Neutral Citation Number: [2005] EWHC 1894 (Admin)
Case No: CO/0234/2005

IN THE HIGH COURT OF JUSTICE
QUEEN'S BENCH DIVISION
ADMINISTRATIVE COURT

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 26 August 2005

Before :
Mr Justice Collins
- - - - - - -
Between:

Rachel Gunter (by her litigation friend and father Edwin Gunter) — Claimant

- and -

South Western Staffordshire Primary Care Trust — Defendant

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Mr Ian Wise (instructed by Messrs Irwin Mitchell) for the Claimant
Mr Roger McCarthy Q.C. (instructed by Messrs Mills & Reeves) for the Defendant

Hearing dates: 4 & 5 July 2005
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Judgment

1. The claimant is now 21 years old. She had had problems with her eyesight throughout her childhood, but it was not until 1999 that the sudden development of a squint prompted a scan and the diagnosis of a tumour which needed immediate surgery. The surgery carried a high risk and unfortunately the claimant suffered two major strokes. She sustained damage to over seventy percent of her brain and is permanently blind. In addition, a substantial portion of the tumour remains and no further surgery is possible. However, her expectation of life is not apparently affected.

2. In addition to these problems, the claimant suffers from a rare form of diabetes. Diabetes Insipidus is a complex condition which requires careful administration of medication. The claimant's brain injury removes the option of self administration. She is incontinent of urine and unable to feel thirst with the result that she can easily become dehydrated. The diabetes can only be managed if there is a correct fluid balance. Her blindness adds to the difficulties and its cause has interrupted and affected the normal production of the hormone ADH which also makes her diabetes harder to manage.

3. As a result, the claimant needs constant nursing care. A life threatening crisis can arise at any time and only a skilled and well trained nurse can detect any warning symptoms (there may be none) and deal with a crisis, which will involve the administration of appropriate medication. It is accepted that the necessary attention and medication must be provided within a period of no more than about 5 minutes. In the result, qualified nursing care is required 24 hours a day. And it is common ground that she needs one to one nursing care at all times.

4. In 2000 the claimant was transferred to a Rehabilitative Centre. This was not a success. She was then looked after at home with the help of Mencap support staff for a time. Her parents were acutely aware of the need for her to have mental stimulation and so to attend some educational establishment, but no college willing to take her with her particular needs could be found. Finally, in October 2003 the claimant was admitted to the Head Injury Rehabilitation Centre in Bath. She was a weekly boarder there, returning home at weekends. The stay in Bath resulted in considerable improvements, not least in the claimant's ability to communicate and so to enable her parents and others to understand and to meet her needs. She was encouraged to take more decisions for herself and this in turn increased her confidence. The discharge report from Bath contained the following recommendations: -

> "It will be crucially important that Rachel maintains the progress she has made on the Unit and has opportunities to build on this progress when she is living back at home and engaging in community activities.
>
> Rachel's growth in confidence is fostered by working with her in a particular way. She has benefited from everyday and frequent opportunities to make choices and decisions and from being given physical and cognitive tasks that have greatly challenged her, but at a pace which is perceived by Rachel as compatible and safe. This has enabled her to develop trust in those working with her. A consistent and dedicated community nursing team would be in the best position to maintain and build on the trust and confidence Rachel has developed throughout her admission.
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> As previously indicated … we would recommend a transition period with community professionals to ensure as smooth and as effective a handover as possible …
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> Rachel would benefit from a weekly structure and routine that incorporates college course activities and visit to the local Headway service".

5. The claimant was due to come home in February 2004. Mr Gunter complained that the PCT had not put any long-term care package in place. He was informed that discussions and consultation would take place because a home placement would require a 'considerable investment' and so the PCT would wish to be assured that all options had been fully explored in order to demonstrate best use of NHS funding. Caring for the claimant has placed a severe strain on both her parents (who have separated, but who remain on amicable terms) and her father's health in particular has suffered. Both recognise that they will be unable to maintain an active involvement in the claimant's care for ever, but they will of course want to do all they can for her. There are other family members who have assisted and will continue to assist. But it is clear that the claimant needs

constant expert nursing care and neither of them should be required (save, no doubt, in an emergency) to provide that care.

