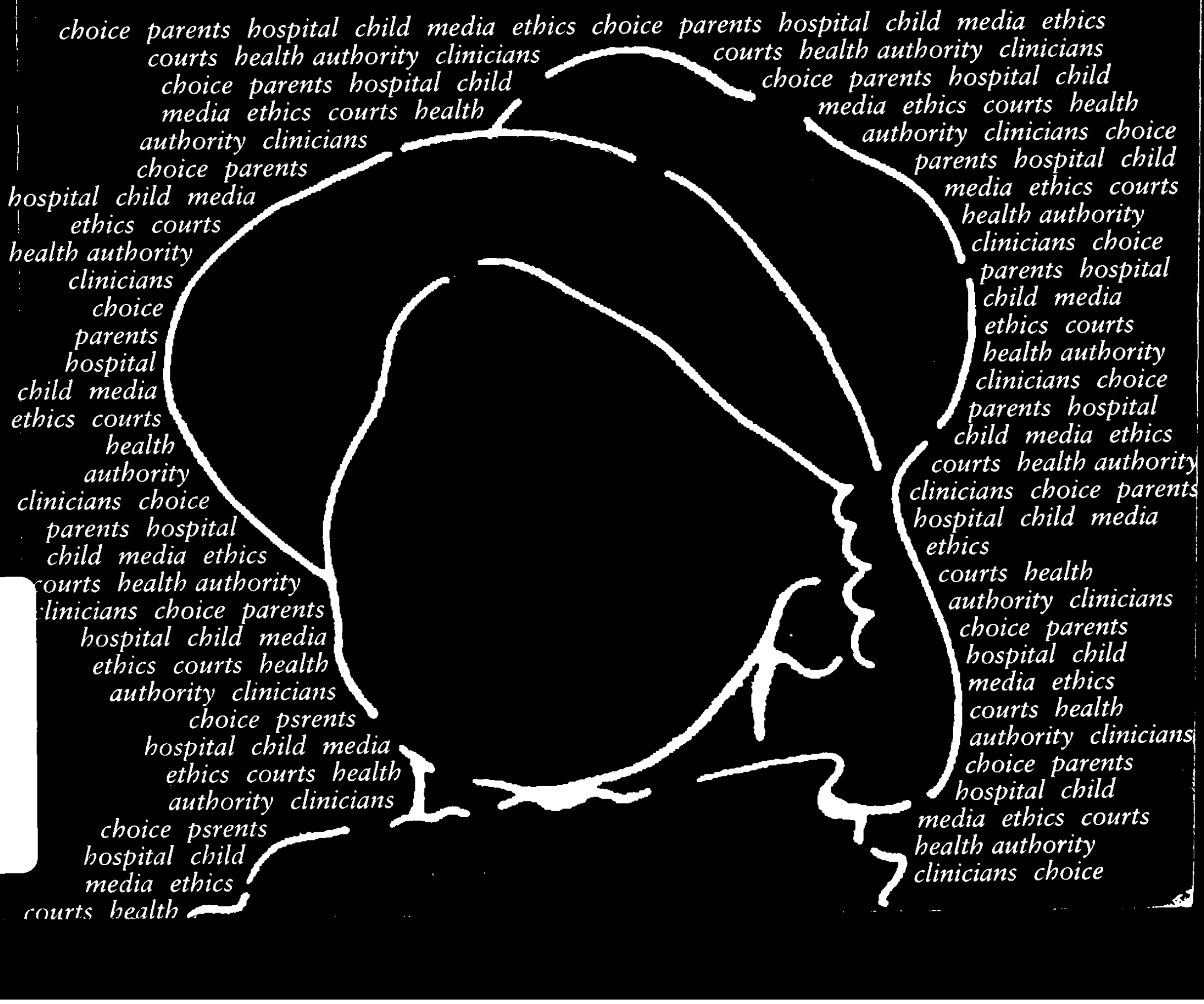
King's Fund

Tragic Choices in Health Care

The case of Child B

Chris Ham & Susan Pickard



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Contents

Foreword

Conflict is at the heart of rationing in modern medicine. We say, 'If it is likely to be ineffective, we shouldn't fund it'. Immediately we go on to say, 'Respect for each individual means that we should treat even a slim chance of success as immeasurably precious'. Often these conflicting sentiments are displaced onto different categories of person: managers versus clinicians; professionals versus patients; representatives versus relatives; the experienced versus the naive; the well versus the sick. The conflict, however, is within ourselves. These antagonistic sentiments are not the property of partisans in a struggle but of persons in a dilemma.

