he is wholly trusting and supportive of his wife in all that she does."

I agree.

Other lay witnesses called by E and A

- 113. At this point it is convenient to mention briefly the other lay witnesses called by the parents. Their daughter, S, is manifestly devoted to her brother and spoke briefly about . It is also clear that she entirely supports her parents. She refused to accept any criticism of her mother. Cross-examined by Miss Bretherton, she said: "my parents do what is best. I don't question them." She believes that the local authority are pursuing this case in order to gain control of M so that they can spend as little money as possible. She said that it seemed to her as though he was being used as an experiment. He was completely different from the person he had been six month ago. At the conclusion of her evidence she read out a further statement setting out her views, beginning with a comment that she "truly believed that the local authority will not stop this hatred campaign until her parents have keeled over and died".
- 114. In addition, E and A called three friends who have autistic children of their own. Other friends, including the family priest, have written letters in support. Two of their three witnesses are parents of another young man who had also attended X College and lived at Y House and

then Z House at the same time as M. They were critical of the way in which their son had been looked after at Y House, including a lack of attention paid to diet and sensory issues which effect some people with autism. Like E, they found Z House to be an improvement after Y House but they, too, thought that the situation had deteriorated after CH took over as manager. They had concerns about the attention being given to their son's health and recounted how he had undergone an emergency operation after staff had failed to appreciate the seriousness of his condition. As a result, they alerted E and it seems that their warnings played a part in leading E to take M home in February 2013 because of concerns about his health.

115. All three of these witnesses were fully supportive of E. One described her as intense and evangelical in their advocacy for M and admitted that this, " ... can be very irritating and exhausting for someone on the receiving end." She added that E had very high expectations of care home staff, which she attributed to E's naivety, adding that at times E:

" appears to have little appreciation of the pressures that care staff are under and is oblivious to the fact that staff, even if interested, do not have time to take in all the valuable knowledge she is so keen to impart to them."

Her partner is herself on the autistic spectrum and spoke movingly of the difficulties that she has faced and took the trouble after she had completed her oral evidence to send me a short note setting out some advice about speaking to M, whom I was going to meet a few days later. All three of these witnesses paid tribute to what they saw as E's devotion to M which amounted, in the words of one of them, to "a determination to stop at nothing to get M the care, support and long-term achievement that he deserves."

Expert witnesses

- 116. The expert witnesses called by the Official Solicitor, whose evidence was accepted by the local authority, were Dr Carpenter, Professor Williamson, Dr Beck and Mr McKinstrie.
- 117. Dr Carpenter is an Honorary Consultant Psychiatrist, having for many years worked as a consultant for adults and children with learning difficulties. Throughout his career he has pursued a special interest in autism, on which he has taught widely. He was a contributor to the guidelines drawn by NICE (the National Institute for Health and Clinical Excellence) on: "Autism; recognition, referral, diagnosis and management of adults on the autistic spectrum." In her closing submissions filed today, E attacked the NICE guidelines on the grounds that they recommend not the most effective medical remedy but only the cheapest. Dr Carpenter was asked to prepare a full chronology of M's medical history, including all complimentary treatments, and provide an opinion as to whether past medical and complimentary medical treatments, investigations and assessments had

- been in his best interests. In a supplementary report he was asked to advise as to M's capacity.
- 118. Professor Williamson is a consultant surgeon at Hammersmith Hospital. He has some 45 years' experience as a gastrointestinal surgeon. He has held a number of posts, including Director of Surgery at the Royal Postgraduate Medical School at the University of London and also President of the Royal Society of Medicine. He was asked to focus on the gastrointestinal aspects of the case, including whether M requires a restrictive diet or dietary supplements.
- Maudsley Hospital. She was instructed to assess, inter alia, M's relationship with his parents, the family's relationship with the local authority and risk issues and the impact of those relationships on M's best interests, whether E exaggerates or falsifies M's medical symptoms and, if so, what psychological factors have given rise to this and how it impinges upon M's best interests, whether E poses any risk to M, the specific effect on M's best interests of E's detailed instructions, her biomedical supplements, therapies, medical investigations and assessments, the risks, if any, to M's development if he lives or does not live with his parents and if control over welfare decisions are restored to his mother, and the level of contact with his family in the event that he does not live with them.
- 120. Mr Keith McKinstrie is a social worker with very considerable experience in disability services. He is currently employed by Sheffield City Council as a service manager for adults with learning disabilities. In addition, he works as an independent social worker providing reports for the Court of Protection and delivers training lectures and leads service development on social work and social care issues, and, in particular, the personalisation of social care and implications of this for local authorities. He was asked to address a series of questions concerning M's residence, care, contact and the issue of biomedical supplements and medical treatments and investigations.
- 121. All four of these witnesses were extensively criticised by E in the course of the case for one reason or another and, in particular, were the subject of a prolonged and vitriolic attack in her closing submissions. In particular, it was alleged that each had tailored their evidence to fit the agendas of the local authority and the Official Solicitor. I therefore record immediately that I found all four witnesses to be wholly reliable and professional. I reject the accusation that they have given false testimony at the behest of the local authority and the Official Solicitor. The summary transcripts of Dr Beck's and Mr McKinstrie's interviews made by E and A, based on their clandestine recordings, do not, in my view, disclose any significant errors or omissions in their reports, nor undermine their reliability.

- 122. E and A instructed three experts: Dr Gwen Adshead, Dr Kenneth Aitkin and Mr Paul Shattock. I have already described the unsatisfactory circumstances in which the last two came to be instructed.
- 123. Dr Gwen Adshead is a psychiatrist with long and well known experience in the field of forensic psychiatry. For 18 years she has been a consultant psychotherapist at Broadmoor Hospital. Amongst her areas of special interest is factitious disorder imposed on others, previously known as factitious and induced illness or Munchausen's syndrome by proxy.
- 124. Dr Aitkin is a consultant clinical psychologist and neuropsychologist with a lifelong interest in autism, in which he has taught and published widely. Amongst his special interest is the use of alternative treatments in the management of autism.
- 125. Paul Shattock is a pharmacist, having acquired a degree in that subject in 1966. He was also for many years a senior lecturer in pharmacy at the University of Sunderland. He is the chairman of organisations called Communities for Autistic People and Education and Services for People with Autism, which provide residential care and support for over 200 people with autism in the northeast of England. He states in his curriculum vitae that he has an autistic child himself and has dedicated most of his career to helping people with autism, receiving the OBE in 1999. He has published widely in a number of books and over 50 articles on many aspects of autism, including the use of gluten and casein free diets. He has devised a programme called the Sunderland Protocol, a strategy for testing the effectiveness of different nutritional interventions on children with autism.
- 126. Dr Adshead was another reliable and professional witness. As for Dr Aitkin and Mr Shattock, while I accept that the views that they expressed were genuine, I was concerned at times as to their qualifications to opine on some of the matters about which they gave evidence

Dr W

Dr W has been the family GP since 2007. Until he went into the witness box, he has managed to maintain a good working relationship with E and A. He has achieved this by adopting an approach that was tolerant and sympathetic to E's concerns and on more than one occasion acceded to her requests to arrange testing for M when his own clinical judgment might have led him to conclude that such testing was unnecessary. He described this approach in evidence as "practising defensively". In some respects, therefore, he was acting in a fashion that could be regarded as typical of an older style family GP. In his evidence he was taken through the list of conditions which E asserted M had suffered from and he excluded a considerable number

In their final submissions filed on the morning of the judgment, E and A expressed a degree of disillusionment with Dr W and said that they were considering their position as to whether or not he should remain their GP. I record that I consider that Dr W has acted in this difficult case in a responsible manner bearing in mind the very difficult circumstances in which he was operating. As a witness, I found him truthful and humane.

Alternative practitioners called by E and A

- 128. The last group of witnesses about whom I wish to make specific mention before turning to the evidence are the three alternative medical practitioners called by E and A: Shelley Birkett-Eyles, Dr Julu and Ms Haywood. Mrs Birkett-Eyles is an occupational therapist and Director of Hemispheres Movement for Learning Limited, a private occupational therapy practice specialising in the assessment and treatment of children and young adults with learning and developmental difficulties. She has seen M on several occasions since 2010 and, amongst other things, ran a training day at X College on the topic of sensory processing. Dr Peter Julu describes himself as a specialist autonomic neurophysiologist and consultant physician. Juliet Haywood is a nutritional therapist who has been advising E on M's diet for the past four years.
- 129. My impression of Mrs Birkett-Eyles was that she was a responsible practitioner working within the proper confines of her particular field, although, as will be clear later, the reliability of her opinion as to treatments given to M was challenged by Dr Carpenter. I was more concerned about the evidence given by Dr Julu and Ms Haywood.
- 130. Dr Julu told the court in oral evidence that his field of interest is not yet part of mainstream medical training in England and that he is the only autonomic neurophysiologist in Europe. I was not satisfied from his evidence that his purported specialism is a legitimate field of medicine and, again, the reliability of his assessments and treatment recommendations for M were challenged by Dr Carpenter. In her supplemental closing submissions filed this morning, E said that the lack of knowledge amongst those challenging Dr Julu's evidence is "startling, as it is easily accessible on the internet."
- 131. Ms Haywood, whose professional qualification is a diploma from the College of National [Natural] Nutrition, has played a major role in advising E in recent years. The papers contain a number of emails passing between E and Ms Haywood and it is clear from reading them that there are others which have not been disclosed. I am satisfied that in the course of her involvement with the family Ms Haywood has given advice that went well beyond her expertise. One glaring example was Lyme disease when, on her advice, given after seeing a photograph of a mark on M's leg, E sent urine samples abroad for further testing. Subsequently, Ms Haywood confidently expressed an

opinion on the interpretation of the results of those tests. She has no chemistry or other qualification that equips her to do so. I was also concerned that Ms Haywood had prescribed the dietary protocol for M without seeing him and with no independent knowledge of his medical history, content to rely solely on what she was told by E; for example, that M had a chronic gut disorder. In contrast to Mr Shattock's Sunderland Protocol, which recommends the systematic testing of diets and supplements individually, Ms Haywood was content to prescribe a dietary programme without testing each individual component separately. She did not agree with the NICE guidelines as to the impact of diet on autism. She had forthright views on many things, saying, for example, at one point that she did not like Cancer Research UK. I was left with a profound anxiety about Ms Haywood's influence on E and her role in the treatment that M has received.

132. There was one other matter which gave rise to concern about this part of the evidence. None of the three witnesses had received any training on the Mental Capacity Act 2005 and it was clear from their evidence that none of them had given proper consideration to the question whether M had capacity to consent to their assessments or the treatment they were prescribing. The family GP, Dr W, also admitted in his oral evidence that he only made a detailed study of the Act and the Code of Practice when he was told that he would be giving evidence in this case, and he identified a number of learning points about the Mental Capacity Act arising out of his involvement in these proceedings. Mr Bagchi reminded me in his closing submissions of the concerns expressed in the House of Lords' Select Committee on the Mental Capacity Act 2005 Post-Legislative Scrutiny Report on the implementation of the Act, dated 30th March 2014, about the general lack of awareness by the general public and professionals of the principles and workings of the legislation. This case has highlighted the urgent need for all health professionals, including those practising in alternative and complimentary medicine, to familiarise themselves with the Act so that they can apply its principles and procedures when they treat a person who lacks capacity, as most of them will at some point.

M

Diagnosis of mental impairment

133. M's diagnosis is a matter of some controversy. E gives the following summary of what she claims to be the diagnosis:

"Pervasive developmental delay and a disordered sensory function. A severe somatic and pragmatic language and communication disorder with associated learning difficulties and autistic tendencies (as a result of regressive autism where brain function presents with autistic traits once neurological developmental milestones have been reached) subsequently added to which was leaky gut syndrome (since reclassified as autistic enterocolitis, defective brain blood barrier with associated digestive intestinal and gut disorder), together with heavy metal poisoning and acute allergic reaction to environmental pollutants, conducive with induced brain damage (meningeal encephalitis), not classic autism."

