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Case No: NU13C00021

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 25/04/2013

In the Matter of the Children Act 1989
And in the matter of Y and Z (Minors)

Before :

THE HONOURABLE MR JUSTICE BAKER

- -

Between :

X County Council	**Applicant**
- and -	
A Mother	**1st Respondent**
-and-	
A Father	**2nd Respondent**
-and-	
Y and Z	**3rd Respondent**
(Acting through their Children's Guardian)	

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- -

David Reynolds (Local Authority solicitor) for the **Local Authority**
Caroline Baker (instructed by **Willsons**) for the **Mother**
Sally Barnett (instructed by **Alsters Kelly)** for the **Father**
Christopher Watson (instructed by **Brethertons LLP**) for the **Guardian**

Hearing dates: 10th April 2013

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Judgment

THE HONOURABLE MR JUSTICE BAKER

This judgment is being handed down in private on 25th April It consists of 28 pages and has been signed and dated by the judge. The judge hereby gives leave for it to be reported.

The judgment is being distributed on the strict understanding that in any report no person other than the advocates or the solicitors instructing them (and other persons identified by name in the judgment itself) may be identified by name or location and that in particular the anonymity of the children and the adult members of their family must be strictly preserved.

The Honourable Mr. Justice Baker :

Introduction

1. Huntington's disease, formally known as Huntington's Chorea and now often shortened to HD, is a hereditary disorder of the central nervous system caused by a defective gene on chromosome IV. The faulty gene causes damage of the nerve cells and areas of the brain which in due course leads to physical, mental and emotional change. Anyone whose parent has the disease is born with a fifty per cent chance of inheriting the gene. Anyone who inherits the gene will, at some stage, develop the disease. The symptoms usually emerge when people are between ages 30 and 50, although in some rare instances they arise at an earlier stage. The extent of the symptoms varies from person to person. In the later stages of the disease, the physical and mental disabilities can become profound and, if so, much care and support is required.

2. This application concerns two small boys who come from a family in which HD is said to be present. The boys are the subject of care proceedings in the county court in which the local authority is likely to propose that they be placed for adoption. The question therefore arises as to whether the boys should be tested for HD in the course of these proceedings.

Background

3. Y, now aged 3, and Z, now aged rising 2, are the children of a 21-year-old mother and a 44-year-old father who never married but lived for several years in a turbulent relationship characterised by drug abuse and occasional domestic violence. The family was referred to social services by the police in January 2012 and a child protection conference was convened in March, at which the father admitted he had been violent to the mother. The father also informed the conference that his mother and brother suffered from HD, and that he suspected that he too suffered from that condition. A child protection plan was drawn up and implemented providing that the father should not return to the family home. In May 2012, however, social services discovered that the father was still at the property. The police were called and illegal drugs were found in the property. At that point, the mother agreed that the children should be accommodated by the local authority under section 20 of the Children Act 1989. She subsequently obtained non-molestation and occupation orders against the father. A parenting assessment of the mother carried out by the local authority concluded that she lacked insight into her problems and the concerns about the children, and did not have the capacity to care for the children so as to enable them to maintain the progress they had made in foster care. The father has chosen not to comply with any proposed assessment.

4. In January 2013, the mother and her new partner attempted unsuccessfully to remove the children from their foster home. On 28th January, the local authority filed an application for care orders in respect of both boys. At the first hearing on 6th February, the Family Proceedings Court transferred the case to the county court on the grounds of complexity including inter alia the question whether the children should be tested for HD. On 14th February, a circuit judge gave directions including listing the matter before a judge of the Family Division to determine whether the children should be

tested for the HD gene. Save for that issue, the proceedings remain in the county court where they are currently listed for an issues resolution hearing on 14th May, some four weeks hence. In those proceedings, it is anticipated that the local authority will file a care plan proposing that the children be placed for adoption.

The Law

5. In respect of a child who is not subject to a care order, disputes concerning the medical assessment of a child can be resolved by an application for a specific issue order under section 8 of the Children Act. Section 9(1) of that Act, however, prevents the court making a specific issue order in respect of a child who is in care.