It is the great merit of this study that it makes intelligible all the conflicting forces at work in the last few months of the life of Jaymee Bowen. Here was a child whose sense of life and its possibilities reached out beyond her person and her years. Difficult decisions had to be made when not only was the evidence contested, but where the expertise to interpret the evidence was also contested. The health authority pursued an ethic of responsibility. A parent acted on an ethic of care. Experienced clinicians made hard judgements according to the highest standards of professional judgement that they knew. The public reacted with the only response open to them – an inchoate generosity. If tragedy is the clash of right against right, here quite simply was a tragedy.

The King's Fund Grants Committee thought long and hard before deciding to support this study. Its members were aware of how easy it is to reopen old wounds to no good purpose. In the end, the Committee decided that the interest of all those concerned about the future of health care in this country would best be served by having the story told in all its complexity and ambiguity. We are grateful to Chris Ham for the sensitive way he has accomplished his task. No doubt this is not the final word on a complex series of events; but it is a study that all concerned with how collectively we secure a humane care system in the face of the need to ration resources will wish to read and reflect upon.

Albert Weale
Professor of Government, University of Essex
and Chair, King's Fund Grants Committee

Acknowledgements

We have incurred the usual debts in carrying out the research which lies behind this report. To begin with we would like to thank the King's Fund for providing the grant which enabled the research to be undertaken. We are also grateful to the people we interviewed who gave freely of their time in enabling us to piece together a complex and fascinating story. The individuals involved are listed in the appendix and we are indebted to them for their patience in recounting events which in some cases were either painful or traumatic. Throughout the research we drew on the advice and support of a reference group whose members commented constructively and comprehensively on successive drafts. The members of the group – Geoffrey Carroll, Heather Draper, Colin Hayton, David Kerr, Jean McHale, David Morton and Sheila Sabin – helped us to turn rough early drafts into the more polished and crafted version presented here. Useful comments on drafts of the report were also received from Susan Elizabeth and Albert Weale. As always, we want to acknowledge the invaluable assistance of Anne van der Salm and Sarah Stewart in providing administrative and secretarial support. Any remaining errors are our responsibility.

Chris Ham and Susan Pickard

About the authors

Chris Ham is Professor of Health Policy and Management at the University of Birmingham and Director of the Health Services Management Centre. **Susan Pickard** was a lecturer at the Health Services Management Centre at the time this research was conducted and is now Research Fellow at the National Primary Care Research and Development Centre at the University of Manchester.

The Health Services Management Centre, University of Birmingham, is grateful to the King's Fund for providing a grant to cover the cost of this publication. Any views expressed in this publication are those of the authors and not necessarily those of the King's Fund, which is not responsible for them.

Executive summary

This book tells the story of Jaymee Bowen, more commonly known as Child B, whose case has come to epitomise the dilemmas involved in making tragic choices in health care. Jaymee was diagnosed as suffering from non-Hodgkin's lymphoma in 1990 at the age of six. In 1993 she was diagnosed as having a second malignancy, acute myeloid leukaemia, and she was treated with chemotherapy and a bone marrow transplant. Nine months later Jaymee's leukaemia returned. The paediatricians responsible for her care recommended palliative care as the preferred option for her further treatment. Jaymee's father refused to accept this advice. He sought other clinical opinions and eventually found an adult cancer specialist willing to undertake chemotherapy and a second transplant if she went into remission following chemotherapy.

The health authority where Jaymee lived, having taking clinical advice, declined to pay for further intensive treatment. Jaymee's father challenged this decision in the courts but his case was rejected on appeal. An anonymous donor came forward to pay for treatment to be provided privately and eventually Jaymee was given an experimental treatment, known as donor lymphocyte infusion. She survived for over a year after the return of her leukaemia was diagnosed but eventually died in May 1996. During this time, her case attracted extensive comment and analysis in both the popular press and the medical literature.