- 134. Dr Khouja in his report for the first Court of Protection proceedings concluded that M has autistic spectrum disorder, with a mild to moderate learning disability. In his evidence in these proceedings Dr Carpenter was in broad agreement, giving a diagnosis of childhood autism, but thought that his learning disability was in the severe to moderate range.
- 135. Dr Carpenter also considered the various other diagnoses that had been suggested over the years. I shall review his observations about the physical diagnoses later, but at this stage I record his comment on the diagnosis of "regressive autism" which was mentioned at various points in M's history and is still cited by his parents as part of the diagnosis. Dr Carpenter points out that there is no such formal diagnosis in the international classification systems, although it is a term often used informally to describe the regression that can occur at about aged 16 to 20 months. He noted that it was mentioned as a diagnosis by the Royal Free Hospital in March 2001 and concluded that this was a reasonable statement having regard to the history supplied by the parents. Dr Carpenter stated that about 25% of children with autism have a history of regression which has over the vears been attributed to a variety of external causes, including at one stage the MMR vaccination. Dr Carpenter says that no single external cause has been identified to explain this common regression, which may be a consequence of normal maturation within the brain and in most cases does not indicate an external brain insult. Dr Carpenter noted that there had been different accounts of M's development in the first two years of life and, in particular, the date on which he was perceived as deteriorating. I shall recount his assessment of the history in more detail later. Assuming the account of his normal development, followed by a dramatic regression is true, Dr Carpenter describes regressive autism as "an informal, unofficial subcategory", which fits the picture. He adds, however, that the contemporaneous notes show no such regression, although there was a lack of progress.
- 136. As for the other elements of the diagnosis that pertained to impairment of the brain or mind as quoted by E, Dr Carpenter stated that the phrase "pervasive developmental delay" was a more general term used at the time of Dr Baird's assessment in 1992 and should not be seen as an alternative diagnosis. Furthermore, he dismisses the use of the phrase "severe somatic and pragmatic language and communication disorder" as adding anything to the diagnosis since there is no evidence that he has communication difficulties going beyond those to

be expected in someone with childhood autism. Dr Carpenter bluntly concludes that M has childhood autism and that anything else should be seen as a euphemism.

Capacity: the functioning element

- 137. An assessment of capacity was carried out by Dr Khouja in the earlier proceedings and reviewed by Dr Carpenter in these proceedings. They reached similar conclusions. Dr Carpenter's impression from meeting with M, the accounts of the staff and the past assessments is that he has been very well trained to do things through rote learning. It is, however, much less clear whether he understands what he is doing and why or when to use what he has learned. Dr Carpenter considers that his apparent low level of understanding is masked by his rote learned skills. With some things M is clear, for example, when he refuses things, but Dr Carpenter finds it telling that lengthy work with advocacy and speech and language therapist has still only enabled them to establish some basic understanding. Frankly, Dr Carpenter has severe doubts that he can reliably communicate any complex decision.
- This is one aspect of the case where there is no substantial 138. disagreement. It is not disputed that he lacks mental capacity to litigate these proceedings, to make decisions relating to his residence and his contact with others or as to his medical treatment, nor is it disputed that he lacks mental capacity to make decisions relating to his dietary or nutritional needs or to have biomedical supplements or engage in medical therapies. Dr Khouja concluded that he was able to make a decision from a list of options presented to him in relation to choices of food, diet and activities and also whether to go home for weekend visits. Dr Carpenter accepted that he had the capacity with regard to food but not other activities or weekend visits. However, decisions as to activities involving an assessment of risks and consequences and decisions about going home are, in Dr Carpenter's phrase, "fraught with value-laden issues." Both Dr Khouja and Dr Carpenter thought that, in those areas where M had capacity, he should be actively supported and given the opportunity to make choices in accordance with the underlying principles of the Mental Capacity Act. Both experts identified his communication difficulties as a significant feature. Dr Carpenter identified:

"the major problem of being confident that M is communicating his wishes accurately. At present, on any choice he makes, one is not totally confident that what is chosen is what he truly wants as his passive acceptance of most instructions makes it possible that, even if he did not really want what he chose, his continuation to use or eat or perform that choice could be evidence of his compliance as much as true desire."

For that reason, the Official Solicitor submits - and I agree - that M has an ongoing need for the involvement of his speech and language therapist and advocate.

My meeting with M

- 139. All parties were keen that I should have the opportunity to meet M, and I was pleased to do so. It is often valuable for a judge to meet the person who is the subject of Court of Protection proceedings, although it is important that such meetings should not be used as a way of obtaining the evidence.
- 140. I met M in the presence of his advocate on 25th June at W House, the establishment recently opened by C Limited, the owners of his current residential home, N House. As stated above, W House is much closer to the family home and, therefore, to the family and social network and activities with which M is familiar. E and A are anxious that M should move to W House as soon as possible, and indeed sought to argue in the course of the hearing that this move should take place immediately. For different reasons, the other parties are opposed to an immediate move; the local authority because of concerns that E was becoming too close to the manager of W House, and the Official Solicitor because of advice from Mr McKinstrie that the move should not occur until a significant number of the other residents have already moved in, before a full complement of staff have been recruited and trained, routines established and teething problems overcome and a rigorous care plan produced in conjunction with C Limited for the approval of the court.
- My meeting with M lasted about 30 minutes. At his choice, it started 141. in the downstairs lounge. M seemed happy and relaxed. His ability to speak was limited but, with his advocate's assistance, using communication tools, including pictures, he was able to tell me about his journey to W House and that he liked certain sports and computing. From photographs he pointed out and named members of his family and other residents and support workers at N House. Later, when we went into the garden, M spent some time on the trampoline, which he plainly enjoyed. My abiding impression of M is of a warm and friendly young man who clearly enjoys life. I can well understand why his family feel so strongly about him and want to do whatever they can to ensure that he gets the most out of life. It is manifestly right that everything should be done to bring this about, for example, by helping him to access a wide range of activities, as he has done in the past when living at home.

E'S REPORTS OF M'S MEDICAL CONDITIONS

142. The local authority asserts that E has stated that M is suffering from numerous conditions, the overwhelming majority of which are not

true, and has subjected M to unnecessary tests and interventions and/or lied about his illnesses or tests.

143. In analysing the evidence about an assessment of the case, I shall focus on a few specific examples of instances in which it is alleged that E has given a false account of M's medical condition.

Reaction to the MMR

- 144. The issue of M's reaction to the MMR vaccination and whether it was the cause of his autism lies at the heart of this case. E and A insist that M had a devastating reaction to the MMR, that his autistic traits date from that time and that this provides clear evidence in support for the Wakefield theory. On the other hand, it is alleged by the Official Solicitor, in particular, but also supported by the local authority, that E and A have fabricated the account of M's reaction to the vaccine and thereby falsely sought to establish a link between the vaccine and his autism.
- 145. As I stated more than once during the hearing, this case is not an inquiry into whether there is a link between the MMR vaccine and autism. The relevance of this issue is whether the account given by E, in particular, of M's reaction to the MMR, is true. Nonetheless, it is necessary to outline briefly the expert evidence that I have received about the possibilities of a link.
- 146. I have already described the history of the controversy in the summary above. The prevailing medical view is as set out information published by the World Health Organisation actually produced by E in the hearing which states that:

"The overall evidence clearly indicates no association of MMR vaccine with either inflammatory bowel disease or with developmental delays, including autism."

This accords with the opinion given by Dr Carpenter. Nevertheless, there is a substantial body of opinion to the contrary, including parents of autistic children and some alternative medical practitioners.

147. Dr Carpenter reached the conclusion in his report that the diagnosis of M's autism as having been induced by the MMR vaccine is inconsistent with the independent contemporary evidence and, therefore, not viable. He notes that M's parents did not link his apparent regression to the MMR injection until after the publication of Dr Wakefield's paper in 1998. Dr Carpenter has carried out, as requested, a full analysis of the medical records and found that the first account of M deteriorating immediately after the MMR vaccination was not given until 2001. E's subsequent accounts of M's reaction to the vaccination - of a child developing normally prior to the vaccination and thereupon having seizures, screaming fits and declining into a vegetative state for six months - is incompatible with

the other records. There is no mention of adverse effects or any reference to a bad MMR reaction in the GP records. Dr Carpenter notes that a few months after the MMR, the GP records show M being described as hyperactive, which Dr Carpenter points out is inconsistent with the account of his being in a vegetative state. When a change of GP took place a few months later, there was no note of any recent adverse event being recounted to the new doctor. If M had been in a severely regressed state at this time, Dr Carpenter would have expected this to have been mentioned to the new GP. Furthermore, 21 months after the MMR, when giving a detailed account of his development to Dr Baird, no mention was made by the parents of any deleterious reaction to the MMR. On the contrary, their account concentrated on an earlier deterioration after an illness at age 10 months - seven months before the MMR was administered. In crossexamination by E, Dr Carpenter said that any adverse reaction to the MMR vaccination which had caused a regression in M's development would have been recorded in his 24 month developmental check and it was not. What was recorded was not regression, but a lack of progress.

- 148. After the allegation of an adverse reaction to MMR was eventually recorded in 2001, it became more dramatic in subsequent accounts. Thus, in 2001 the description was: "Distressed after injection. Had fever. Eyes glazed, dilated and fixed." E's account became more florid over time, with references to screaming, jolting, spasming and a persistent vegetative state. In her final statement she said that: "M died within six hours of the MMR." In the witness box she gave a full account of the events on the day on which the MMR was administered and M's reaction to it. E acknowledges in her final statement that she uses certain words and phrases in her own particular way. example, for her the phrase "vegetative state" means "slipping in and out of consciousness, not responding and appearing lifeless." And her use of the word "died" to describe what happened to M means "stopped breathing and lost consciousness". For E, her use of these words and phrases is as valid as the way in which they are used by medical professionals.
- 149. For some time E has alleged that part of M's medical record is missing. The inference that she invited the court to draw was that pages had been deliberately removed to conceal contemporaneous records of his reaction to the MMR. It is now clear that no part of the records have been removed. One page of the records was missing and copies produced by E and A, but the original record was intact. I am not going to speculate on the reason why the copies produced by E and A are incomplete.
- 150. If M had an experienced an extreme reaction to the vaccine, as now alleged, it is inconceivable that E and A would not have sought medical advice and thereafter told all doctors and other medical practitioners about what had happened. As I put it to E in the course of

the hearing, there are only three possible explanations for what has happened. The first is that E did give the account to Dr Baird and all the other practitioners at every appointment, but each of them has negligently failed to record it. The second is that she gave an account but all the practitioners have chosen not to include it in their records. That is what E maintains has happened, alleging that the whole of the medical profession is deliberately concealing the truth about the MMR vaccine. The third is that E has fabricated, or at least grossly exaggerated, her account.

- 151. Mass negligence can obviously be discounted. In my judgment, it is also completely fanciful that the whole of the medical establishment had decided to act deceitfully in the way alleged by E. I therefore conclude that the account given by E as to M's reaction to the MMR is fabricated.
- 152. For the purpose of this case, it is unnecessary to make any finding as to why it has been fabricated. It is unnecessary to explore whether E truly believes that M reacted in the way she now alleges. It is notable that A also, apparently, adheres to the same account, although he is noticeably more reticent in his evidence about it. The key point for the purposes of this case is that E has fabricated her account of a crucial aspect of M's medical history and thereafter relied on this false account to direct the course of his future treatment.