6. When a child is subject to a full care order, the local authority has overriding parental responsibility for the child under section 33 of the 1989 Act. Whether or not the provisions of section 33, and in particular subsections (3) to (5), give the local authority an unchallengeable power to arrange the testing of children in these circumstances against the opposition of their parents is an interesting question, but not one which arises in this application because the children are still only subject to interim care orders.

7. In respect of children who are subject to interim care orders, there is an express power concerning medical testing set out in section 38(6) to (8), which provides as follows:

> "(6) Where the court makes an interim care order, or interim supervision order, it may give such direction (if any) as it considers appropriate with regard to the medical or psychiatric examination or other assessment of the child; but if the child is of sufficient understanding to make an informed decision he may refuse to submit to the examination or other assessment.
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> (7) A direction under subsection (6) may be to the effect that there is to be
>
> (a) no such examination or assessment; or
>
> (b) no such examination or assessment unless the court directs otherwise.
>
> (8) a direction under subsection (6) may be
>
> (a) given when the interim order is made or at any time while it is in force; and
>
> (b) varied at any time on the application of any person falling within any class of person prescribed by rules of court for the purposes of this subsection."

8. The effect of these provisions is to give the court the power to determine whether children who are subject to interim care orders should be subject to medical or psychiatric examination or other assessment. Most cases concerning applications

under section 38(6) involve a proposal to examine or assess the child for the purposes of obtaining information specifically to assist the court in reaching its ultimate decision in the care proceedings: see eg Re C (Interim Care Order: Residential Assessment) [1997] 1 FLR 1, and Re T (Residential Parenting Assessment) [2011] EWC 8 Civ 812, [2012] 2 FLR 308. However, the terms of section 38(6) plainly cover wider circumstances such as those arising in the present case.

9. Since the question I have to determine manifestly involves the upbringing of the children, section 1(1) of the Act applies so that the welfare of each child is my paramount consideration. As the application is for an order under Part IV of the Act, section 1(4) (b) requires the court to consider the relevant factors in the welfare checklist in section 1(3). Furthermore, the rights of the children under Article 8 of ECHR are also plainly engaged.

10. The issue in this case can therefore be summarised as follows: does the welfare of each child require him to be subjected to genetic testing to establish if he has the gene for HD?

The Evidence

11. The evidential context in which I consider this question consists of, first, the evidence of the social worker concerning the prospects of adoption; secondly, the evidence, such as it is, that other members of the boys' family suffer from HD; and, third, the expert evidence obtained by the parties about HD, supplemented by citations from research and literature which have been put before me by the parties.

(1) Social Worker's Evidence

12. The evidence about the prospect of adoption was provided by the operations manager of the local authority's adoption team, SS. She has very considerable experience in the social care field including adoption. She was asked to advise as to the prospects of placing the boys for adoption. It is her evidence that, if Y and Z do not have HD, the local authority should be in a position to identify an adoptive placement for them within six months. Although it is more difficult to find adoptive placements for sibling groups, the fact that the boys are young should be a positive factor when seeking such a placement in this case. At present, this local authority has two families approved for a sibling group of two children, together with others whose application to be approved are in the pipeline. In the event that the local authority is unable to find such a placement from its own resources, it is able to widen its searches to seek to find a suitable family from within the region or nationally.

13. SS advises that if, either of the boys have the gene for HD, this will make the task of identifying an adoptive family much more difficult. It is her experience that many adopters are unwilling to offer a home for two children where there is a serious medical condition. SS has consulted colleagues working on the National Adoption Register who expressed a similar view.

14. If no test is carried out, so that it remains uncertain as to whether the boys have the

HD gene, it is SS's experience that this, too, will make it difficult to identify adopters willing to offer the boys a placement. She cites an example of difficulties finding an adoptive placement for a young sibling group where there was a possibility that they might have the fragile X gene. It was only after blood tests showed that it was present that the agency was able to identify an adoptive placement for the children.

15. In her statement, SS does not address the question of what would happen if one child were found to have the gene and the other not. In submissions on behalf of the local authority, Mr. Reynolds informed the court that, in those circumstances, the local authority would look for a single adoptive placement for about six months, but if unsuccessful would then extend the search for two placements. If it proves impossible to find a placement that will take both children where one has the gene, the local authority would consider separating the children so that the child without the gene is placed for adoption and the child with the gene remains in foster care.