As this book shows, the story of Child B was complex and was not simply an example of health care rationing. While the media reports of the case emphasised the difficulty facing the NHS in deciding whether to fund high cost experimental treatment of unproven effectiveness, for many of those involved the central issue was less to do with the availability of finance than what care was appropriate for a child with Jaymee's medical history. On the question of appropriateness, clinical opinions were divided, with paediatricians favouring palliative care, and the adult specialists who were consulted recommending further intensive treatment. The health authority involved was faced with the challenge of managing clinical dissent and of coping with a father unwilling to accept the advice of the doctors who had been responsible for his daughter's care. The attention that the case attracted from the media meant that these issues were played out in the public eye, especially at the point when lawyers became involved and the case went to the High Court. Underpinning all of these issues lay a series of ethical dilemmas concerning the autonomy of individuals, the interests of the community, and the concern of clinicians to do more good than harm. The case also raised fundamental questions about the rights of children and their ability to give consent to treatment.

On the basis of an analysis of these issues from the perspective of those most closely involved, the book draws out the implications for patients, doctors, managers and others, and makes a series of recommendations on how cases of this kind might be handled in future. At the heart of these recommendations is a concern to strengthen the process of decision-making on tragic choices in health care. Of particular importance is the way in which health authorities make decisions and communicate these decisions to patients and their families.

The book proposes that health authorities should be required to give reasons when they decide not to fund treatment. There should also be an appeal mechanism to enable patients and their families to question and challenge decisions. In these and other ways it should be possible to give greater legitimacy to priority-setting decisions and to enhance the process of democratic deliberation in health care.

Introduction

The aim of this book is to describe the case of Child B (Jaymee Bowen) and to use the case to understand how decisions on health service treatment and priorities are made.

Chapter 1 concentrates on telling the story of Jaymee from the perspective of those who were involved in her case. It draws on interview material and other sources to trace the progression of her illness and treatment. The story is told from the perspective of her father, the doctors who treated Jaymee, the health authority that was requested to agree to her treatment, the journalists who reported the case, the lawyers who became involved in challenging and defending the decision of the health authority, and the ministers and civil servants in the Department of Health who liaised with the health authority.

Chapter 2 analyses the main issues to emerge from the story and identifies the implications for health authorities, patients, clinicians, and the Department of Health. These issues encompass the decision-making process followed by the health authority, the differences of opinion between clinicians on the treatment of Jaymee, the way in which consent to treatment is obtained, especially in relation to children, the respective roles of the Department of Health and health authorities in cases of this kind, and the involvement of the courts in resource allocation decisions. By analysing how these issues were handled, the book seeks to draw out the wider significance of this case for the NHS as a whole.

Chapter 3 sets out the conclusions of the study and makes a number of recommendations.

The story of Child B is complex and contains a number of interwoven strands. Although the public presentation of the case emphasised its relevance to the debate about health care rationing, to the NHS staff involved the issues that arose were primarily about the appropriateness and effectiveness of treatment rather than the availability of resources. The case also brought out fundamental differences between paediatricians and adult cancer specialists in the philosophy and practice of medicine, and it came to epitomise the tension that arises between the interests of the individual and of the community. Add to this the role of the courts and the media, and the multifaceted nature of Jaymee Bowen's story is readily apparent. In the pages that follow these strands are examined in turn in order to describe the full complexity of the case.

The book has been written with a variety of readers in mind. It is aimed at people working in the NHS – clinicians, managers and others – who are involved in the dilemmas that arise when decisions have to be made about the treatment of seriously ill patients. The book is also intended for a lay audience, including politicians, the public, patients and the organisations representing their interests. In order to be accessible to this audience, the book seeks to describe as clearly as possible the complex chain of events which make up the story of Child B, and it analyses these events using language which will be comprehensible to non-specialist readers. Inevitably, this entails some simplification of a complicated case, but, by testing earlier drafts on the central characters in the story, we have sought to reflect the complexities that arose and to avoid the hazards that face researchers who seek to communicate their findings to interested lay readers. The book is also meant to be read by students and teachers of health policy as a case study of decision-making in the health services.