"Autistic enterocolitis"

- 153. As recounted above, part of M's diagnosis as expressed by E is that M has autistic enterocolitis, or leaky gut syndrome. Just as this case is not an inquiry into whether there is a link between the MMR vaccine and autism, so also it is not an inquiry into whether there is a form of colitis associated with autism. I note, however, that in his report Dr Carpenter advised that autistic enterocolitis is not a recognised condition. It was put forward by Dr Wakefield, and is now discredited and withdrawn by The Lancet paper, and no independent peer review paper has been published subsequently to confirm the findings of colitis in autism. Professor Williamson described autistic enterocolitis as "a controversial entity".
- 154. E has repeatedly stated that M was diagnosed with enterocolitis at the Royal Free Hospital in 2001. In his report, Dr Carpenter observed that, if this is the case, then it must have occurred at an examination that is not contained in the Royal Free records and not communicated to the GP. He was unable to find any evidence in the papers disclosed to him to support the parents ever having been given a formal diagnosis of enterocolitis. The Royal Free tested for gluten free sensitivity and bowel inflammation but found no evidence of any anomaly other than constipation.

- 155. Professor Williamson also noted that, unlike some patients seen by Dr Wakefield and his colleagues, M was not given the label of autistic enterocolitis. In his careful analysis of the relevant medical records, Professor Williamson found no evidence to support an organic disease of the gastrointestinal tract in M, with the sole exception that, according to the doctors at the Royal Free who saw M in 2001-2, when they were reporting accounts given by his carers, M's bowel habit had alternated between diarrhoea and constipation. Professor Williamson noted that M had had none of the typical symptoms of inflammatory bowel disease. In his evidence, Mr Shattock disagreed, suggesting that constipation was a symptom associated with gut disorders seen in persons with autism. On this point, I was concerned that Mr Shattock was speaking outside his sphere of expertise, but it is of little consequence so far as this hearing is concerned.
- 156. Throughout the hearing, E insisted that M had been given the diagnosis of autistic enterocolitis or leaky gut syndrome and alleged that some of the Royal Free medical records must be missing. I reject that assertion. I find that not even the Royal Free team, who at that time were leading the way and postulating the link between autism and a form of colitis, found any evidence in 2001 of significant gut disorder in M. In his case no diagnosis of autistic enterocolitis or leaky gut syndrome was ever made.
- 157. I therefore find that on this point E has, again, given a false account of part of M's medical history and thereafter relied on this false account to direct the course of his future treatment, in particular with regard to diet and nutritional supplements.

Lyme disease

- 158. The clear evidence of Dr W, the family GP, was that M did not have Lyme disease. Although he was not instructed as an expert witness, it is significant that Dr W's clinical practice has included experience in rural areas where he has come across cases of this condition, which is caused by a tick bite. He advised that it is a diagnosis based on biochemical testing in the context of the overall clinical picture. I therefore conclude that he has the expertise to give a definitive opinion as to whether M was suffering from it, and I accept his evidence that M was not.
- 159. E, on the other hand, did not accept Dr W's view and persisted in obsessively pursuing her theory that M was suffering from this disease. Her unshakeable view was based initially on two newspaper reports of women who were diagnosed with the disease that had gone undetected for some time. She thought the mark on M's leg had been caused by just such a bite. Her fears were stoked by comments from Ms Haywood, speaking about a matter in which she was completely unqualified, who warned that testing carried out by British laboratories was inadequate. At her suggestion, E therefore insisted that samples

be sent abroad. The results suggested that one marker consistent with, though not diagnostic of, Lyme disease was present in one sample. On this basis E maintained that M had indeed had that condition and continued to include it in summaries of his health history. For example, when he was admitted to hospital in August 2013 for the dental extraction, E said that he "had tested positive for Lyme disease".

160. I accept Dr W's evidence. M did not have Lyme disease. This is yet another example of E giving a false account of M's medical history. In this regard she was supported by Ms Haywood, who showed no doubt in the witness box about her ability to express an opinion about Lyme disease without having any appropriate qualifications.

Tooth abscess/sinus problems

- 161. On 21st June 2012, E took M to the family dentist's surgery suffering from pain. The regular dentist, DC, was not at work, so M was examined by a locum, Ms Malik, who works regularly at the surgery. Ms Malik had not originally been scheduled to give evidence at the hearing before me but was located at the last minute and duly called by the Official Solicitor.
- 162. Ms Malik's computerised record of the examination stated that M had complained of pain and that E had been informed by his support worker that he had not been eating well on the previous day. On examination she found slight tenderness in tooth upper left 6. An x-ray was taken and revealed that he had an area of periapical infection. Ms Malik was shown the x-rays in the witness box and confirmed the diagnosis. The records indicate that she told E that M needed to be assessed urgently for extraction or root canal treatment under general anaesthetic and that E said that she would like to monitor it for now as M was unable to have a local anaesthetic. The records further indicate that Ms Malik offered antibiotics for M, but E declined. Ms Malik said that she had told E to make a further appointment to see DC when he returned to the surgery.
- 163. It is E's case that Ms Malik has given a false account of this examination. E says there was no mention of any periapical infection or abscess, but instead Ms Malik had told her that there was a problem with M's sinuses. She denies that there was any talk of root canal treatment or extraction or that antibiotics were offered. E put this version to Ms Malik in oral evidence, who emphatically stood by her evidence: she had not mentioned sinuses.
- 163. Two days later after M was examined by Ms Malik, E called an out of hours doctor about M because he had pain and facial puffiness. When M was examined by the doctor, E reported that he had been seen by a dentist who, according to the doctor's record, said he had sinusitis. In court, E denied using the word "sinusitis" but said that she had told the doctor that the dentist had said there was a problem with his sinuses.

According to the doctor's note, on examination the doctor did not detect any definite tenderness in the sinuses, but after E said that M would not definitely say if there was tenderness, the doctor recorded the diagnosis as "likely sinusitis" and prescribed antibiotics. When M returned to X College and Z House on the Monday after Ms Malik's examination, a diagram was provided (now at page N202 in the bundles) showing the sinuses and recording that the x-rays taken on 21st June had indicated no tooth or gum infection or decay, no nerve irritation, but swelling of the sinuses and pressure from a ruptured wisdom tooth. This was completely at odds with what Ms Malik said she had advised E. On 27th July 2012, M was seen by a different dentist at a surgery close to Z House. On examination nothing untoward was detected. It seems likely, as suggested in evidence by Ms Malik, that the antibiotics prescribed by the out of hours doctor on 23rd June temporarily alleviated the symptoms. E requested that no radiographs be taken at the examination on 27th July. evidence, Ms Malik told the court that a clinician would need to see xrays to diagnose the presence of abscesses.

- 164. In due course, on 23rd May 2013 some 11 months after Ms Malik's examination E took M to a different surgery not far from the family home called The Tooth Fairy Holistic Centre, where x-rays confirmed the presence of periapical areas in upper left 6 and 7, indicating the presence of abscesses confirmed by a surgeon to whom M was then referred and who then subsequently extracted the teeth under general anaesthetic
- E's case is that Ms Malik is lying about her examination on 21st June 165. 2012 and that she somehow altered the communication on the computer record. I completely reject that submission. I found Ms Malik to be an utterly truthful and a reliable witness. At one stage in the hearing, E suggested that the records had been falsified and Ms Malik had lied to the court because DC was concerned about his surgery being sued for negligence. For that reason, DC was called by the Official Solicitor, although in the event E did not put it to him that he had falsified the records. When DC gave evidence, he described Ms Malik as an excellent clinician to whom he had entrusted his patients as locum for many years. I accept Ms Malik's account of the examination and what she said to E. Amongst the many revealing details is her note that E had told her that M could not have a local It has been E's case that she is allergic to local anaesthetic. anaesthetics following an incident when she was younger, for which there was no independent evidence, and that this has been inherited by M. Ms Malik's note, therefore, contains something that E must have told her.
- 166. It follows that this is yet another example of E giving a false account of part of M's medical history and thereafter relying on this false account to direct the course of his future treatment.

- 167. In this instance, it is possible to trace the consequences for M of this fabricated account. In ignoring Ms Malik's advice, failing to make an urgent appointment with DC on his return, taking M to another dentist, failing to give a full or accurate account to that other dentist and expressly declining further x-rays which would have been likely to reveal the abscesses, E was solely responsible for allowing M's infected mouth to go untreated for over a year, thereby condemning him to further pain and suffering as the area of infection gradually got worse. Throughout the period of 14 months between Ms Malik's examination and the eventual surgery to extract teeth, M suffered pain, repeatedly described by E, which Ms Malik advised in evidence was probably caused by the abscesses. Meanwhile, as I find, E pursued other increasingly extreme theories for the causes of M's pain, none of which has any basis in fact, at a time when she knew or ought to have known that the cause of the trouble was the dental infection which she was concealing.
- 168. On any view, this was deplorable and dangerous behaviour. M was and is a highly vulnerable young man, totally incapable of communicating his needs. E was his deputy and carer. He was dependent on her. She failed to protect him and acted in a way that was plainly contrary to his interests.

Other examples

- 169 The history shows other examples where E gave descriptions of M's health, notably to KH, but also to others, for which there was no independent supporting evidence. These include that M had lost sensation in his hands and feet; that he was suffering from an adverse effect to electromagnetic energies; that he had been diagnosed with what appeared to be brain seizures; that his urinary system had shut down; that he was finding it difficult to walk very far; that M's immune and nervous system were down; that he had tumours in his gum sockets; that he had been diagnosed with chronic blood poisoning; that he had a black shadow sitting on his left sinuses that he had black gunge oozing from every orifice. Other diagnoses put forward by E and dismissed by Dr Carpenter were: rheumatoid arthritis; heavy metal poisoning (based again on an isolated test result when such a diagnosis turns on repeated elevated levels); and a defective blood brain barrier. I share Dr Carpenter's astonishment at reading E's account of how M had attended a cranial osteopathy appointment which:
 - " ... had focused on the contorted membranes between the two frontal lobes, apparently where the optical and auditory brain stems sit. The twist in the central membrane was significant for most of the treatment to be spent on it and it would appear to have come from M's head overheating, obviously trying to release body heat."

- 170. Many of these were repeated, along with others, in the document entitled, "Overview of M's health" which E attached to the application at the start of these proceedings seeking the summary dismissal of the local authority's application. I find that these were all false, or at least grossly exaggerated accounts of M's symptoms. During the period June 2012 to September 2013, when this crescendo of false and exaggerated reporting took place, M was subjected to a large number of different tests, examinations and assessments, a number of which were invasive and all of which took up his time which would have been better occupied elsewhere.
- 171. It is unnecessary to go into these or other examples in any greater detail. The local authority's case on this aspect is plainly proved. I find that E has stated that M is suffering from numerous conditions, the overwhelming majority of which are not true, and has subjected M to unnecessary tests and interventions, and/or lied about his illnesses or tests.
- 172. Relying on the professional view of Dr Beck, supported by Dr Adshead, it is asserted by the local authority that this amounts to factitious disorder imposed on others. I shall return to this assertion at the end of the judgment. Before doing so, it is appropriate to consider the other findings sought by the local authority.