6. Their concern at the absence of a long-term package led Rachel's parents to instruct solicitors. Care has been provided through a private firm, Allied Health Care Agency. There have been problems. Rachel's parents believe (indeed, Allied have confirmed to them) that the absence of a long-term commitment has made it difficult to find nursing staff who have the necessary qualifications and experience. Suggestions have been made that Rachel's mother has from time to time behaved unreasonably so that some carers have refused to continue to act. Further, it has been suggested that the inability to achieve a long-term solution has been exacerbated by her parent's refusal to co-operate in considering the possibility of Rachel going to residential care as opposed to staying at home. Those suggestions are not accepted. As to the first, it would be surprising if there were not occasional difficulties. Rachel's mother is inevitably under considerable strain and is concerned if she feels that a particular carer is not assisting Rachel as he or she should. The need for consideration on both sides is obvious. As to the second, there is no doubt that both her parents are clear that for Rachel to have to leave home would not be in her best interests, indeed, would be detrimental to her continuing well-being. But they have recognised that Rachel cannot be looked after at home forever and that, as they get older, it may become impossible for her to stay at home. They recognise that cost is a factor which can properly be taken into account. The minutes of a meeting held on 2 June 2004 read: -

> "Mrs Gunter is willing to explore the residential package option as long as it is suitable and appropriate safeguard, can be put in to cover the transition phase".

There may well have been some misunderstandings, one of which related to the defendant's perception that Rachel's parents did not want to involve themselves as her carers. They recognise and have said that they could not be regarded as long-term carers, but that is not to say that they want to cease to be involved. Their only concern, as I understand it, is that they should not be regarded as providers (save in emergencies) in any package which is put in place.

7. I have noted, but have not found it necessary or desirable to seek to resolve, the allegations of lack of co-operation. Litigation often leads to a confrontational approach. In cases such as this, it should if possible be avoided. What matters is Rachel's quality of life and what is necessary for her. I am glad to say that that was recognised in the course of the hearing, and I am particularly grateful to Mr McCarthy, Q.C. for the sensitive and sensible manner in which he put forward his client's case. I am equally grateful to Rachel's parents for recognising that the defendants (despite some unfortunate comments made in witness statements) are also concerned for Rachel's well being, but have to have regard to their obligations to others within their area. In the light of the sensible approach for the future from both sides, nothing would be gained from resolving issues which would have the effect of laying blame on either side.

8. On 11 May 2004, a meeting was held by those concerned to try to determine the future for Rachel. This followed a letter from the parents' solicitors which emphasised the urgent need for a package to be put in place. That letter, dated 8 April 2004, stated that the family opposed any move for Rachel to be placed in a residential home and asserted that "any move to another residential home away from her family would be in breach of Article 8 of the ECHR failing to respect the right to a family life for this particularly vulnerable individual". At that meeting, it was noted that legal advice indicated that "placement in a

residential care home does not of itself infringe any Article 8 rights, as long of course as the placement is suitable and appropriate to the patient's reasonable needs". It was agreed that placement in a care home would not contravene Rachel's Article 8 rights. It was recognised that an experienced qualified nurse had to be "on site" day and night. The conclusions reached were as follows: -

> "The main merit of the home care package is greater parental contact. This has to be counterbalanced with higher risks of poor clinical care and decreased interaction with peer group when compared with other options. The differences between the lowest cost home package and residential accommodation is £150K. The preferred option of the panel is a residential package, as this would provide the best clinical care and the best value for money. The panel wishes to negotiate the package with the parents, as their approval is important. Any assistance that can be provided to parents e.g. travelling costs etc should be explored during negotiations".