In the course of the research which lies behind this book, it became clear that it is impossible to tell Jaymee Bowen's story in a way which entirely satisfies all the main participants. The case aroused strong feelings on all sides and there are many competing interpretations of events. In writing up the research for publication, our aim has been to do justice to these interpretations by telling the story as far as possible in the words of the participants themselves, leaving the reader to judge the part played by different actors. Inevitably, this entails describing some of the conflicts which occurred and the clashes of personality and philosophy which ensued.

Although it can be argued that the personalities in this case are not relevant in drawing out the lessons for the NHS as a whole, we have taken a different view. Without the coming together of a father who was determined to seek the treatment he believed was best for his daughter, clinicians who disagreed about appropriate treatment, managers who were prepared to take a stand on the use of scarce resources on treatments of questionable effectiveness, lawyers who were willing to test the decision of the health authority in the courts, and journalists who saw the case as epitomising the dilemmas of health service decision-making, then Jaymee Bowen's story would not have received the attention it did. In this sense, it is impossible to analyse the issues that emerge without an appreciation of the individuals involved and the various influences on their decisions.

A description of the methods used and people interviewed can be found in the appendix. In order to make the text as accessible as possible, references have been kept to the necessary minimum. The quotations used are all drawn from interview notes which have been checked with interviewees, except where other sources are indicated in the text. The extracts from the High Court and Court of Appeal judgement are drawn directly from the court transcripts.

The story in summary

Jaymee Bowen was originally diagnosed as suffering from non-Hodgkin's lymphoma (NHL) in 1990 at the age of six. She was treated at Addenbrooke's Hospital in Cambridge under the care of Dr Valerie Broadbent. In 1993 Jaymee became ill again and was diagnosed as having a second malignancy, acute myeloid leukaemia (AML). She went into remission following chemotherapy and received a bone marrow transplant at the Royal Marsden Hospital under the care of Professor Ross Pinkerton in March 1994.

Only nine months later, at the beginning of 1995, Jaymee's leukaemia returned. The clinicians involved in her case, including Dr Broadbent at Addenbrooke's and Professor Pinkerton and his colleague, Dr Simon Meller, at the Royal Marsden, all advised against intensive chemotherapy and a second bone marrow transplant. They estimated Jaymee's chances of going into remission following chemotherapy as less than 10 per cent with a similar probability that a second transplant would be successful. This meant that the chance of further intensive treatment working was around 1 per cent. The paediatricians felt that the pain and discomfort that the treatment would entail, combined with the low likelihood of its success, meant that it was not in her best interests to be subjected to it. Palliative care was recommended as the only realistic option, although other possibilities were discussed.

Jaymee's father, David Bowen, was not willing to acquiesce in this decision. Accordingly, he sought opinions in the USA, discovering two clinicians, Dr Zeltzer at UCLA and Dr Cairo at the Children's Hospital, Orange County, California, who put her chances of coming through a second transplant successfully at 60 per cent, and thereafter a 30 per cent chance that her leukaemia would still be in remission after two years (Barclay, 1996, p.53). Jaymee's clinicians at Addenbrooke's and the Royal Marsden did not agree with these assessments which were much more optimistic than their own. Undeterred, David Bowen sought the opinion of a professor of leukaemia at the Hammersmith Hospital, John Goldman, who felt that it would be reasonable to give Jaymee further chemotherapy with the hope of achieving complete remission. His estimate was that there was a 20 per cent chance of chemotherapy leading to remission, at which point a second transplant would be an option.

Having made his own arrangement to see Professor Goldman, David Bowen asked Dr Broadbent if she would fax a letter to Professor Goldman making a tertiary referral. Dr Broadbent did so expressing reservations. David Bowen then approached the local health authority in Cambridge and asked if it would authorise treatment for Jaymee at the Hammersmith Hospital. The authority's Director of Public Health, Dr Zimmern, declined. At this point, Professor Goldman suggested to David Bowen that he seek treatment in the private sector and recommended Dr Peter Gravett at the London Clinic. When David Bowen contacted Dr Zimmern to ask the health authority to cover the cost of treatment in the private sector, Dr Zimmern refused.