(2) Evidence of HD in the family

16. There is no conclusive evidence, in the form of medical reports or records, demonstrating that any member of this family has HD. All we have are the assertions made by the father that his mother and brother have the disease and that he himself has symptoms consistent with it. No statement from the father's mother or brother has been put before the court, nor have their medical records been produced. The father has given inconsistent accounts about his own condition. At the case conference on 6th March 2012, he stated that his mother and brother have been diagnosed with HD and that he suspects that he has the condition as well. He has told the police that he has the disease, but told the health visitor that he does not. In his position statement in these proceedings, the father says that he does not know if he has the disease and is himself unwilling to undergo the test.

17. There is therefore some uncertainty about whether the disease is indeed present in this family, and the local authority invites the court to take that into account when making an analysis of the probability that these children carry the gene.

(3) Expert Evidence – Professor Patton and research literature

18. Professor Michael Patton is a consultant clinical geneticist and Professor of medical genetics at St. George's London. For the last 25 years he has run the HD service in South West London, Surrey and West Sussex and in that time has seen about 700 families in the clinic, many of whom have had predictive testing to establish whether the gene is present.

19. Professor Patton advises that HD is passed from generation to generation as an autosomal dominant disorder. All genes come in pairs and the defective parent will have a normal gene and an abnormal gene. When they come to have children, they have a 50:50 chance of passing on the abnormal gene. When genetic testing is carried out, there is a clear answer in 98% of cases. In small minority where the answer is unclear, it is now known that these intermediate results may cause a milder later onset

pattern of disease. Otherwise, the test does not predict the age of onset of the disorder. It simply determines whether the gene is passed on or not. This aspect of the test is accurate and as it is usually run twice in the laboratory, there is no scope for false positive or false negative results.

20. Professor Patton advises that he has carried out about 500 predictive tests over the last 25 years. He has tested a few teenagers who were particularly mature for their age, but the only occasions on which he has tested children was in two cases where the child appeared to have specific neurological signs. He has on occasions been asked to test babies who are being considered for adoption, but he did not feel it appropriate to carry out the test and in those cases the matter was not taken further by the adoption agency.

21. If the individual is referred for predictive testing, it is Professor Patton's practice to meet the patient, go through the family history in detail, and try to confirm the diagnosis. He then discusses the nature of HD in terms of its neurological and psychological features, stressing that there is at present treatment but no cure. He discusses the pros and cons of predictive testing and goes through the reasons why people at risk may choose to take the test, for example to reduce uncertainty, because they wish to start a family, or to deal with issues about insurance and employment. He draws attention to the progress in research and informs the patient that it is his view that there may be new approaches to treatment that will alleviate the condition. After this preliminary consultation, Professor Patton allowed the patient a period of about a month to consider the points raised. Thereafter, if the patient wishes to proceed, the test is taken and the results are available within 4 weeks.

22. Professor Patton helpfully appended to his report and these proceedings a report of a working party of the Clinical Genetics Society (UK) headed the 'The Genetic Testing of Children' written in 1994 (J Med. Genet., 1994, 31:785-797), which dealt with a range of genetic disorders. The conclusion and recommendations of the report include the following:

> "(1) The predictive genetic testing of children is clearly appropriate where onset of the condition regularly occurs in childhood or there are useful medical interventions that can be offered….
>
> (2) In contrast, the working party believes that predictive testing for an adult onset disorder should generally not be undertaken if the child is healthy and there are no medical interventions established as useful that can be offered in the event of a positive test result. We would generally advise against such testing, unless there are clear cut and unusual arguments in favour. This does not entail our recommending that families should avoid discussing the issues with younger children, but rather that formal genetic testing should generally wait until the 'children' request tests for themselves, as autonomous adults. This respect for autonomy and confidentiality would entail the deferral of testing until the person is either adult, or is able to appreciate not only the genetic facts of the matter but also the emotional and social consequences of the various possible test results.