9. On 27 May 2004, there was a meeting of the Board to make the defendants final decision. It was agreed that a residential package was the preferred option. The minutes record the final summary and recommendations as follows: -

> "The patient had had problems since birth, having had a tumour removed which had resulted in blindness. The patient also suffered from Diabetes Insipidus and therefore had problems in maintaining fluid balance within the body, and had had several strokes. Care was currently being provided by one parent in the home setting, with private 24 hour nursing support. The need for a long term solution was prompted by the parents wishing to withdraw from "hands on" care.
>
> The four care options considered were a Residential package from the Independent Sector, Home Care in the Community from the Independent Sector, Home Care in the Community provided by an NHS Trust and a Residential Package provided by an NHS Trust.
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> Major issues surrounded the need for clinical care. It was clear that one to one nursing care around the clock was essential and a balanced view had to be found regarding how best this could be provided.
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> Continuity of Care was also an important factor, and the problems of maintaining this within the home setting was considered. It was noted that there was often a high turnover in agency nursing and that a high degree of specialised nursing was required (in some instances, medication being required within as little as five minutes of a problem occurring).
>
> Ultimately the overriding considerations for making a decision were based on the need for patient safety and twenty four hour nursing care, it being essential that the patient was not put at risk by the package put in place to meet their medical needs".

10. The main factors in favour of residential accommodation were cost and the view that there was less risk if a crisis developed and there was a need for immediate specialist attention. In addition, it was believed that there would be greater social interaction in a residential home. I am bound to say that I do not think this supposed advantage will bear close scrutiny having regard to the arrangements whereby Rachel is able to see members of her extended family and friends and is taken to educational and recreational activities.

11. Mr Gunter met with representatives of the defendants on 2 June 2004. I have already noted his expressed willingness to explore residential accommodation. His concern to have an explanation of the perceived risks to Rachel involved in care at home so that he could explore how they might be overcome is noted. It seems that the concern was that, if a carer fell ill or was temporarily unavailable for whatever reason and Rachel needed immediate attention, no one would be available to attend within the 5 minute timescale. At a residential home, a qualified nurse could always be on the premises, even if not dedicated to Rachel's care alone, and so would be available. So long as either of Rachel's parents was present (and there are, it appears, other close family members nearby sufficiently trained to help in a real emergency), emergency action could be taken. Further, it has been pointed out that illness or temporary unavailability could occur at a residential home. It does not seem to me that great weight should be attached to this concern so long as Rachel's parents are available to deal with emergencies, and in terms of cost comparisons, a 24 hour presence of a nurse trained to assist Rachel in her needs is required whether at Rachel's or a residential home. Of course, as time passes, if her parents are no longer able to provide the necessary support to cover emergencies, the question of risk will undoubtedly become more important. While the package should be long term, it cannot be permanent.

12. The failure to make progress led to threats of judicial review which were allayed by a further meeting on 16 September 2004, which was attended by a representative of her parent's solicitors. A letter from the defendants recording what was discussed notes that explanations were given of the family's unhappiness with the residential accommodation decision. This said: -

> "The family wishes to stay as close together as possible, preferably in Stafford so that local contacts can be maintained; that Rachel's education programme can be sustained; and that Rachel should have good access to social facilities. Rachel herself has expressed her desire to remain in her current home".

This led to a discussion of her ability to understand the longer term and risk implications and it was agreed that her capacity to consent should be assessed by a psychologist. It was again made clear that the family had "no wish to obstruct any consideration of suitable residential provision and would provide whatever physical access was necessary to enable assessment to move forward".

13. Unfortunately, no real progress was made. Each side blamed the other for that lack of progress. Eventually, on 5 January 2005 the solicitors wrote a letter stating that an application would be made to the court unless the defendants agreed to provide a '24 hour, 7 days a week care package which allows Rachel to continue to live within the family home and one which is administered through a Independent User Trust''.