Subsequently, David Bowen brought legal proceedings against Cambridge and Huntingdon Health Authority in March 1995. The High Court judge, Mr Justice Laws, ruled that the health authority must reconsider its decision. However, the same afternoon three judges in the Appeal Court overruled this decision. The case then captured the attention of the press and an anonymous donor offered to pay for the treatment. A few days later Jaymee was admitted to the Portland Hospital and began her treatment privately under Dr Gravett. Having used chemotherapy to get Jaymee into remission, Dr Gravett had to consider how to tackle the next stage of her treatment.

At this point, Dr Gravett went to an international conference at Davos in Switzerland. It was on a train to Davos when talking to two colleagues that he first seriously considered donor lymphocyte infusion as a possible treatment option. Although nobody really knew whether and how it would work in children with AML, Dr Gravett decided to opt for donor lymphocyte infusion instead of a second bone marrow transplant. The treatment ended in July and Jaymee was well enough to return to school and to celebrate her eleventh birthday in August. The health authority took over the costs of her continuing care in September and in October the ban on her identification was lifted and her identity was revealed in a BBC television programme, *Panorama*.

In the last few months of her life, Jaymee developed complications associated with her illness and she died in May 1996. Nevertheless, she survived longer than most experts had predicted. The doctors who treated Jaymee felt that the new technique had given a few extra months of life of reasonable quality. It was this that stimulated widespread discussion of the case in both the newspapers and the academic literature. Child B came to epitomise the dilemmas involved in making tragic choices in health care, particularly those involving individuals with life-threatening illnesses. The fact that the treatment concerned was expensive, and was perceived as having a limited chance of success, accentuated these dilemmas.

Synopsis of key dates

September 1990	First biopsy on Jaymee diagnosing non-Hodgkin's lymphoma.
December 1993	Jaymee diagnosed as having acute myeloid leukaemia.
March 1994	Jaymee's bone marrow transplant at the Royal Marsden.
January 1995	Tests showed that Jaymee had relapsed: Jaymee given 6–8 weeks to live. Meeting of David Bowen with Dr Valerie Broadbent. David Bowen meets with Professor Ross Pinkerton. David Bowen makes contact with Drs Zeltzer and Cairo.
February 1995	David Bowen meets Professor John Goldman. Jaymee's first meeting with Dr Peter Gravett. Cambridge and Huntingdon Health Authority's decision to refuse funding of Jaymee's treatment.
March 1995	Judicial review. Jaymee begins treatment privately with Dr Gravett.
August 1995	Jaymee's eleventh birthday.
October 1995	Anonymity order lifted in Court of Appeal. *Panorama* television programme broadcast.
May 1996	Jaymee dies.

Glossary of key medical terms

non-Hodgkin's lymphoma	A cancer of lymphoid cells which usually appears as enlargement of the lymph glands and may involve other organs.
acute myeloid leukaemia (AML)	A cancer of the blood which affects white blood cells and which gradually takes over and destroys the bone marrow.
bone marrow transplants	The collection and transfusion to a patient of bone marrow cells collected from a healthy donor, usually a family member. Transplantation follows very high dose chemotherapy which destroys the patient's own bone marrow.
donor lymphocyte infusion	The collection and transfusion to a patient of lymphocytes collected from the original bone marrow transplant donor in order to mediate a 'graft versus leukaemia' effect for the treatment of leukaemia in relapse.
extra-contractual referrals (ECR)	Referrals made to providers not covered by a health authority's normal contracts.
tertiary referral	Referral of a patient from a secondary centre (i.e. from specialist to specialist) as opposed to GP referral to specialist.