<u>DIETS, SUPPLEMENTS AND ALTERNATIVE REMEDIES AND TREATMENTS</u>

- 173. The local authority alleges that one aspect of E's control of M's life is over his diet and supplements. This is linked to its allegation that E has exposed him to unnecessary alternative treatments and therapies.
- 174. Autistic spectrum disorder has generated a vast medical, scientific and other literature, much of it on the subject of alternative and complimentary treatments. Once again, it is important to emphasize that this case is not an inquiry into the efficacy of diets, supplements and alternative treatments and therapies, either generally or specifically for people with autism. The issue to be determined in these proceedings is whether E has acted in M's best interests by insisting that he is placed on a strict diet, that he receives a range of daily supplements and undergoes a range of treatments and therapies. It is right, however, that I should outline briefly the evidence put before me as to the efficacy of diets, supplements, treatments and therapies given to M at E's behest.
- 175. As stated above, E distinguishes between "mainstream medical" opinion and "mainstream autism" opinion. In her view, each is equally valid. That view is plainly shared by others and the validity claimed for alternative treatments and therapies is not confined to autism, but extends to many other diseases and health abnormalities. In the case of autism, however, the popularity of such treatments seems to be

greater because, as Dr Carpenter observes, there is no "cure". The only approach that has consistently worked, according to Dr Carpenter, is concentrating on education and training and improving skills. There is, therefore, a greater incentive for people - in particular, parents facing the arduous task of managing an autistic child - to search for anything that might help. As this case demonstrates, there are plenty of people offering help. Whether what they are offering is truly helpful is debatable. Dr Carpenter in oral evidence observed that no medical treatment has been identified that stands up to scrutiny and most of the evidence of the impact or therapies is anecdotal rather than robust, double-blind research science.

- 176. Dr Aitkin is a proponent of the use of alternative treatments in cases of autism. He contended that there are no standard approaches to the treatment of all individuals with autism. There are a number of accepted processes, depending on the clinical presentation, but no agreed prescriptive evidence-based approach that is universally endorsed. He stated that a large number of clinical conditions requiring specific approaches to treatment have been identified as affecting some groups of people with autism. Mr Shattock is another proponent of alternative treatments who, through the Sunderland Protocol, had developed a strategy for determining the effectiveness of individual treatments.
- 177. In his closing submissions, Mr Bagchi observed that many people with no relevant mental impairment undergo quasi-medical therapies or take nutritional supplements because they hope and believe that it may promote their health and well-being, even if conventional medical science cannot establish the effectiveness of the treatment. Those people are able to weigh up the advantages and disadvantages of such products and therapies and make free choices about their own health. Even if there may be limited physical benefits of such therapies, there may be a beneficial psychological effect in terms of a person's sense of well-being. Clinicians speak openly of the placebo effect of certain Mr Bagchi submitted, however, that the position in treatments. relation to a mentally incapacitated person is quite different. A person like M, without the mental capacity to make his own decisions about health care or diet, is unable to weigh up the advantages and disadvantages of any particular therapy or supplement. He is reliant upon others to decide whether he should be given the treatment in his best interests by family members, clinicians and, where appointed, a deputy. It can be accepted that in this context "best interests" may take account of factors other than clinical or medical benefit - as observed by Baroness Hale in the Aintree case (supra). There must, however, be a clear benefit.
- 178. Dr Carpenter observed that most of the dietary and nutritional therapies given to M are ones that he has experienced with other patients over the years. He has not objected to them being used in most cases. He also observes that E appears to have normally sought

professional help when using therapies; that she has not devised treatment protocols without advice. He adds, however, that he found little evidence that E carried out what he would expect a best interests decision-maker to do when using non-conventional therapies for an adult who does not have capacity to choose for himself: namely, (a) draw in as wide a range of advisors as possible, and (b) ensure that the therapists are fully aware of the medical history. Dr Carpenter is very concerned that the therapists in this case were not given copies of any diagnostic reports but were, rather, given accounts of how the MMR vaccine had induced a vegetative state and a diagnosis of enterocolitis, which was not supported by any contemporaneous medical records.

- 179. Dr Carpenter also criticises E for failing to question the reason and purpose of any of the therapies or interventions used or seek unbiased evidence about their effectiveness. He is concerned at the lack of evidence that E looked at the arguments against therapies, as well as the arguments for. He is concerned at the apparent inadequacy of some of the assessments prior to starting therapy. He is also concerned at the apparent lack of monitoring of the effects of therapies. He notes that, despite the lack of evidence that any of the supplements work, the number and manner of taking them has been allowed to grow so that they now seemingly dominate M's life and care regime. It is the quantity and intensity of the supplements given to M that causes concern for Dr Carpenter rather than any single supplement.
- 180. For a number of years, until his placement at N House, M was on a gluten and casein free diet. The efficacy of this diet for people with autism is a matter of controversy. Dr Carpenter quoted the guidelines issued by NICE in 2013, which he helped to draft, which recommended against the use of exclusion diets such as gluten or casein free diets for the management of core features of autism in children and young people. He cites research published by "Research Autism", which he described as a generally respected organisation that attempts to review the evidence of main treatments and interventions in an unbiased manner and which concluded:

"The theory behind the gluten free/casein free diet ["GFCF"] is weak and unproven and there is limited evidence as to whether GFCF diets are actually effective for individuals with autism. Reviewers have found the research evidence to be inconclusive. Despite this lack of evidence, many people embark on a GFCF diet with high expectations that there will be beneficial effects. However, these diets can involve significant inconvenience and costs, as well as a significant limitation on what the individual can eat. Because of this we cannot recommend the use of such diets."

- 181. A different opinion was expressed by several witnesses called by E and A. Mr Shattock said that excluding gluten and casein from the diet had been reported as leading to measurable improvements in a high proportion of subjects, though in some instances the improvements were minor and not worth the effort, cost or possible disruption to life. Those reports are, however, based on the impression of parents and carers rather than any scientific analysis. Mr Shattock conceded that the benefits of the diet are clinically unproven and frankly acknowledged in his report that, had he been on the NICE committee himself, he would not have been able to disagree with the negative conclusion as to the use of such diets for people with autism. Dr Aitkin said that in general there are several reasons why such a diet might be considered as part of a management approach in an individual with an autism diagnosis and not merely used as a placebo. He cited research that suggested that such a diet is safe if properly adhered to and that there is some limited evidence of benefit. Some individuals with autism showed improvements on such a diet, for reasons other than a casein or gluten free intolerance. Again, however, the evidence of such improvements is the subject observations of parents and carers rather than any clinical or scientific analysis. Ms Haywood, however, was clear that there is now overwhelming evidence about how much autistic people benefit from a gluten free diet.
- 182. In M's case, there is no clear evidence that being on a GFCF diet is beneficial. The notes of the Royal Free Hospital recorded on 18th March 2001 that E had tried M on such a diet, but by January 2002 the hospital was recording that "he remains on a normal diet as there were no improvements in his behaviour or bowel habits on a gluten and dairy free diet" and there is no evidence that the Royal Free made any subsequent recommendation that he be put back on that diet. The diet was subsequently reintroduced unilaterally by E without positive medical approval. Professor Williamson regards it as a "telling fact" that, since M became resident at N House, he has remained in good physical health despite eating a normal diet, free of any restrictions and devoid of any of the numerous supplements that he had previously been obliged to take. On the contrary, he is eating well and gaining weight. When Professor Williamson saw him, he thought that he looked in excellent physical shape. Professor Williamson advised that, if M can stay well after a restricted diet, vitamins and minerals, it provides "strong evidence to suggest that they are unnecessary."
 - 183. For Dr Carpenter the key feature was that the reason given for M being on a diet that he had a diagnosis of enterocolitis was fallacious. In those circumstances there was no good reason for his diet being restricted in this way. It seems plain that those who advised E about the diet, in particular Ms Haywood, assumed that the diagnosis of enterocolitis given by E was correct. The concern about the insistence of the diet in this case was, therefore, not so much about the use of the diet per se, (which is plainly not uncommon amongst people with autism, notwithstanding the clear view expressed in the NICE

guidelines), but, rather, the fabricated diagnosis which led to the diet being imposed.

184. If the only alternative treatment therapy provided to M had been the GFCF diet, there would be relatively little concern. But it was not. Rather, it was one of a multitude of treatments given. In her final statement, E described M as an:

" ... ever-changing minefield of biochemical hormone surges that require constant awareness of and treatment in terms of biomedical natural supplementation and dietary intake."

In terms of nutrition, he was supplied with a large number of supplements to be taken daily. Here, it was Ms Haywood's advice on which E acted. In contrast to the approach recommended by Mr Shattock in the Sunderland Protocol, there was no incremental approach (testing the efficacy of each individual supplement) but rather the prescription of a cocktail of supplements every day.

- 185. Dr Carpenter quotes the NICE guidelines again as not recommending the use of such supplements for the treatment of the core symptoms of autism in adults. He notes that: "Research Autism" observed the evidence of nutritional supplements being untested or incapable of being proved and, therefore, it was not a treatment that they could recommend. Dr Carpenter notes, however, that most of the supplements appeared to have no known toxic overdose limit. He acknowledged that he is not an expert, although he expresses concern in general about how over the years the number of supplements delivered to M has increased dramatically and how the rigidity of instructions given for the supply of the supplements produces what he describes as unnecessary behaviour and choice restrictions of M.
- 186. I accept Dr Carpenter's opinion on this point. There is no evidence that the supplements caused physical harm, but I am not persuaded that there is any reliable evidence that they cause any benefit. The important issue is the manner and the quantity in which they were prescribed, without proper objective analysis, to a young man who lacked capacity to make decisions about whether or not to take them.
- 187. This approach to supplements was replicated with other treatments and therapies. By and large, it is the sheer range and number of the treatments and their indiscriminate use on an incapacitated person that gives rise to concern, rather than the risk of any harm befalling the individual. I accept Dr Carpenter's evidence that there is no evidence that cranial osteopathy, rheumatology, colloidal silver or homeopathy generally are clinically beneficial. In the case of some treatments, they may have been harmful. I accept, for example, Dr Carpenter's evidence that there may be concern about the use of auditory integration therapy. He quoted NICE as finding no good evidence that such therapy works. Research Autism quoted research evidence to say that such therapy was not helpful in improving perceptions of autism,

although it may be of limited use in the help with sensory problems. Dr Carpenter was concerned, however, that people with hearing loss or infection or damage to the inner ear should not be treated in this way. Dr Carpenter observed that, for M, who has recurrent ear problems, such therapy was potentially dangerous. Equally, he was concerned about the use of oxygen therapy. In his report, his concern was about the use of hyperbaric oxygen therapy, which is associated with risks to ear and teeth, and would have been potentially risky to M. Throughout the hearing, E stated that the oxygen therapy had not been hyperbaric, although I note in her final statement E said at paragraph 245 that M "uses a hyperbaric oxygen chamber for health reasons." The main concerns about oxygen therapy in M's case were, first, the sheer degree of interference with the life of an incapacitated adult required to have oxygen administered to him for up to six hours a day and, second, the question of the theoretical process for the therapy provided by Dr Julu - neurodevelopmental dystautonomia - which is not mentioned in any international classification known to Dr Carpenter.

- 188. I accept Dr Carpenter's opinion that there is no evidence that any of these treatments were individually beneficial for M and that collectively they were intrusive and contrary to his best interests. M's life was increasingly dominated by the programme of treatment to the exclusion of other activities. I find that E has implemented a programme of diet, supplements and treatments and therapies indiscriminately, with no analysis as to whether they are for M's benefit, and on a scale that has been oppressive and contrary to his interests. She has exercised total control of this aspect of M's life.
- 189. I stress, again, that I am not making any definitive findings on the efficacy of alternative treatments generally. That is not the subject of these proceedings, which are about M. I do, however, find that: (1) there is no reliable evidence that the alternative treatments given to M have had any positive impact on people with autism generally or M in particular and (2) the approach to prescribing alternative treatments to and assessing the impact of such treatments on people with autism in general and M in particular has lacked the rigor and responsibility usually associated with conventional medicine.
- 190. This demonstrates the fallacy of E's belief that there are two parallel approaches to the diagnosis and treatment of autism "mainstream medical" and "mainstream autism" each of which is equally valid. The evidence in this hearing has demonstrated clearly that there is one approach the clinical approach advocated by Dr Carpenter that is methodical, rigorous and valid, and other approaches advocated by a number of other practitioners, for which there is no evidence of any positive impact and which (in this case at least) have been followed with insufficient rigor. Whilst each treatment may be harmless, they may, if imposed collectively and indiscriminately, be unduly restrictive and contrary to the patient's interests. These disadvantages are compounded when, as in several instances in this case, insufficient

consideration is given by the practitioners to the question of whether a mentally-incapacitated patient has consented to or wishes to have the treatment

ISSUES WITH THE LOCAL AUTHORITY AND CARE HOMES.