14. The suggestion that an Independent User Trust (IUT) would be put in place was a novel one. An IUT has been used as a vehicle for the provision of assistance by

local authorities to those with disabilities. It has not been used by any Care Trust such as the defendants or for the provision of the sort of care package which is said to be needed to enable Rachel to stay at home. There is an issue whether these defendants could lawfully enter into the necessary arrangements. Broadly speaking, the trustees of an IUT who should include a representative of the defendants, would provide the necessary package of care for Rachel with funds provided by the defendants. The major benefit of such an arrangement would, it is said, be the avoidance of the profit costs otherwise payable to an independent agent such as Allied Health Care, whose profit margin is in the order of 35%.

15. This claim was instituted on 18 January 2005. It sought relief on the basis of the courts' inherent jurisdiction as well as judicial review. On 2 March 2005 at an oral hearing Munby J directed that the former claim could not be pursued but that permission for judicial review should be granted. He refused to accede to the defendants' submission that they be given more time to consider what course should be taken in the light of the information provided to them. Notwithstanding this, the defendants did reconsider the issue at a meeting of the relevant officials on 22 March 2005. It was stated that clarity was required regarding the level of parental input on a long-term basis. In the absence of this, it would be assumed that the input would be zero. It noted that no information was forthcoming about how an IUT could operate. It decided that 'there was not enough information to review the decision and therefore the original decision stands pending the outcome of a future review'. A nursing care report was provided subsequently in May which confirmed that Rachel needed 24 hour qualified nursing care and there was the possibility of skilled nursing intervention being required within less than 5 minutes of the need being identified. The conclusion was that overall the nursing assessment was that the risks associated with a home care package with little parental input were too high from a clinical and professional perspective and that a residential placement offered the more favourable environment from a nursing prospective following a holistic assessment of Rachel's needs.

16. Mr Gunter's evidence has been consistent. He and Rachel's mother would continue so long as they were able to do so to be there in a supportive role and to provide emergency care. They recognise that it is not fair or possible for her to remain dependent on them for the rest of her life and it is the hands on aspect of care that they do not want to continue. In his third statement Mr Gunter says this: -

> "It is difficult for me to provide any further clarification as to the level of support myself and Rachel's mother, (Marie), are willing to provide to any home care package. My statement of 11 January 2005 at Paragraphs 72, 74 & 55 contain details of the level of care and advice we can give. Further clarification was provided in my witness statement dated 16 April 2005 at Paragraphs 3 & 4. Marie Bailey and I are prepared to provide the level of support required to cover any emergency staffing issues. We are willing to step in as a contingency when there are staffing problems. The staffing problems would reduce when a long term home care package is in place and on the occasions when we are required to step in at short notice we can do this but not at the level we have been required to in the past. It is the level of hands-on support that we wish to withdraw from. We would not withdraw from any consultative role. This is particularly relevant to Marie who all the health professionals recognise as being expert in spotting illness and will be available for thus type of support. In that sense,

> the homecare package has a true contingency as myself and Marie will be on hand and able to step in on very short notice. This could not be possible if Rachel was placed in a residential home and the cost of providing for any contingencies in relation to emergency cover must be higher in a residential home to reflect this difference".

17. The parents' solicitors commissioned a report from a Chris Wall to provide an independent assessment of Rachel's community care needs. Mr Wall is a qualified social worker. He sought advice from a nurse in compiling his report. He is the chief executive of a company which provides independent assessments on complex cases where care of disabled persons is needed. He has considerable experience in the field. He dealt with costing and the possibility of an IUT. His conclusions are not accepted by the defendants.