Chapter 1

Jaymee's story

The father's tale

Ever since Jaymee was diagnosed as having cancer in 1990, her father, David, had become accustomed to living with the uncertainty that accompanies such a diagnosis. After the initial shock had worn off, his response was to do everything in his power for his daughter and he left no stone unturned in the search for a cure. In this quest, he was both single minded and largely single handed. David Bowen's marriage to Jaymee's mother, Alyson, had broken down in 1986 and he then took responsibility for bringing up Jaymee and her younger sister, Charlotte (Barclay, 1996). Throughout this period he received support from his new partners and from his parents. But it was his determination to seek out the best possible treatment for Jaymee that led to the events set out below.

Until Jaymee relapsed in 1995, David was largely satisfied with the way in which the NHS treated Jaymee. As he commented to us during interview:

> 'The overall care was fine'.

If there were complaints, these were of a relatively minor nature, such as the difficulties for parents who wanted to stay overnight in hospital with their children and the lack of time for staff to explain what was happening. The clinical care provided at both Addenbrooke's and the Royal Marsden was good with David observing:

> 'I knew if I had to have a bone marrow transplant, Ross Pinkerton was the one'.

Following the transplant which Professor Pinkerton undertook at the Royal Marsden in 1994, Jaymee went back to Addenbrooke's for routine blood tests and as a result of these early in 1995 it was found that Jaymee had relapsed. David described how he knew something must be wrong because Jaymee was called back to the hospital after one of these tests. He remembered being told that Jaymee's leukaemia had returned.

On hearing this he described how:

> 'The ground opened up and swallowed me. It was utter helplessness. I was on the floor'.

The advice from the specialists at Addenbrooke's was that palliative care was the preferred option in the circumstances. David Bowen recalls being advised:

> 'Go home and help her to enjoy the rest of her life'.

To the father of a dying child who had fought for five years to find a cure, this was difficult for him to accept. Not only did he feel that there was a lack of sensitivity in how the news was broken, but also he was unwilling to accept that the end of the road had been reached. Accordingly, Jaymee's doctor at Addenbrooke's, Dr Broadbent, arranged for him to see Professor Pinkerton at the Royal Marsden for a second opinion, having told David that Jaymee had between six and eight weeks to live. Professor Pinkerton confirmed Dr Broadbent's view, although he did discuss alternative options with the family, whilst making it clear that at best these would buy time rather than offer a cure.

As time was of the essence, David Bowen short circuited most of the standard routines, making his own arrangements to seek professional advice, using faxes and phones, and working long hours on Jaymee's behalf to research alternative methods of treatment. One of the most important sources of help was the library at the Royal Society of Medicine in London. Initially, David had to pay £15 for a ticket to use the library but after that it was free and the librarians were very helpful. He used the library's resources to learn about different kinds of leukaemia and research into treatment. As a result, he felt he was more knowledgeable about Jaymee's illness than some of the doctors responsible for her care. His view was that:

> 'oncologists are the general practitioners of the cancer world'.

In making this comment Bowen was arguing that only those with detailed knowledge and experience of particular forms of leukaemia were in a position to advise on the latest treatment options. In his view haematologists were better equipped to treat Jaymee's form of cancer than paediatric oncologists.

He therefore began a worldwide search for help, contacting doctors in Europe, New Zealand, the USA and elsewhere.

David explained that he did this by reading books, using his brother who lived in the USA, and phoning doctors at home and in hospital. The fact that he needed little sleep – no more than four hours a night – was particularly helpful in making contact with specialists in other time zones. If he couldn't speak to them directly, he would explain his situation to their wives or secretaries, in the process winning their sympathy for a child's illness and ensuring that the phone calls were always returned. His search eventually led to California where Drs Cairo and Zeltzer advised that a second bone marrow transplant could be undertaken with a higher chance of success than indicated by specialists in the UK. David obtained the protocol used in California and recounted how a few days later he turned up with a sheaf of faxes and notes to see Professor Pinkerton at the Royal Marsden.