> In circumstances where this type of testing is being contemplated, there should be full discussions with both the family and between parents and genetic health professionals (clinical geneticists or non-medical genetic counsellors); the more serious the disorder, the stronger the arguments in favour of testing would need to be."

23. The working party identified a number of possible advantages and disadvantages of predictive testing in childhood set out in a table at page 790. The advantages included

> 1) Relieves anxiety about possible early signs of the disorder.
>
> 2) Family uncertainty about the future is reduced.
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> 3) More accurate genetic counselling becomes possible.
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> 4) The child's attitude towards reproduction in adulthood will be more responsible.
>
> 5) Children who might benefit from genetic counselling in the future might be identified.
>
> 6) Practical planning for education and career, housing and family finances becomes possible.
>
> 7) Parental expectations of the child's behaviour become altered.

The possible disadvantages included

> 1) Removes the child's right to decide whether or not to be tested in adulthood.
>
> 2) Parental expectations of the child's future reproductive behaviour become altered.
>
> 3) Damages the child's sense of self esteem.
>
> 4) Generates unwarranted anxiety about possible early signs, before any genuine manifestation of the disorder.
>
> 5) Leads to future difficulties in obtaining life insurance.
>
> 6) Rarely leads to clarification of the genetic status of other the family members.

24. The working party addressed in particular the merits of genetic testing in respect of children who are being considered for adoption. In such cases, the arguments for

testing, in addition to those set out above, include the specific point that appropriate carers may more easily be found for the child. Arguments against testing, in addition to those identified above, would include specific points relating to adoption namely 'that the diagnosis will label the child and affect the (already difficult) process of identity development [and] that it is irrelevant to the needs of the child for the acceptance as he/she is…..' The working party continued:

> "The arguments will have to be made in each case, but their force will not differ greatly from the standard case of a child in the original birth family, unless it proves difficult to find suitable prospective adoptive parents for a child at risk of a late onset genetic disorder because of the uncertainty surrounding the child's possible genetic status when either the decision to put the child forward for adoption, or the decision about genetic testing, will need to be reconsidered. In practice, this situation may arise infrequently, but will call for a careful consideration of the child's overall best interests when it does so. In general, it would seem best, wherever possible, to find adopters who can accept the child as a whole, and subsequently participate in any testing that is appropriate for the child as a confirmed member of their family."

25. In addition, Professor Patton appended a more recent report, produced for European Huntington Disease Network in 2012 (to be found in Clinical Genetics, 2012) entitled 'Recommendations for the predictive genetic test in Huntington's Disease'. These included (as recommendation 2.1):

> "It is recommended that the minimum age of testing be 18 years. Minors at risk requesting the test should have access to genetic counselling, support and information, including discussion of all their options for dealing with being at risk."

To this recommendation, the authors of the document append this comment:

> "Testing for the purpose of adoption should not be permitted since the child to be adopted cannot decide for him/herself whether he/she wants to be tested. It is essential, however, that the child should be informed about his/her at risk status."

26. In view of this consensus amongst professionals as to the inadvisability of testing for HD in childhood, there is, according to Professor Patton, no protocol for testing young children. Professor Patton summarises his own experiences of the main reasons for not using predictive testing in a child as being that it would not produce any medical gain for the child and, whilst there may be no medical harm as a result of the test, there could be adverse psycho-social consequences from having a diagnosis of an adult disorder in the future. He highlights, in particular, the risk of discrimination, altered relationships with parents and siblings, and the removal of the child's autonomy in making his or her own decision at a later and more relevant stage in his life. Furthermore, Professor Patton points out that, whereas the likelihood of both children being free from HD mutation is 25%, the chances that one is affected and the other not is 50%. There is therefore a significant risk that testing may lead to the children being separated if an adoptive placement can be found for the child who does

not carry the gene.

27. Professor Patton concludes:

> "I do not believe that Y and Z should be tested at this stage in their lives for the purposes of adoption. This view point is endorsed by the European Huntington Disease Network and the working party of the British Society of Clinical Genetics. Instead, the prospective adopters should have the option of knowing more about the disorder and in particular how to today's research is leading to the possibility of treatment in the future."

28. In addition to Professor Patton's report and the documents appended thereto, the advocates put before the court a number of papers they have identified in the research literature which may be relevant to this decision.