18. In addition, a report was obtained from Dr Milne, a consultant psychiatrist. This has been summarised since part of it dealt with Rachel's best interests. The remainder was concerned with her capacity. It was apparent to Dr Milne that Rachel wanted to remain at home and that that was her genuine desire and not what she believed her parents wanted her to say. She was not able to appreciate the full extent of her care needs, but her attitude to being placed in a residential home was that it would make her 'sad, cross, angry, it would be murder'. It was apparent that she had a very close and mutually caring relationship with her mother and it was Dr Milne's opinion that, despite her lack of capacity to make decisions about her care needs, she was able to express her wishes and those wishes should be taken into account in deciding on her future. Mr McCarthy does not dispute that this is a correct approach and that her wishes are a relevant consideration. Dr Milne also notes that Rachel had made a far greater recovery than was predicted at the time of her surgery and had continued to improve since being at home. This accords with the views of others and it is apparent that the care provided to her by her parents, in particular her mother, has resulted in a remarkable improvement in her condition. That is, as it seems to me, a very important consideration which must be given due weight in deciding on her future.

19. Shortly before the hearing, there was an attempt to resolve matters through mediation. It did not succeed and I did not explore why. I am sorry that it failed. Judicial review is an unsatisfactory means of dealing with cases such as this where there are judgments to be made and factual issues may be in dispute. At best, it can identify failures to have regard to material considerations and a need for a reconsideration. Very rarely if ever will it result in mandatory orders to the body which has the responsibility to reach the relevant decision. In this case, Mr McCarthy accepted – indeed, this has throughout been the defendants' attitude – that there should be a reconsideration based on all up to date material. But it has, I think, been helpful to clarify some issues which have been in contention so that any reconsideration is based on correct legal principles. It is of course essential that Rachel's welfare is regarded as a very important individual factor, but perfection cannot always be achieved and financial considerations are material. However, I do not regard evidence of what benefits could accrue from the expenditure of sums which could be saved in providing a less costly package for Rachel as helpful. It is obvious that Health Authorities never have enough money to provide the level of services which would be ideal, but that cannot mean that someone such as Rachel should receive care which does not properly meet her needs.

20. It is apparent that to remove Rachel from her home will interfere with her right to respect for her family life. Mr Wise has also relied on the positive need to give an

enhanced degree of protection to the seriously disabled. This is in my view an unnecessary refinement. The interference with family life is obvious and so must be justified as proportionate. Cost is a factor which can properly be taken into account. But the evidence of the improvement in Rachel's condition, the obvious quality of life within her family environment and her expressed views that she does not want to move are all important factors which suggest that to remove her from her home will require clear justification.

21. Although Article 8 was raised and considered in May 2004, the real impact of it does not seem to have been appreciated. Certainly, all the evidence now produced requires that the reconsideration gives it its proper weight. And that weight is considerable.

22. Finally, I must consider whether there is power to set up an IUT. The concept of an IUT in care cases was approved by Munby J in *R(A & B) v East Sussex CC and another (No1)*[2003] CCLR 177. It was there called an User Independent trust – the name matters not. In the case before him, Munby J summarised the arrangements thus (Paragraph 30): -

> "(i) All payments are made to the trust company"
>
> (ii) It is a legal entity distinct from those who are to be cared for and their parents
>
> (iii) The parents do not control the company and, since they are in a minority on the Board, they cannot exercise a veto
>
> (iv) The company is non-profit making and any surplus on winding up must be repaid to the Council.

23. Thus any payment to the company would not be to the end user but to an independent agency. So, it was submitted by Mr Wise, there is no difference in principle between an IUT and a private agency which provides the relevant nursing care. There is no doubt, as Mr McCarthy submitted, that the powers of a local authority are wide and Section 30(1) of the National Assistance Act 1948 as amended enables it to employ any voluntary organisation as it agent. Thus the question Munby J regarded as determinative was whether an IUT could be regarded as a voluntary organisation.

24. The definition of voluntary organisation in s.64(1) of that Act was: -

> "a body the activities of which are carried on otherwise than for profit, but does not include any public or local authority".