David described Professor Pinkerton's reaction as one of shock when confronted by the results of this research. He persuaded Professor Pinkerton to phone Dr Zeltzer who had already received details of Jaymee's condition. Despite the advice coming from the USA, Professor Pinkerton remained of the view that palliative care was the best option. In this he was influenced by experience of conducting second transplants on other patients and observing the agony they experienced. He was also 'a little surprised' at the high probabilities of a successful outcome cited by US clinicians, not least given the paucity of published data on second transplants. For his part, David Bowen argued that Jaymee had always responded well to treatment in the past and there was no reason she should not do so again. He was prepared to persist rather than to accept the advice he was given because:

> 'I was all a little girl had'.

In his own words, he recognised from the doctors' point of view:

> 'I was being a pain in the arse',

but he felt he had no option in the face of the unwillingness of the doctors to change their minds, particularly given the short time Jaymee had been given to live. Dr Broadbent experienced David Bowen's anger at first hand, noting during interview that:

> 'It is very rare to come across a father, a person, like this'.

She added that the difficulties encountered at this point were part of a pattern of an established behaviour. There had been previous occasions on which David Bowen would 'cause an almighty scene' on the ward and in the hospital in order to get his way. This caused problems for both staff and other patients and affected how he was seen by those responsible for Jaymee's care.

In the light of this, it was perhaps not surprising that David Bowen's relationship with Dr Broadbent came under strain. He described phoning Dr Broadbent from a pay phone outside Professor Pinkerton's office to ask what she thought of the information he had sent her on the US treatment programme. According to David Bowen, Dr Broadbent replied that she had been too busy to study this information and:

> 'she told me my time would be better spent with my daughter in the time she had left rather than running around trying to find a cure'.

At this he snapped and made a complaint to the hospital about her behaviour.

Following his meeting with Professor Pinkerton, David Bowen decided to seek a further opinion within the UK. The advice he received from overseas was to contact Professor Goldman at the Hammersmith Hospital. Because time was short:

> 'I lied to get to see him'.

David Bowen explained to Professor Goldman's secretary that a referral was on its way, even though this was not the case, and he and Jaymee were given an appointment almost immediately. Professor Goldman put Jaymee's chances of going into remission following chemotherapy at around 20 per cent and advised that further treatment rather than palliative care should be considered. At this point David Bowen approached the health authority to fund the treatment, having persuaded Dr Broadbent to fax a referral to Professor Goldman retrospectively.

In his dealings with the health authority, David Bowen emphasised the value of the help he received from secretaries and junior staff – the 'little people' as he described them – who told him what to do and to whom to speak. At no point did he meet directly with the health authority's staff and communication was entirely by phone or more usually fax. Having taken clinical advice, the authority refused to pay for the treatment. On Professor Goldman's recommendation, David Bowen then approached Dr Peter Gravett, a cancer specialist working in the private sector.

Dr Gravett agreed to take on Jaymee as a private patient with a commitment to offer chemotherapy followed by further treatment if she went into remission. At this point, Dr Gravett understood that the Bowen family had private health insurance cover and that the costs of treatment would be met in this way. In fact, the insurers decided that Jaymee's leukaemia was a pre-existing medical condition and therefore was not covered by the terms of the policy. David Bowen then went back to the health authority to request that they cover the costs of her care. As he explained to us:

> 'I was on my knees, pleading for the money'.

Again, the health authority refused. As a final gamble, David Bowen approached his solicitors to seek leave for a judicial review to challenge the authority's decision. This was granted and with legal aid in place preparations were made for the court proceedings. The High Court took the view that the authority should reconsider its decision but this was overturned on appeal. By now the intense media interest in the case had made Child B headline news and a private donor offered to provide funds for the treatment. David Bowen accepted this offer through his solicitors and Dr Gravett took over Jaymee's care.

David Bowen had complete faith in the way Dr Gravett handled the case and he felt this faith was shared by Jaymee. Bowen argued that Dr Gravett had time to explain what was happening in a way that some of the other doctors involved in her treatment did not. In his view, this helped in accounting for Jaymee's positive response. David Bowen felt so strongly that he commented:

> 'I have nominated him [Gravett] for sainthood'.