191. The local authority asserts that E has exercised an unacceptable level of control over M during his periods in residential care and subsequently, and that she is unable to work with the local authority social workers and residential home staff. E and A deny the allegations of excessive control, assert that E is a devoted mother who has at all times acted in the best interests of her son, and complain that the local authority has relentlessly pursued its own agenda of seeking to remove M from their care, enlisting the support of residential home staff to that end. It is convenient to consider the evidence on these issues together. The local authority claim that its evidence disclosed a pattern, with each placement having a honeymoon period at the start, followed by a deterioration as the staff struggled to cope with E's demands and her insistence on controlling every aspect of M's life. The parents responded by claiming that the true pattern was staff at all the homes were acting under the pressure of the local authority to fit in with their overriding agenda.

Y House

- 192 The evidence from Y House staff was that they found E controlling and difficult throughout M's time there. CS, the manager of the home when M arrived, described how E was very demanding and tense throughout the whole process of moving M into the property, and thereafter would purchase all his food, provide a detailed weekly menu, check the food cupboards every week, provide cleaning and laundry products, with guidance on how to use them, supply a large box of supplements and alternative remedies to be given to M and leave a large number of Post-it notes in M's room and the kitchen giving further instructions. On a weekly basis, the home would receive an email setting out E's concerns and raising issues about M's care. Any failure to follow the guidelines would lead to a phone call and further work. Dealing with these issues was extremely time consuming, to an extent that they came to dominate the staff's work. CS had never previously been expected to communicate with family members to this extent.
- 193. On one occasion, when E had not received immediate attention because CS and his colleague, PL, who was M's key worker, had been attending to another patient's medication in a locked cupboard, E, according to CS, started screaming and shouting outside the cupboard in the hearing of M and other residents. As a result, she was asked to leave the property. When cross-examining CS, E implied, without expressly asserting, that CS and PL had acted improperly in some way by administering medication to a resident in that way. E's behaviour,

according to CS, affected the mood of the staff. In the end, CS found the difficulties of managing her and the parents of another resident - in fact, the couple who E called in evidence at this hearing - impossible and decided to leave the job.

194. The evidence of the staff at Y House was that, once E had been appointed M's deputy by the Court of Protection, she used this position to assert even greater control. Staff felt that the deputyship was impeding M's choices in a number of ways, including diet, clothing and social activities. RR, the agency's operations manager, spoke of how E had been unhappy that M was expected to do activities with some of the other less able residents. She objected when staff used the word "peers" to describe the other residents, explaining that in an email to RR dated 19th April 2011, quoting the dictionary definition of "peers" and adding that: "we usually do ignore 'ignorance' as knowing no better" and asking her to arrange a training session to enlighten staff on this matter. As stated above, a major issue at Y House arose over the parents refusing to allow M to be registered with a local GP. PL said in evidence that all residents in any care home require a local GP so that they can access the local services that are channelled through NHS referrals. PL, who took over as acting manager, was particularly concerned that M was being denied his own voice, for example, in the question of whether he should have a local GP. He said in evidence that he is a believer in the importance of advocacy for people with learning disabilities and had, therefore, referred M to an advocacy service. He said he felt that M needed an advocate because his life was being controlled by E and he needed to have his own voice. In cross-examination of PL, E suggested that the purpose was not to give the service users a choice but, rather, to take the voice away from the parents and family members. PL did not accept that this was so. He said that he wanted to help M to live his life to the full.

Z House

195. The evidence from staff at Z House was that relationships deteriorated after a relatively cordial start. CH, who took over as manager during the course of M's time at the home, described how difficult it was working with E as deputy. Information had to be passed through E rather than directly to the local authority. CH was unhappy at this restriction. In cross-examination, E put it to CH that she had never mentioned her deputyship to him. He disagreed. It was his evidence that every aspect of M's life was under E's control. The amount of documentation provided by E, setting out guidelines to be followed, was more than CH had ever experienced. CH felt that this was unduly restrictive of M's life. For example, whereas other residents could choose what they ate, M did not have that opportunity. Instructions were given as to the contents of the drawer in his room. He had so many supplements that they had to be stored in their own cupboard. Health reports were provided every week. Sometimes CH would receive a long email from E which he would read carefully. He said that it became quite difficult for him to manage and still give time for the other residents and staff. Staff found E difficult and said that when she visited it was like treading on eggshells. They felt threatened and anxious. Other residents also resented the long hours that E was present at the property, and at their request a policy was drawn up which set down fixed visiting times.

- 196. KH was a junior member of staff who was a classroom assistant at X College and was allocated to work with M at Z House in the last few months. CH said that KH had a great relationship with M. KH confirmed that staff and other residents had felt anxious about E's presence and he described how M would also be at his most anxious when his mother was there. He thought that he had a good relationship with E and A and described how E had offered him a job helping to look after M at home. KH described how on one occasion he had heard M say "Mummy ruined my life." Given M's communication difficulties, I do not draw any conclusions from that evidence. KH said that he found E intimidating and said that on one occasion she had said to him that she knew he would not mess with her "because Z College have learnt" and that she would sue the local authority.
- 197. According to the staff at Z House and the local authority evidence, the placement had finally come to an end when the staff refused to comply with E's direction to give more pain relief medication than the recommended maximum, whereupon E took M home. E denied that she had made such a request and claimed that her decision to remove M had been made because of concerns that his health was not being attended to properly at the home. After M left, KH was sufficiently concerned about him that he rang every week to check on his health. He has given a detailed account of his conversations with E during these calls in written notes and stood by this account in oral evidence. In cross-examination, he denied that he had been trying to give evidence against E to impress his employers. In his evidence, E suggested to him that it was he who had raised the possibility that M might have cancer because he, KH, had been tested for a bowel problem. KH said that no such conversation had ever taken place. He reiterated that it was E who told him that the dentist had found a tumour. He also stood by his note which recorded that E had asked him to arrange an autograph book for M from everyone at X College and Z House to sign and that she had said "so, if he doesn't pull through, it's something he can take to the grave."

N House

198. The evidence from the staff at N House was that E and A found it very difficult accepting the restrictions placed on them after M had been removed from their care following the order of 6th March 2014. AA, the owner of the agency that runs the home, recorded in his statement that, whilst A had remained focused on spending time with his son, E

had become increasingly demanding and challenging during the visits. E and A secretly recorded some of their sessions at N House. AA was alarmed that this had happened. He was very concerned that staff had not been asked and that there was a risk that the confidentiality of other residents might have been compromised. Matters came to a head when a visit was terminated early because of the way, it was alleged, that E had treated a junior member of staff - AR - who had been asked to supervise a contact session and to make notes about it. E told the solicitor then acting for her, in an email that she has voluntarily disclosed to the court, that they could not have chosen someone more insulting and offensive if they had tried. Thereafter, AA refused to permit the parents' contact to take place at the property.

- In her statement, AR described E as being patronising and rude to staff and how she verbally pushed A out of the way when he attempted to talk to staff. Most of the time when she had been supervising visits had been spent by E asking questions. In cross-examination, E accused AR of spending most of the time during the visits on the phone. AR did not accept that this was so. On one occasion, AR had been sitting in her car outside the home when E and A approached her unexpectedly. They had arrived and were unable to get into the home. In her oral evidence, AR said that she felt very intimidated on this occasion, in particular by E. She described how they had banged on the window of her car. She described in detail what E and A had asked and what she had done to try to get someone who was on duty to see them. E put it to her that she had fabricated her account in order to fit the local authority's agenda. She denied that this was so.
- AA's evidence was that, generally, M was doing very well at N House. His parents, however, accused the staff there of neglecting him and said that, because of the ill-treatment and poor diet he was then being allowed, he had put on weight and his health had deteriorated. A GP local to N House, with whom he has been registered, has seen him during this hearing and reports that, although he has put on weight, he remains in the healthy weight range. In cross-examination by E, AA denied that he was making the situation look rosy to justify the decision to remove M from home, or that he had tailored his evidence out of a desire to maintain his commercial relationship with the local authority. He accepted, however, that he had identified as a potential issue that other residents had moved in and were causing a noise that may have an adverse effect on M.

The social workers' evidence

201. The evidence from the local authority social workers was that E was uniquely challenging and difficult. JR told the court that this was the longest-running and most expensive case in the experience of this authority's adult services team. It was for that reason that two senior members of staff had been assigned to this case after MS withdrew because of the complaint made by E and A. The local authority had

statutory duties in respect of M and it was in carrying out those duties that the social workers came into conflict with E. JR said that it was her preferred approach to work with families to support young people for whom they have statutory responsibilities. E put it to JR that, since the outcome of the judicial review proceedings, the local authority has pursued a vendetta against them. JR denied that this was so.

- 202. LG described how she had checked out the complaints made by E about the quality of care at Y House and found that they were unjustified. It was suggested that it was naive of her to trust the home staff. LG disagreed. There had been a process undertaken before the contract had been approved by the local authority, as commissioning body, to check to see if there were any safeguarding issues. The CQC reports about the unit are publicly available. LG corroborated the evidence given by several others that E had used her deputyship to restrict the local authority access to information. That was what she had been told by staff at Y House and was also her own experience. LG conceded that sometimes there might be a small element of truth in some of E's complaints, but they were exaggerated out of all proportion.
- 203. It is LG's evidence that, after M was removed from Z House, she sent emails to E on several occasions but received no reply. She visited on two occasions, was denied access on the first occasion but saw M on the second, when he seemed in good health. It has been E's case that she did not receive the emails. She endeavoured to argue that the reason had been because of the way her address had been written at the top of the email.
- 204. Following the incident which led to the cessation of contact at N House, the local authority put in place protocols setting out the basis upon which contact could take place. JR said that she had done this because of the escalating problems with E's behaviour at N House and in order to try to make arrangements which would enable contact to take place. She rejected the suggestion that the wording of the protocol was inappropriate and designed to cast E in a bad light. The Head of Adult Services, MW, denied that the local authority had an agenda to assert power over the family because it was providing funding for the family. It was his evidence that, with the deputyship, E had adopted the position of wanting to be in total control.

The parents' response

205. In response to all these allegations by care home staff and the social workers, E, supported by A, asserts that she has done nothing wrong other than fight for her son's best interests in a reasonable way. She asserts that all three residential homes have been neglectful in their care of M in different ways and set out to undermine her relationship with her son. She is particularly critical of Y House, complaining that he acquired fungal infections and ringworm, was unshaven and

unwashed and generally unkempt and that his clothes were shrunken and creased and stained. She describes Y House in her final statement as:

"a very unhealthy place, with constant outbreaks of infection and diseases, such as Swine Flu, MRSA and pneumonia, and having communal areas that were filthy. Activities were ill-planned or ill-thought through."

She also said that Y House was "utterly dysfunctional", with frequent changes of senior staff, and said that the home provided, at best, a minding service based on the convenience of staff. The quality of care at Z House is not criticised in quite the same terms, but the parents assert that over time the staff there came to adopt the local authority's agenda. It is the parents' case that the local authority has put pressure on the agencies which run the various homes where M has lived to provide evidence that fits the authority's agenda of removing E's deputyship and gaining control over M. It is also their case that, far from E being controlling, it was in fact the managers of the homes, in particular PL at Y House and CH at Z House, who were seeking to control the lives of the residents.