29. On behalf of the local authority, Mr Reynolds draws attention to a 1992 paper, published in the New England Journal of Medicine, entitled 'The psychological consequences of predictive testing for Huntington's disease' by Wiggins and others. This article reported on a programme of genetic testing in which the participants were divided into three groups – the 'increased risk group', consisting of people who had taken the test and found that they had an increased chance of inheriting the disease, the 'decreased risk group', consisting of those who had taken the test and been told that their chances of inheriting the disease were reduced, and the 'no change group' who included those who had not wanted to take the test and those for whom the test was uninformative but who chose not to withdraw from this study. The abstract of the article summarises the conclusions as follows:

> "At each follow up assessment, the decreased risk group had lower scores for distress than before testing…[T]he increased risk group showed no significant change from baseline on any follow up measure, but over the year of study there were small linear declines…for distress and depression…[T]he change group had scored lower than at baseline on the index of general well-being at each follow up…[A]t the 12-month follow up, the increased risk group and the decreased risk group had lower scores for depression and higher scores for well-being than the no change group."

Mr Reynolds submits that this research paper suggests that the psychological consequences for those who do not undergo testing may be worse than for those who do, irrespective of the results of the test.

30. I think some caution must be applied when considering this paper in the context of this case. All the participants in the research study group were adults. It would be unwise to rely on this paper as significantly undermining the clear views expressed by the authors of the papers published by the Clinical Genetics Society (UK) and the European Huntington Disease Network cited by Professor Patton.

31. Secondly, and to my mind more pertinently, Mr Reynolds cites a paper published by the British Society for Human Genetics, the 'Report on the Genetic Testing of Children 2010'. This paper considers the question of the advantages and disadvantages of genetic testing in childhood and covers much of the ground set out in the earlier papers. Mr Reynolds relies in particular on the following passage at page 9 of the report:

> "It is difficult to determine the psychosocial harms and benefits of testing in childhood. Most discussions on this issue have focussed on the right to make the decision and the impact on the child's (future) autonomy. Opposition in genetic testing in childhood where there is no direct or medical benefit is rooted in concerns to protect the future autonomy of the child, i.e. preserving the right of the child to make his/her own decision. On the other hand, it has been argued that parents have the right to make decisions on behalf of their children because they have primary responsibility for their child and they know their child best. The lack of evidence to corroborate that testing young people would cause psychosocial harm and the fact that existing guidelines are based on assumptions rather than empirical evidence has also been highlighted. Assumptions about harms have included the possible lessened self esteem, distortion of the family's perception of the child, altered upbringing, discrimination and increased anxiety both of parent and child. Arguments in support of testing children/young people are that the untested child loses the opportunity to grow up with and adapt to genetic knowledge during his/her formative years and that not testing may cause harm if parents were made anxious and the young person finds uncertainty difficult."

32. It should be noted, however, that in a passage about adoption, the authors of this paper state (at page 12):

> "A family willing to adopt the child at risk of an inherited disorder and to find out about their genetic status over time, as in the biological family, appears preferable to a family that sets genetic conditions upon accepting a child. On the other hand, adopting parents face multiple uncertainties about any child they adopt, and the desire to reduce uncertainty, when this is possible, is understandable. We think that there may be special circumstances which mean that genetic tests are undertaken for adoptive children, although they would not be carried out at that stage for children in the care of their birth families. Even so, we recommend caution for carrier testing (or future reproductive significance only) and <u>even more so for predictive testing for later onset conditions (with no useful medical interventions in childhood)</u> [my emphasis]."

33. Finally, the parties have referred me to a paper produced by the British Association for Adoption and Fostering ('BAAF') in 2006 headed 'Genetic Testing and Adoption' which makes the following comments about genetic testing, adoption and the rights of children:

"In all circumstances, the best interests of the child must be paramount. However, in adoption proceedings it can sometimes be difficult to judge whether a particular course of action is in a child's best interests. Each situation will need to be judged on its own merits, taking a number of factors into consideration.

- All children have a right to information about their genetic heritage. Adoptive children who through circumstances beyond their control are not living with their birth parents must not be further disadvantaged by being denied this information.