That same definition is repeated in s.128(1) of the National Health Service Act, 1977. Munby J decided that an IUT quite plainly was a voluntary organisation within the meaning of that definition. I entirely agree.

25. The defendants are not a local authority and so cannot use the powers under s.30(1) of the 1948 Act which Munby J was able to rely on. The legislation which sets out the obligations and powers of the various bodies which form part of the National Health Service is not a model of clarity and I am not at all surprised that there have been difficulties in deciding whether the defendants can fund an IUT in order that it can provide the necessary services for Rachel. There is no doubt that there is a duty upon the Secretary of State to provide the necessary care for Rachel – see s.3(1) of the 1977 Act which includes as part of his duty the provision of medical and nursing services (s.3(1)(a)) and 'facilities … for the care

of persons suffering from illness' (s.3(1)(e)). Section 23 of the 1977 Act provides (as far as material): -

> "(1) The Secretary of State may, where he considers it appropriate, arrange with any person or body (including a voluntary organisation) for that person or body to provide, or assist in providing, any service under this Act.
>
> (2) The Secretary of State may make available –
>
> (a) to any person or body (including a voluntary organisation) carrying out any arrangements under subsection (1) above, …
>
> any facilities (including goods or materials …) provided by him for any service under this Act.
>
> (3) The powers conferred by this section may be exercised on such terms as may be agreed, including terms as to the making of payments by or to the Secretary of State, and any goods or materials may be made available either temporarily or permanently".

Although this section refers to the powers of the Secretary of State, it is common ground that it applies to the defendants and enables them, for example, to use agencies such as Allied to provide the relevant services. In addition, Paragraph 12 of Schedule 5A to the 1977 Act, which deals with Primary Care Trusts, provides: -

> "(1) A Primary Care Trust may do anything which appears to it to be necessary or expedient for the purpose of or in connection with the exercise of its functions.
>
> (2) That includes, in particular …
>
> (b) entering into contracts".

26. It seems to me that Parliament has deliberately given very wide powers to Primary Care Trusts to enable them to do what in any given circumstances seem to them to achieve the necessary provision of services. I have no doubt that this could involve the use of a voluntary organisation such as an IUT as the supplier. There seems to me to be no difference in principle between an IUT set up specially for a small number of persons or an individual and a nursing or other agency so far as the defendants are concerned. It would obviously be necessary for a member of the defendants to be a trustee so as to ensure that money was properly and prudently spent.

27. While I have no doubt that the power exists, I recognise that there are a number of practical problems which may make the suggested arrangement impossible to achieve. Mr McCarthy pointed out a number of difficulties which would have to be overcome.

The IUT would have to be registered and some past track record would normally be needed. The structure would have to be carefully organised so as to ensure financial accountability, and a proper co-ordination between management and staff. The defendants would (and I am sure that this is entirely reasonable) require that they were the ultimate decision makers in relation to what has been

called clinical governance. There must be minimum standards set up and a scheme spelt out to govern the way in which the necessary care is to be provided. Whether or not these difficulties (I have not detailed all those referred to) can be overcome I do not know. But I am satisfied that the possibility of an IUT with the substantial saving in cost which it may produce for care at Rachel's home is one which can and should be explored.

28. The claimant and her parents cannot assume that home care will necessarily result. I certainly hope that it can since it is obviously benefiting Rachel. But cost is an important consideration and it may turn out that the IUT route is not satisfactory or does not provide the sort of saving which can to a sufficient extent bridge the gap between care at home and residential care. The risks to Rachel must also be carefully assessed. While I have doubted that, so long as her parents are available to provide back up in an emergency, the risk is as great as has been hitherto believed, I am not the decision maker.

29. I am inclined to the view that no positive relief is necessary. Certainly, no form of mandatory order is appropriate. Thus the only remedy could be in the form of a declaration, but I think the judgment speaks for itself and both parents are well aware of the powers which the defendants can exercise. However, I will of course hear counsel on the form of any relief which either may consider appropriate.