206. In her statement finally filed towards the end of the hearing, E reiterated and expanded her case set out during the hearing and during her questioning of various witnesses: she asserted that the aim of the local authority was "to dehumanise me and render me irrelevant." Various reasons for the challenge to her deputyship were alleged in this statement, including a mutual interest and a tension between the local authority and service providers to conceal service failures; to prevent the involvement of the CQC; to misrepresent M as more able than he is; to enable the local authority to take over decision-making powers in respect of M; to prevent E and A escalating their complaint at the way in which their complaints had been investigated; retribution for the local authority's loss of credibility following the various earlier judicial review proceedings; and various financial reasons, including gaining access to M's benefits.

Discussion.

When evaluating the evidence at this point I cannot avoid having regard to the way in which E cross-examined the various witnesses. At times I found her manner towards the witnesses intimidating, in particular to the junior members of staff, such as AR and KH, but also towards CH and, indeed, JR. During her cross-examination of JR, in particular, E became increasingly strident and angry, accusing her, for example, of violating her deputyship behind her back, using M as a pawn to get at E over the last three years and of getting to know him better so that she could, in E's phrase - "kidnap him". JR calmly denied all the increasingly extreme allegations put to her by E.

- 208. In contrast, E adopted a different tone while examining MS, the social worker allocated to the case in the first few months after M went to Z College. MS was a notably assured witness who was not at all intimidated by being cross-examined by E. She rejected the suggestion that she had been motivated against E and A because her husband had been passed over for promotion in favour of A. She described how E had become angry with her. E then became agitated, accusing her of telling lie after lie. MS remained calm. She denied that she had been pursuing any agenda or that she had retaliated against E after a complaint against her had been made. In her final statement, E described MS as "a very nasty, incompetent and unprofessional person." In her supplemental closing submissions filed this morning, E asserts that, "The social workers' obsession is to punish me" and adds that "they seem to take a sick pleasure doing so."
- In assessing the witness evidence, I take into account that not every 209. relationship between E and a professional is fraught with difficulty identified by the local authority. Although there has been little evidence about it, I am satisfied that the relationship between E and the staff at X College was mostly better than her relationship with the social workers and care staff. In her final statement, E says that she and A both had "an exceptional working relationship with everyone throughout M's 13 years of specialist education." Another example is their relationship with the family GP, Dr W. Having heard Dr W in oral evidence, it is clear to me that his relationship with E was more subtle and nuanced. He had no concerns from his own experience that M was coming to harm in her care and he appreciated the great challenge facing any parent looking after an autistic child. He was critical of E's inaccurate use of medical terminology when describing M's symptoms, and he adopted what he described, as I have already said, as a defensive approach. So far as I can see, whilst he tried on a number of occasions to dissuade E from taking a certain course, there was no occasion when he challenged her outright on any issue that mattered. As a result, they maintained a relatively good relationship. The local authority and the Official Solicitor submit that the reason for E and A's reluctance to agree to M having a local GP when he was living at Y House was because they found Dr W to be emollient and unchallenging. E has also been on excellent terms with a number of alternative practitioners, but I am satisfied that is because they have not challenged her but rather tended to support her uncritically, reinforcing her beliefs and in some cases feeding her anxieties and prejudices.
- 210. I also take into account, importantly, that all parents who, after caring for a disabled child for many years decide that he should move into residential care, must find the transition very difficult. It is not surprising, having had no dealings with social services at any stage in their lives, that the involvement with the local authority in 2007 and onwards has required E and A to make adjustments. Many people who are obliged to seek the assistance of social services find it irksome

and bureaucratic. At home the young person will have received devoted personal attention. He will have been the main focus of his parents' lives. They will have done everything within their power to give him whatever he needed in his best interests. It is inevitable that, however well run a residential home, the move into residential care will involve making compromises. The quality of care will not be quite the same, the attention will never be quite as personal and there will not be quite the sense of devotion that a parent can give. Such a move will be very difficult, particularly in the case of a home catering for disabled adults, each of whom will have different and special needs.

- 211. I do not doubt the devotion which E and A feel for their son. In some ways his life at home was far richer than could possibly be achieved in any care setting. The range of activities arranged for him was plainly very stimulating and beneficial. I am sure that in some respects the quality of care given to M at the three residential homes was inferior to that he received at home. In such circumstances, it is only to be expected that parents may complain about some aspects of the care offered to their beloved son. A degree of criticism would not be surprising and, indeed, would be expected, but the level of complaint and criticism, in particular of Y House, goes far beyond what might normally be expected and far beyond what is supported by most of the evidence, in particular the evidence of LG, a very experienced local authority senior social worker, whose evidence I accept. I find that the level of criticism made by E and A is grossly disproportionate and unjustified.
- I should record one minor point on which it is appropriate to criticise JR, arising out of the instruction of Dr Delamont. He prepared a report at an early stage of the proceedings and it was the local authority's case that this had been at the instigation of the parents. E and A denied that this was so, and when an inquiry was made of Dr Delamont, who did not give oral evidence, he replied that the request had come from JR. JR subsequently apologised for misleading the court and the parents on this and explained in a further statement that she had forgotten about a conversation with Dr Delamont. I accept her apology and her explanation. I do not find that she was deliberately concealing information from the court. In any event, this is a relatively unimportant detail in the wide-ranging issues in this case.

Conclusion on the issues involving local authority and care home staff.

213. Having heard a number of witnesses, I am now in a position to form a clear view as to what has happened with regard to these issues. Without exception, I accept the evidence of the social workers and care staff. Where their evidence conflicts with that given by E, I prefer their evidence and reject that given by E, and indeed A. I find that E has not told the truth about a large number of matters. For example, I find that she has grossly exaggerated the deficiencies in the

standards of care at Y House. I am sure that they were not perfect, and no doubt some care staff were better than others, but the picture painted by E in her evidence is completely distorted and inaccurate. I find that she repeatedly referred to her deputyship in dealing with social workers and staff, including when speaking to CH, in order to impose her will. I find that staff and some residents at Y House, Z House and N House have found her difficult and intimidating.

- 214. I accept KH as a witness of truth as to his accounts of dealings with E and, in particular, his accounts of phone conversations after M was removed from Z House. E and A assert that KH has a tendency to elaborate and sensationalise situations. I exonerate him from this charge. I found KH to be a careful and truthful witness who was plainly motivated only by concern for M. I accept his evidence as to the content of his phone calls with E in the months after M left Z House. As those phone calls demonstrate, it is in fact E who has a tendency to elaborate and sensationalise situations. conclusion of the evidence, E sought to introduce extracts from her diary which, although alluded to in the course of the hearing, had not been disclosed, which purported to support her account of her dealings with KH. I do not accept that these extracts from the diary, if genuine, undermine the reliability of KH's evidence. I accept AR's accounts of how she found E's behaviour difficult and threatening at N House.
- 215. I reject E's account that she never received the emails sent by LG after M was removed from Z House. There are a number of email exchanges in the papers - see, for example, at N600 to 618 - in which her email address has been written in exactly the same way as in the emails to which LG referred and to which E has responded. E's explanation about this was wholly implausible and I have found it to be untrue. I found that she did receive these emails and chose not to respond. I find that E has a fanatical desire to maintain control over her son's life and there is little she will not do to achieve it. I find that E has restricted the access of professionals to M, for example, by seeking to prevent the staff at Y House from speaking to the local authority social workers, by scuppering the proposal that he should have an advocate and by refusing to allow him to be registered with a GP local to Y House. E's practice is to look for professionals and others who are biddable and compliant and then use them for her own ends. She bombards professionals with written instructions and emails in order to get her own way. If challenged, she will threaten and intimidate and, if that does not work, she will launch a professional complaint.
- 216. Furthermore, E's attitude to professionals led her to secretly record conversations with a number of those instructed in this case, including Dr Beck, Dr Adshead and Mr McKinstrie. All were highly critical of her acting in this way. Dr Adshead described this as a symptom of a state of mind associated with mistrust and antagonism. Dr Beck said that this level of mistrust was an element of E's narcissistic personality

disorder. Mr McKinstrie described it as "highly unethical". He added that to record a conversation that he had had with M was more than unethical. As Mr Bagchi observed in closing submissions, E:

"is simply oblivious as to why secretly recording all of these professionals is seen as wrong. She cannot really see what all the fuss is about. In her view of the world, it is a necessary safeguard to those who would conspire to do her down."

- 217. Moreover, I find that E has grossly abused her position as deputy, to control M's life and to restrict the roles of the professionals. Indeed, I find that this was the very reason why she sought to be appointed deputy in the first place as her application asked to be appointed his "lifelong custodian" and specifically asked the court to decide that "lifelong advocacy is also included in this role unless otherwise delegated by me." She expressly said in the application that she wanted to be able to take decisions "without the influence of external pressures or distractions". This is completely contrary to the underlying purpose of deputyship under the 2005 Act, as described in the Code of Practice and previously reported cases.
- 218. I reject the parents' case that the local authority has been motivated by a desire for revenge after the outcome of the judicial review proceedings, or by a desire to get control of M and his money. The social workers have not been vindictive, nor malicious, nor cruel, nor vengeful, nor callous. They have tried to do their job, meeting the local authority's statutory responsibilities to M, in the most difficult circumstances, caused entirely by E's completely unreasonable behaviour. In 35 years of family law and in the Court of Protection, dealing with many hundreds of families, I have rarely, if ever, come across someone who is so difficult to work with, who presents so many challenges to hard working professionals and who takes up so much of their valuable time and resources.
- 219. I therefore make the findings sought by the local authority: that E controls all aspects of M's life and does not allow him to develop his independence, restricts access to M and information about M and is unable to work with professionals. In closing submissions, Mr Bagchi submitted that this degree of control was unnecessary, unreasonable and constituted a suppressing effect on M's life. I agree.

FACTITIOUS DISORDER

- 220. I therefore return to the question of whether this is a case of factitious disorder imposed on others.
- 221. Dr Adshead provided some background information about this disorder. She advised that it is not a diagnosis of an illness from which people "suffer". The term is, rather, used to describe highly abnormal behaviours in relation to health care professionals,

demonstrated by a person who has responsibility for another person. To date, such abnormal behaviours have been most commonly described in mothers who have care of dependent children, but they have also been seen in nurses and in those who have care of the elderly and other vulnerable adults. In essence, the key feature of the disorder is that the person who has care giving responsibility elicits professional health care in one of the following abnormal ways.

- (1) The carer gives exaggerated accounts of symptoms and does not accept results which suggest that nothing is wrong.
- (2) The carer gives false accounts of nonexistent symptoms that are not observed by others and do not occur when the dependent person is away from the care home.
- (3) The carer fabricates symptoms, for example, by putting blood or other contaminants in bodily fluids used for medical investigations.
- (4) The carer actively makes the person for whom they are responsible ill, usually by some form of direct or indirect behaviour that causes physical harm and then is presented or described as symptoms.
- Dr Adshead advised that abnormal behaviour of types (1) and (2) is 222. probably common and may go undetected. The commonest forms of abnormal behaviour are giving exaggerated or false accounts of symptoms. There is, obviously, an overlap of those mothers who have unusual levels of health anxiety, who tend to misinterpret any symptoms as a sign of dangerous illness. Abnormal behaviour of types (3) and (4) are probably less common and are detected by clinicians who are familiar with some of the recent presentations in the literature. Detecting these behaviours is, however, often extremely difficult. The commonest presentation is by a mother of a young child with limited verbal ability. Perpetrators are not typical of criminal offenders in general or even other maltreating parents. They often have features of good mental health and physical health and no previous contact with the criminal law. Dr Adshead stresses that it is important to emphasize that perpetrators do not "have" factitious disorder; they are exhibiting behaviours which may or may not be associated with a psychiatric diagnosis. In one study half the mothers were recognised as showing abnormal illness behaviour on their own account and slightly over half were diagnosed with having a borderline However, a substantial sub-group had no personality disorder. underlying psychiatric diagnosis and it is important to emphasize that there is no direct connection between any psychiatric diagnosis and this behaviour. There is little published evidence available on the treatment of perpetrators. They tend to deny any such behaviour and disclosure and acceptance usually takes place over time in the context of support and therapy. If there is an identifiable mental disorder, then treatment of this probably increases the chance of an ongoing

relationship with the child. However, it has been described by Dr David Jones, the well known child psychiatrist, that abnormal illness behaviour by proxy is a bad prognostic sign in terms of family reunification.