- Most looked after children, even those from high risk backgrounds, are healthy. Neither birth nor adoptive parents can be 'guaranteed' a perfectly healthy child who will develop normally. All parents have to live with risk.

- Potential adoptive parents have certain rights. These rights include the right to be given relevant family history and a full health and developmental profile of the child they are considering adopting.

- There is no evidence that collecting extensive family histories and discussing the potential risks to a child in detail before placement either deters adopters or delays a placement.

- 'Matching' a child with informed, well prepared and supportive adoptive parents is the best way of ensuring a successful adoption placement.

- All children, whether they are living with their birth families, being looked after by local authority or adopted need protection from the potentially negative effects of genetic testing. Therefore, wherever possible, unless there are convincing indications to the contrary, looked after children should have the same rights as children who are living with their birth families. The threshold for testing should be the same. Testing should never be undertaken to make a child more adoptable."

Submissions

34. The local authority alone supports the immediate testing of the children in this case. It submits that, given the uncertainty as to whether the father is carrying the gene, the chances of the boys having it are reduced. Mr. Reynolds invited the court to conclude that the uncertainty about the father had the effect of halving the statistical likelihood of the boys carrying it, so that the chances of both boys having inherited the gene were reduced to 12.5% and of one boy having inherited it but not the other reduced to 25%. As I understand their submissions, the respondents accepted this statistical analysis.

35. The local authority relies principally on the evidence of SS as to the greatly increased difficulty of finding an adoptive placement if testing is not done. Furthermore, whilst acknowledging the clear opinion of Professor Patton, the local authority draws on the research papers cited above to identify further advantages to the boys if the test is carried out. In particular, it is submitted that, from a psychological perspective, knowing the position one way or the other is better than not knowing at all. The local authority's case is that, from a welfare perspective, whatever the psychological consequences of testing, they are outweighed by the likelihood that an unknown diagnosis will significantly decrease the chances of a successful adoption.

36. The other parties to the care proceedings – the mother, the father and the guardian on behalf of the children – all oppose testing at this stage. They rely on the preponderance of professional opinion as set out in the various research papers cited above and in Professor Patton's report. All counsel on behalf of these parties make similar points which can be summarised as follows.

37. Firstly, whilst accepting that uncertainty is likely to make it more difficult to find an adoptive placement for the boys, they do not accept that adoption would be impossible. It is pointed out that adopters are found for children with the most profound disabilities. Although it may be difficult to find suitable adopters for children in these circumstances, it is not impossible. The passage cited from the BAAF above lends support to this submission.

38. Secondly, the respondents submit that testing the children at this stage would significantly increase the risk of separating the children, since there is a real possibility that one child will be found to have the gene and the other not, and that as a result, one child will be placed for adoption leaving the other child in foster care. The respondents submit that any outcome which leads to the separation of the children should be the last resort. Separating the children will deprive each of the life long sibling relationship which is so important to children who are removed from their birth parents. In addition, the child left in foster care will be in danger of particular disadvantage, carrying a stigma of a child in care throughout his childhood as well as the difficulties he will face having inherited the gene. The respondents contend that it should be an overriding priority and those planning for the future of these children that they should stay together.

39. Thirdly, the respondents submit that there is a likelihood of significant psychological harm for the child if testing shows that he carries the gene. He will grow up with the knowledge of something for which he has not been prepared. Although there are well established procedures, as described by Professor Patton, for preparing and counselling adults before and after testing, no such protocol is in place with respect to children.

40. Fourthly, the respondents adopt and rely on the arguments based on personal autonomy set out in the research papers cited above. They invite the court to reject the local authority submission that autonomy arguments are irrelevant in this case. The respondents submit that autonomy is an element of welfare within the meaning of section 1 of the Children Act.

41. Fifthly, it is submitted that the court should be slow to go against the clearly

established position of the medical profession on this issue. On behalf of the guardian, Mr Watson reminds me of the dicta of Lord Donaldson in Re J (A Minor) (Child in Care: Medical Treatment) [1992] 4 All ER 614 at page 622:

> "The fundamental issue in this appeal is whether the court in the exercise of its inherent power to protect the interests of minors should ever require a medical practitioner or health authority acting by a medical practitioner to adopt a course of treatment which in the bona fide clinical judgment of the practitioner concerned is contra-indicated as not being in the best interests of the patient. I have to say that I cannot at present conceive of any circumstances in which this would be other than an abuse of power as directly or indirectly requiring the practitioner to act in contrary to the fundamental duty which he owes to his patient."