- 223. If it was established that E has exaggerated M's condition and/or made false claims about illnesses that he does not have and/or given him medication that was unnecessary and/or obstructed a normal relationship with health care professionals, Dr Beck and Dr Adshead both concluded that it would then follow that factitious disorder imposed on other people has taken place. Both Dr. Beck and Dr. Adshead observed that the degree of contradiction between E's claims and the medical records record indicates a pattern of abnormal illness behaviour which seems to have escalated in the last few years. The nature of the diagnoses put forward are couched in increasingly dramatic narrative terms but are not supported with corroborative medical evidence.
- 224. Dr Beck believes that the underlying driver for the mother's factitious disorder is that she is suffering from narcissistic personality disorder. Dr Adshead agrees with Dr Beck that there are significant features of personality disorder in E's presentation, mainly narcissistic and histrionic features, and, in addition, Dr Adshead suspects that she may have some feature of an emotionally unstable personality disorder. As a psychiatrist, Dr Adshead reported that she had seen no evidence that E suffers from a severe mental illness. Dr Beck and Dr Adshead both thought that M's health care and his identity as an illness sufferer is a key part of his mother's relationship with him and that M's health status clearly dominates that relationship. Dr Beck expressed the view that the mother's desire to find other people to blame appeared to serve functions for her. First, it distracts from her own shame (self-imposed) and, secondly, it draws attention to her and her own needs. Dr Beck concluded her first report by observing that, whilst she did not doubt that E loves her son, she does not believe that she is capable of putting his needs above her own.
- 225. Dr Adshead advised that, if the facts are proven that support the accounts of factitious disorder imposed on another, together with a diagnosis of personality disorder, this provokes questions of further future risk and how the relationship between carer and a dependent other should be managed in the future. In her experience, the risk of harm to the dependent other is real, especially if the carer has no insight, although the nature of the harm may not necessarily be severe or dangerous. Having seen there is a real risk, it should be fairly clear that the risk can be managed if E is prevented from being the person responsible for M's care. Once a carer is removed from the role of a carer, there is usually no danger in the carer and the dependent other spending time together. Dr Adshead advises, however, that in such circumstances there must be a proper health care plan put in place, overseen by a senior health care professional. It is Dr Beck's

- recommendation that all of M's health needs hereafter should be overseen by the local authority. Dr Beck agreed that there would be the real risk of an emotional mental and physical nature were M to return to live with E. She also believed that M's access to opportunities to make choices and grow as an individual would be curtailed.
- 226. I accept the opinion evidence given by Dr Beck and Dr Adshead. I find that E's behaviour amounts to factitious disorder imposed on others. It was suggested by E in the course of the hearing, relying on material available on the internet, that the diagnosis was made without justification, as a means of attacking mothers of children with autism with a view to removing them from their care. I have no reason to believe that there is any basis for this assertion, but it certainly does not apply in this case. I am sure that the diagnosis of factitious disorder in this case is valid.

ORDERS

- 227. Whilst it would be desirable to make final orders and bring these proceedings to an end, I have concluded that that outcome is not possible at this stage. The course I propose to take is to make further interim orders and list the matter for review once the parties have had a chance to digest my findings on a date in the week of 8th September, in London, to be fixed by the Clerk of the Rules in consultation with counsel's clerks, with a time estimate of two hours. In view of the complexity of this case, further interim orders may then be required postponing the final decisions to a later date.
- 228. In making decisions as to M's future, I remind myself again that I must have regard to the principle that such decisions must be made in M's best interests and I must apply s.4 of the Act in so far as it is relevant to this case. I must have regard to M's wishes and feelings, to his beliefs, to the beliefs and values that would be likely to influence his decision. In view of his limited capacity as analyzed above, I accept Mr McKinstrie's opinion that it would be unwise to form any opinion as to his wishes based on a single remark or when he has been encouraged to express particular views. What is known is that he has not expressed a consistent wish as to where he wishes to live in the future. I accept that family life is important to him, as is the aim of helping him to achieve his maximum potential. The court must also have regard to the views of his family. E and A wish their family, culture and values to be respected and for M's right to a family life to be upheld. They ask that as soon as possible M be returned to the family home.
- 229. Mr McKinstrie identifies several advantages of a return home. First, M clearly has a longstanding affectionate relationship with his parents and sister and they continue to be important people in his life. Furthermore, each is committed to M and in supporting him in what they consider to be his best interests. The family home is a known

environment for M and he has established routines that are familiar to him. Furthermore, if he went home he would be able to access activities in the community that he has previously attended and enjoyed. As Mr McKinstrie recognises, however, these advantages are manifestly outweighed in this case by the disadvantages which flow from my findings. It is inevitable that, were M to return home, he will be subjected to the same regime as before in which his mother sought to reimpose control over all aspects of his life. Furthermore, it is likely that she would continue to misrepresent his state of health and expose him to unnecessary examinations and treatments. It is inconceivable that M could return home unless E demonstrates a fundamental change of attitude.

- 230. I accept that A and S are devoted to M and want what is best for him, but I conclude that they are completely under the influence of E as to what should be done, blind to her faults and, therefore, unable to protect M from the risks that would arise were he to return home. As Mr Bagchi observed in closing submissions, A has become so enmeshed in E's view of the past that he has been unable to protect M from his mother in the past and his lack of insights into her difficulties and the risks she may present offers little confidence that he would be able to do so in the future. As for S, it is notable that she has not played any active part in these proceedings until late in the day. I am unclear about S's role and position in this family in recent years. This is a matter which may merit further investigation by the local authority in due course.
- As to the alternatives, Mr McKinstrie reaches the clear view that a 231. move to W House is the best option for M. It is a large, detached house with four floors each of which has their own separate living space. There is also a shared communal lounge for the whole house on the second floor. There is capacity for up to 12 residents. The intention is for each floor to have people with similar needs to each other. People with the most complex needs are to be on the first floor, whereas the two bed-sits on the top floor will be available for people with more ability. It is proposed that, were he to move to W House, M would occupy one of those two bed-sits. Within each bed-sit there is a kitchen range, a sofa and a single bathroom to be shared between the two bed-sits. W House is intended to support young people at a transitional stage of their lives. A quarter of the staff are already in post and the rest are being recruited. The plan is to build a permanent staff team so that the property does not have to depend on temporary or agency staff. It is not proposed that W House should be a permanent home. It has been set up with the intention of assessing and assisting young people to maximise their potential to live as independently as possible and then support them to move to live in supported housing or similar in the community.
- 232. Mr McKinstrie does not consider that there are benefits for M continuing to live at N House for any longer than the short-term. W

House is managed by the same provider as N House and so this would provide some continuity in the approach, care and support. The current staff at W House have spent time at N House and have therefore become familiar with M. W House is more spacious than N House and able to offer M a greater variety of living areas. M spent time at the property and staff at W House and family members have begun the process of building relationships focused on M. Finally, W House is relatively close to the family home and would provide M with the opportunity to renew some of his local activities and contacts, as well as making contact with his family easier.

- 233. There are some disadvantages to W House perceived by Mr McKinstrie. It is a larger property, so there would be times when the environment is busy and noisy - a disadvantage to M given his acute perceptual awareness. In addition, W House is a new, untried residential unit and the staff are new and still being recruited. Furthermore, it is not known who the other residents will be and, in particular, there is no other person yet nominated for the second bedsit on the floor where M will live. The size of the staff group and the number of residents may mean that he is not always supported in a person-centred way as would be desirable. Overall, however, Mr McKinstrie indicated that he thought the benefits of a placement at W House outweighed the risks. The property is intended to support people of his age and ability, the stated ethos is to encourage young people to move on and to be able to live more independently, consistent with the long-term plan for M. The bed-sit property seems particularly ideal for that purpose. It would be a long-term planned placement for M and potentially allow for stability to enable him to move in a further planned way into supported living accommodation within two years. Living at the property would provide him with the option of attending day services that he has attended in the past and revisit past friendships.
- 234. In his oral evidence, however, Mr McKinstrie added that M should not move to W House until certain things had been established. First, it was important that a significant number of other residents move into W House first and that a full complement of staff be recruited and trained, routines established and teething problems overcome. In addition, there should be a rigorous care plan approved by the court. None of these steps have yet been achieved so, relying on Mr McKinstrie's oral evidence, the Official Solicitor suggests that it is premature for the court to sanction a move to W House.
- 235. In the course of the hearing the local authority, which had initially been very supportive of a move for M to W House, became increasingly concerned about the relationship between E and the manager of the home. In final submissions, Miss Bretherton indicated that the local authority did not support an immediate move but proposed instead that the local authority be given time to explore other

options. It is the ardent wish of E and A that M move to W House as quickly as possible.

- 236. I have decided that it is too soon for the court to reach a conclusion whether it is in M's interests to move to W House. The next move will undoubtedly be of crucial importance. If it is, indeed, the aim that he should move into a form of supported living and happily this is one issue on which all parties seem to agree it is vital that his next residence should be able to equip and prepare him for that move. W House may be the best resource to achieve that and it has the added advantage that it is close to his home so that, if he moves there, contact arrangements will be easier and he will be able to access some of the activities he enjoyed when living at home. But I accept the views of Mr McKinstrie, the Official Solicitor and the local authority that, for different reasons, now is not the right time for such a move.
- 237. I have therefore decided that, for the time being, he should continue to reside at N House. I have thought carefully about the strong views of his parents that he should not stay there. Having considered all the evidence, including that of Mr McKinstrie, it seems that it is better for him in the short-term to remain there. Although it is not an ideal place for him, I do not accept that he is suffering harm there and I agree with Mr McKinstrie that a precipitous move to W House will be counterproductive. This placement is intended only as a short-term option while decisions are taken as to where M should live in the medium-term pending a long-term move into supported living, as supported by all parties, it seems.
- 238. This court has not been addressed at this hearing on the question whether or not his current placement amounts to a deprivation of liberty. I do not propose to analyze that issue in this judgment. Instead, I shall simply declare that in the interim, in so far as the placement amounts to a deprivation of liberty, the same shall be lawful. In their final submission, E and A asked that the

"DOLS [by which they mean the Deprivation of Liberty Safeguards under Schedule A1 of the 2005 Act] imposed upon M is removed whatever the outcome of these proceedings and with immediate effect as M does not deserve this. It is shameful that this was insisted upon by those who purport to have his best interests otherwise."

I do not understand this submission. The purpose of a declaration that M is being deprived of his liberty is to protect M, not stigmatise him. If necessary, this issue can be revisited at the next hearing.

239. So far as contact is concerned, I note that, following the difficulties that arose at N House, arrangements were varied so that contact now takes place once a week for four hours at W House and a further session for two hours within the community near to N House at

weekends. Mr McKinstrie noted, and I agree, that it is clear that, since contact moved away from N House, it has been a less intense and more constructive experience for all concerned. There continue to be tensions, but they are at a lower level and supervisors have been able to manage things differently by having an external focus to the contact. I agree with Mr McKinstrie that it would be in M's best interests for contact to continue to take place in the community.

- 240. As for the future, Mr McKinstrie stresses that E, A and S continue to be significant people for M and it is important and in his best interests to be supported to maintain these relationships. He warned, however, that contact will only continue to be in M's best interests if it is not secondary to or subverted by tensions between E and others. Mr McKinstrie advises that contact should be face to face rather than indirect and there should be a clear understanding between all parties that contact sessions are to allow M and family members to spend time together, that there should not be any discussion during contact of how M is cared for or supported or his health or other issues concerning his future plans. Furthermore, Mr McKinstrie advised that contact should continue to be supervised directly to mitigate any potential risk to him from the arrangements and ensure that the conditions attached to contact visits are followed. Supervision should only be relaxed as a result of a review of arrangements and when there is confidence that all parties are able to maintain the conditions attached to contact. Mr McKinstrie does not at this stage consider that contact should take place at the family home.
- On the issue of supervision, Dr Beck expressed a different view. She 241. advised that, if no observer was present at contact and E were allowed contact only on the basis that she was fully compliant with a set of guidelines, Dr Beck thought that E would be much less able to exercise control or protection. She would therefore be interested to see how short periods of unsupervised contact between M and his family worked. She thought that unsupervised contact in a fixed place was less likely to be antagonistic to E. I understand Dr Beck's point but on the issue of supervision I am firmly of the view that Mr McKinstrie is right and that all contact should for the time being remain supervised. Until the next hearing M should continue to have supervised contact with his parents twice a week as he has done in the course of this hearing. I also agree with Mr McKinstrie that the local authority should carry out a risk assessment of all contact arrangements. There should be a contact agreement signed by all parties and a clear process for reporting and monitoring the work of the arrangements.
- 242. I turn to the question of deputyship. It is plain from my findings that E has grossly abused her position as deputy, and there is no question of her being reinstated. She is the last person who should be entrusted with that responsibility, and her application to be restored as deputy is refused. The question arises whether there is a need for a deputy to be appointed at all, either for M's personal welfare care or for his property

affairs. Both the local authority and the Official Solicitor question the need for any deputy having regard to the legal framework in the Mental Capacity Act and the guidance in the Code of Practice and previous reported cases.

243. So far as property and affairs are concerned, I agree that a deputy is probably otiose. M's financial affairs are relatively straightforward and can be managed by an appointee. I therefore invite the parties to identify, and if possible agree, an appointee. So far as a personal welfare deputy is concerned, I reiterate what I said in <u>G v E</u>, at paragraph 58, that:

"The vast majority of decisions concerning incapacitated adults are taken informally and collaboratively by individuals or groups of people consulting and working together."

In view of the very great difficulties that have arisen between the parents and various professionals in this case, I foresee that similar difficulties will arise in future, so that the normal process of decisionmaking through collaborative working together is unlikely to occur. Paragraph 8.39 of the Code of Practice makes it clear that the appointment of a deputy may be required, inter alia, where there is a history of serious family disputes that could have a detrimental effect on the person's future care unless a deputy is appointed to make necessary decisions, or where the person who lacks capacity is felt to be at risk of serious harm if left in the care of family members. Mr McKinstrie advises that the relations between E and social care and other professionals are likely to remain difficult due to the fundamental disagreements between them as to what constitutes M's best interests in virtually every aspect of his life. I agree. I doubt whether E is going to change her attitude as a result of this judgment. Indeed, in so far as her attitude is determined by her personality disorders, she may be incapable of changing without long-term therapy. It is plainly impossible for the Court of Protection to take these decisions. It seems to me that it is, therefore, highly likely that a deputy will have to be appointed for M's personal welfare. I shall not make a final decision on this issue at this stage, however, and, therefore, adjourn the question whether a deputy should be appointed to the next hearing. I ask the parties to reflect on this matter in the light of my findings and the rest of this judgment and at the next hearing make further representations as to whether there should be a deputy and, if so, the identity of that person and the terms of appointment.

244. Mr McKinstrie made some sensible suggestions about the practical arrangements for future decision-making in this case. It is important to remove as far as possible the opportunity for misrepresentation by any party. To assist in achieving this, all communications should be formalised and recorded. E and A should be a party to relevant information concerning M and should receive any formal communications that concern him. They should also be included as a

- matter of course in any formal assessments or reviews of his health and social care needs and in planning for his future, with their views taken into account as part of those processes.
- 245. The local authority and the Official Solicitor suggest that Dr W should no longer be M's GP, on the grounds that he has been over-influenced by E and that there is a possible conflict of interest as he remains E's own GP. The issue does not arise for consideration at this stage as M will remain at N House for the time being and should, therefore, remain registered with his current GP. The question of who should be his GP in the event that he returns to a placement nearer to the family home can be decided at a later hearing.
- 246. It is unnecessary for the court to make any detailed decisions as to M's health management at this stage. I shall give directions as appropriate for a supplemental report on that issue to be prepared for the next hearing. At this stage I merely give these directions. First, as just stated, I direct that M should continue to be treated by the GP local to N House as necessary. Secondly, I conclude that he should receive a tetanus booster injection if in the opinion of the GP such an injection is in his best interests. His parents are opposed to all vaccinations, but their opposition stems from their erroneous view that his autism is attributable to the MMR and that he is the victim of what E calls "vaccine assault". There is no objective reason why M should not have an updating tetanus inoculation and, if he is going to take part in outdoor activities such as farm visits, there would seem to be every reason why he should have it. If his GP recommends that he has the booster injection, then this court will give its approval. Thirdly, I direct that his diet shall be in accordance with the practice at N House and any recommendations by his GP. I am sure that the staff at N House will allow M an element of choice as to what he eats - that being an issue on which, as Dr Khouja and Dr Carpenter have found, he has limited capacity. I would be grateful if counsel would draw up an order reflecting these directions and submit it to the Clerk of the Rules by 4 p.m. on Thursday 14th August, with a request that it be forwarded to me.
- 247. There are three residual matters that I should mention, about which I am not making orders, at this stage, despite requests from the parties. First, there are ongoing financial issues between the local authority and the parents. Those have not formed a central part of this hearing and I make no findings or orders about them at this stage, but I foresee that they may have to be considered at the next hearing or in due course.
- 248. Secondly, E and A seek the lifting of what they call the "gagging clause", namely, the order made at the hearing on 11th March 2014 and subsequently renewed, that they should not publish or disclose any information relating to the proceedings to any person, including any media organisation, save for their legal representatives. For the time being that order will remain in force, but I will in due course hear

submissions that any party wishes to make as to the lifting of that provision and as to the lifting as to the confidentiality which attaches to all Court of Protection proceedings unless otherwise ordered, and also as to the imposition of any further injunctions. I remind all parties that the proceedings in the Court of Protection are held in private and information may not be disclosed without the court's permission. I also indicate that I propose that a transcript of this judgment be published in accordance with the President's recent guidance, suitably anonymised to protect M's privacy.

249. Thirdly, E and A have requested that the court takes steps to recommend an independent inquiry into the use in this country of the Urabe strain of the MMR vaccine. I suspect that part of their aim in this litigation has been to bring about such an inquiry. I do not propose to make any such recommendation, not least because, as I have found, M's case has nothing to do with the MMR vaccine, save in the false accounts given by E. Suffice it to say that nothing has emerged in the course of this case to undermine the prevailing view quoted above that the overall evidence clearly indicates no association between the MMR vaccine and autism.

CONCLUSIONS

- This court acknowledges the enormous demands placed on anyone 250. who has to care for a disabled child. Even though such carers are motivated by love - and I accept that both E and A love M and are deeply devoted to him - the burdens and strains on them are very great. Every reasonable allowance must be made for the fact that they love their vulnerable son and want the absolute best for him. Every reasonable allowance must be made for the impact of these burdens and strains when assessing allegations about the parents' behaviour. However, having made every reasonable allowance for those factors, I find the behaviour exhibited on many occasions, by E in particular, was wholly unreasonable. I agree with the insightful observation of the independent investigator appointed to consider the parents' complaints in 2010 quoted above. E and A do feel that their mission has meant having to fight every inch of the way, against health and legal services and, more recently, social care services. This has influenced the extent to which they are able to work in partnership with statutory agencies. As they have such clear ideas about all aspects of M's life and believe the conclusions they have reached about him are correct, it is understandable that they have had difficulty in accepting the views of others where they differ from their own. However, their attitude and approach has far exceeded anything that could be considered as reasonable.
- 251. E's friends admire her determination to stop at nothing to get M the care, support and long-term achievement he deserves. Unfortunately, I find that this determination has led her to behave in a devious and destructive way, relentlessly criticising, occasionally bullying,

repeatedly complaining about those who do not follow her bidding. Throughout this hearing she has repeatedly accused the local authority of pursuing its own agenda. I find that it is she who has an unshakeable agenda to follow her own course in pursuit of her own beliefs about M's condition and how it should be treated.

- 252. E's allegations of multiple conspiracies are a fantasy. It is nonsense to suggest that there has been a conspiracy by large numbers of the medical profession to conceal the truth about the MMR vaccine. It is ridiculous to suggest that the local authority has pursued a vendetta against E and set out to remove M from his family for financial reasons and that the staff at the various residential homes have fallen into line and in some cases perjured themselves under financial pressure from the local authority. It is delusional to suggest that the Official Solicitor has been motivated in this case by an agenda designed to prevent a revival of the claims arising out of the MMR and to that end suborned experts. The tone of these outlandish claims by E has become increasingly more strident as the case progressed, culminating in the documents filed after the conclusion of the hearing in which she expresses outrage at the conduct of the local authority and the Official Solicitor at the hearing on 6th March, in terms that are barely coherent. In their final submissions, E and A have made a number of further attacks on the integrity of the Official Solicitor, all of which I reject. It is unnecessary to go into any further detail. They are wholly misconceived.
- 253. The critical facts established in this case can be summarised as follows. M has autistic spectrum disorder. There is no evidence that his autism was caused by the MMR vaccination. His parents' account of an adverse reaction to that vaccination is fabricated. The mother has also given many other false accounts about M's health. He has never had meningitis, autistic enterocolitis, leaky gut syndrome, sensitivity to gluten or casein, disorder of the blood brain barrier, heavy metal poisoning, autonomic dysautonomia (which, in any event, is not recognised in any classification of medical conditions), rheumatoid arthritis or Lyme disease. As a result of E maintaining that he had these and other conditions, she has subjected M to numerous unnecessary tests and interventions. He did have a dental abscess for which E failed to obtain proper treatment and caused him 14 months of unnecessary pain and suffering. E has also insisted that M be subjected to a wholly unnecessary diet and regime of supplements. Through her abuse of her responsibility entrusted to her as M's deputy. she has controlled all aspects of his life, restricted access to him by a number of professionals and proved herself incapable of working with the local authority social workers and many members of the care staff at the various residential homes where M has lived. This behaviour amounts to factitious disorder imposed on another. In addition, E has a combination of personality disorders - a narcissistic personality disorder, histrionic personality disorder and elements of an emotional unstable personality disorder.

254. Despite her serious conclusions about E's personality, it is Dr Beck's view that these parents have a lot to contribute to their son if they are capable of offering the care and support he needs under the guidance of an overarching programme of care coordinated by the local authority. I agree that they would have an enormous amount to offer their son if they could work in collaboration with the local authority social workers and other professionals in M's best interests. I have not given up hope that this may be achieved. Such an outcome would be manifestly to M's advantage. It will not be achieved, however, unless E and A – in particular, E – can demonstrate a fundamental change of attitude. If this does not happen, this court will have to take permanent steps to restrict their involvement in his life.

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