42. I remind myself, however, that, whilst the court must pay particular attention to expert evidence, the ultimate decision is a matter for the court since it is the court which alone has all the evidence upon which to make the decision: *A County Council v K D and L* [2005] EWHC 144 (Fam) per Charles J at paragraphs 39 and 44

Conclusion

43. There is, as all parties accept, a significant possibility that both boys carry the gene and a greater possibility that one boy carries it but not the other. Professor Patton assesses the former possibility as 25% and the latter at 50%, assuming their father has the gene. On the latter point, however, there is uncertainty. One course would be to make a finding as to whether the father has the gene, but given the paucity of the evidence that would not be feasible. The local authority, supported on this point by the other parties, invites me to halve the figures cited by Professor Patton to take account of the uncertainty about whether the father has the gene. In the absence of expert evidence from a statistician, however, it would be unwise to make a precise calculation as to the statistical possibility of one or both of the boys having the gene. In all the circumstances, I consider that the right basis on which to make the decision about testing is as stated above, namely that there is a significant possibility that both boys carry the gene and a greater possibility that one boy carries it but not the other.

44. The principal arguments in favour of testing seem to me to be as follows. First, and most importantly, a decision not to direct genetic testing will reduce the number of prospective adopters for the boys. I accept that, if Y and Z cannot be returned to the care of their parents, it is in their interests to be found permanent placements that provide them with as much security as possible. In most cases, adoption is the option that provides the greatest security. In every case, however, an assessment has to be made as to which outcome meets the needs of the children. I accept the opinion of SS and the position of the local authority that, if the tests are not carried out, it will be significantly harder to find adoptive placements for the boys. I do not, however, accept that it will be impossible to find adoptive placements in those circumstances. The guardian considers that it is possible to find adoptive placements for both boys and that accords with this court's experience of cases involving children being placed for adoption. Many children with profound disabilities are successfully adopted. Nevertheless, I accept that it will be significantly more difficult to find adoptive placements and that this is a factor that points in favour of authorising the genetic

testing at this stage. Furthermore, there is considerable force in the argument that matching children with adopters who are fully informed about the children affords the best opportunity for a successful placement.

45. There are, in addition, other factors in favour of authorising testing in this case. As a general rule, all children have a right to be brought up with knowledge of their background and inheritance. Unless and until testing is done, there will always be uncertainty which will affect the children's carers and in due course the children themselves. I note the point made in the research literature that, as children are not, as a matter of course, tested and thus do not acquire knowledge about the genetic inheritance until they have become adults, the medical consensus against testing in these circumstances is substantially based on assumptions about psychological and social harm rather than empirical evidence. In addition, although there is no course of counselling specifically designed for children to assist them to come to terms with the knowledge that they will develop a serious disease in adult life, it would obviously be possible to devise a course drawing on counselling that is given in other circumstances.

46. On the other hand, there are a number of cogent arguments against carrying out testing in these circumstances.

47. First, it is the general practice not to provide genetic testing to children to determine whether they have a condition whose onset occurs in mid adult life where there is no treatment which could be provided in childhood. I accept the evidence of Professor Patton, who is a world-renowned expert in this field, that it is generally recognised that it is contrary to the interests of the patient for testing to be carried out under the age of 18. Professor Patton describes in careful detail the preparatory steps he takes with all patients prior to a decision being taken about testing. Those steps require the patient to have the capacity to comprehend and reflect on the issues before taking the decision. Professor Patton also describes the programme of therapy and counselling available for dealing with adults who have been diagnosed as having the gene, and for helping them come to terms with the risk of psychological harm and the sociological and economic consequences of the diagnosis. Although as stated above I think it likely that a course of counselling could be devised for children in these circumstances, I accept his evidence that there is currently no set or recognised process for addressing the risks of psychological harm which, I find, will be likely to arise.

48. Secondly, and following from the previous point, I accept the principle that it is undesirable to treat children differently simply because they are being considered for adoption. I accept the argument set out in the BAAF paper quoted above that all children, whether they are living with their birth families, being looked after by local authority or adopted, need protection from the potentially negative effects of genetic testing. Therefore, wherever possible, unless there are convincing indications to the contrary, looked after children should have the same rights as children who are living with their birth families. Save in exceptional circumstances, all other children will be given the opportunity to decide for themselves when they are older whether or not they should have the test. To order testing of Y and Z at this stage would deny them the right to make their own decision when they are older. I reject the submission that this point should carry little weight because it is based on personal autonomy. Manifestly, personal autonomy is part of the characteristics of a child, and thus a

factor within the checklist in s.1(3)(d) to be taken into account in any assessment of his welfare. Furthermore, personal autonomy is an integral aspect of a person's right to private and family life under Article 8. As Dame Elizabeth Butler-Sloss P observed in *NHS Trust A v M* [2001] Fam 348 at para 41 ,"Article 8 protects the right to personal autonomy, otherwise described as the right to physical and bodily integrity. It protects a patient's right to self-determination and an intrusion into bodily integrity must be justified under Article 8(2)". More recently, the European Court of Human Rights has observed in *Jehovah's Witnesses of Moscow v Russia* [2011] 53 EHRR 4 (at para 136) that : "The freedom to accept or refuse specific medical treatment, or to select an alternative form of treatment, is vital to the principles of self-determination and personal autonomy."

49. Thirdly, as already stated, whilst I accept that it may be harder to find an adoptive placement if there is an unresolved possibility that the boys may carry the HD gene, I do not accept that it will be impossible to find such a placement. Adopters are found for children with profound disabilities with reduced life expectancy. Here, it is very unlikely that a child carrying the gene will develop the disease until mid life. A crucial component of any search for adoption is educating those who come forward. I agree with Professor Patton's view that prospective adopters should have the option of knowing more about the disorder and in particular how today's research is leading to the possibility of treatment in the future.

50. Finally, when children have been removed permanently from their birth family, it is important, if possible, that they be placed permanently together. As stated above, there is a significantly greater risk that one boy will be found to carry the gene and the other not. In those circumstances, there is, on the basis of the local authority's plans, a significant prospect that these children will ultimately be separated. Such a course would not only cause emotional harm to each boy by separating him permanently from his brother but also be likely to cause additional harm to whichever boy is left in foster care in the form of psychological harm through having to grow up with knowledge for which he may not be prepared and the risk of severe damage to his self-esteem. I accept the view of the guardian, and the parents, that this course should be avoided if possible and that the children can be placed together.

51. Balancing all these factors together, I have reached the clear conclusion, on the facts of this case, that it is not in the welfare interests of Y or Z for the court to order testing to establish whether they are carrying the gene for HD. The risk, identified in the consensus of opinion amongst professionals working in this field including Professor Patton, of emotional and psychological harm to the boys if one or both of them has the gene, including the risk of separation of the siblings and the damage to their personal autonomy by being deprived of the right, available to all other children, to decide for themselves when they reach adulthood whether or not to undergo the test, outweighs the risk of harm arising from the likelihood that it will be harder (though not, in my judgment, impossible) to find an adoptive placement if genetic testing is not carried out.

52. Furthermore, I consider it to be plainly in the interests of the boys for this decision to form the basis of future planning for the boys and to be included in any care plan drafted by the local authority for the final hearing of the application for care orders.

53. As requested by counsel, I shall give leave for this judgment to be reported, but it

must be remembered that each case will turn on its own facts. Whilst it is likely in my judgment that, in most instances, a court will reach a similar conclusion, each case turns on its own facts and in some cases the balancing exercise will lead to a different outcome. It is to be stressed that this decision involves an untreatable condition which is unlikely to develop until mid-adult life. Cases involving conditions that develop during childhood, or which are susceptible to treatment in childhood, will involve a very different balancing exercise and are likely to lead to a different conclusion.

54. This case will now be returned to the county court for determination of the local authority's application for care orders.