In the event Dr Gravett decided not to undertake a second transplant but instead treated Jaymee using an experimental form of treatment known as donor lymphocyte infusion. He had used this treatment on three previous patients, one of whom was a child relapsing after bone marrow transplant for acute lymphoblastic leukaemia. At the Davos conference in Switzerland, where he decided to use donor lymphocyte infusion, Dr Gravett tracked down 47 case reports of patients in Europe who had been treated in this way. His discussions at Davos with colleagues persuaded him that this option held out the best hope for Jaymee, although her particular form of cancer, acute myeloid leukaemia as a second malignancy, meant that the outcome was inherently uncertain.

In Jaymee's case, donor lymphocyte infusion enabled her to enjoy a few extra months of life. Both David Bowen and Dr Gravett felt that these months of life were on the whole of reasonable quality. In David's view, this more than justified his persistence. As he argued:

> 'I was not just grasping at straws, but taking a calculated gamble'.

As a father he wanted to do whatever he could for his daughter and he felt that the evidence he had been presented with warranted further medical intervention. He sought to protect Jaymee from full knowledge of her condition and prognosis, at least until the anonymity order was lifted in October 1995, in the belief that the chances of a successful outcome would be enhanced by keeping her happy and feeling positive. In this respect his approach was paternalistic in the true sense. As he commented:

> 'Jaymee would have shut down if she knew she only had 6 to 8 weeks left and was very ill'.

David Bowen believed that Jaymee's response to both the chemotherapy and donor lymphocyte infusion confirmed that he was right to protect her from full knowledge of her condition. Although she became seriously ill again in the last stages of her life, this did not involve the horrifying side effects that some doctors had feared when they advised against further intensive treatment. To this extent, both he and Dr Gravett had little doubt that the correct course of action had been taken.

The health authority's perspective

Jaymee Bowen's case came to the attention of Cambridge and Huntingdon Health Authority in February 1995 when its director of public health, Dr Ron Zimmern, became aware that David Bowen was seeking a range of clinical opinions on her illness and alternative treatment options. Dr Zimmern happened to be at Addenbrooke's Hospital at the time and described how he went immediately to see Dr Broadbent whom he found in a distressed condition. By this stage David Bowen had taken Jaymee to see Professor Goldman at the Hammersmith Hospital without a referral from Dr Broadbent. David Bowen then approached the health authority to fund treatment at the Hammersmith.

After taking advice from the doctors who had been involved in Jaymee's treatment up until that point, and following consultation with the authority's chairman and chief executive, Dr Zimmern sent the following response to David Bowen:

> 21 February 1995
>
> Dear Mr Bowen
>
> Thank you for your fax. I have spent much of today in detailed discussions with colleagues about Jaymee's care, including Professor Goldman. I understand totally your concerns and the sense of distress which you must feel. Should there be any misunderstanding I should state quite clearly that any decision taken by the Commission* will be made taking all clinical and other relevant matters into consideration and not on financial grounds.
>
> The Commission has funded, and continues to fund, bone marrow transplantations. The Commission is also supportive of second, and in difficult cases, third opinions and is grateful to have had the benefit of Professor Goldman's opinion from the Hammersmith following her out-patient consultation, which we understand was arranged by yourself. Dr Broadbent confirms that she subsequently sent a fax to Professor Goldman, at your behest, outlining Jaymee's clinical condition. I understand from Professor Goldman that his opinion was subsequently sent to Dr Pinkerton and Dr Meller at the Marsden and to Dr Broadbent at Addenbrooke's. I have had the benefit of seeing that correspondence and of noting Professor Goldman's views.
>
> ./.

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* The term 'Commission' is used here as a synonym for the Cambridge and Huntingdon Health Authority.

He has subsequently confirmed to me that the line of treatment that he indicated might be a possibility for Jaymee was at variance with majority opinion and would be properly categorised as experimental rather than standard therapy.

I have discussed the nature of Professor Goldman's opinion with Dr Broadbent and Dr Meller and have noted also Dr Pinkerton's view about current Marsden policy of not re-transplanting allografts in the paediatric unit because of the very low likelihood of long term benefit outweighing early morbidity. I know that the clinicians involved in her present care have discussed between themselves the best way forward in the light of Professor Goldman's opinion. My understanding is that they have not changed their opinion after careful consideration.

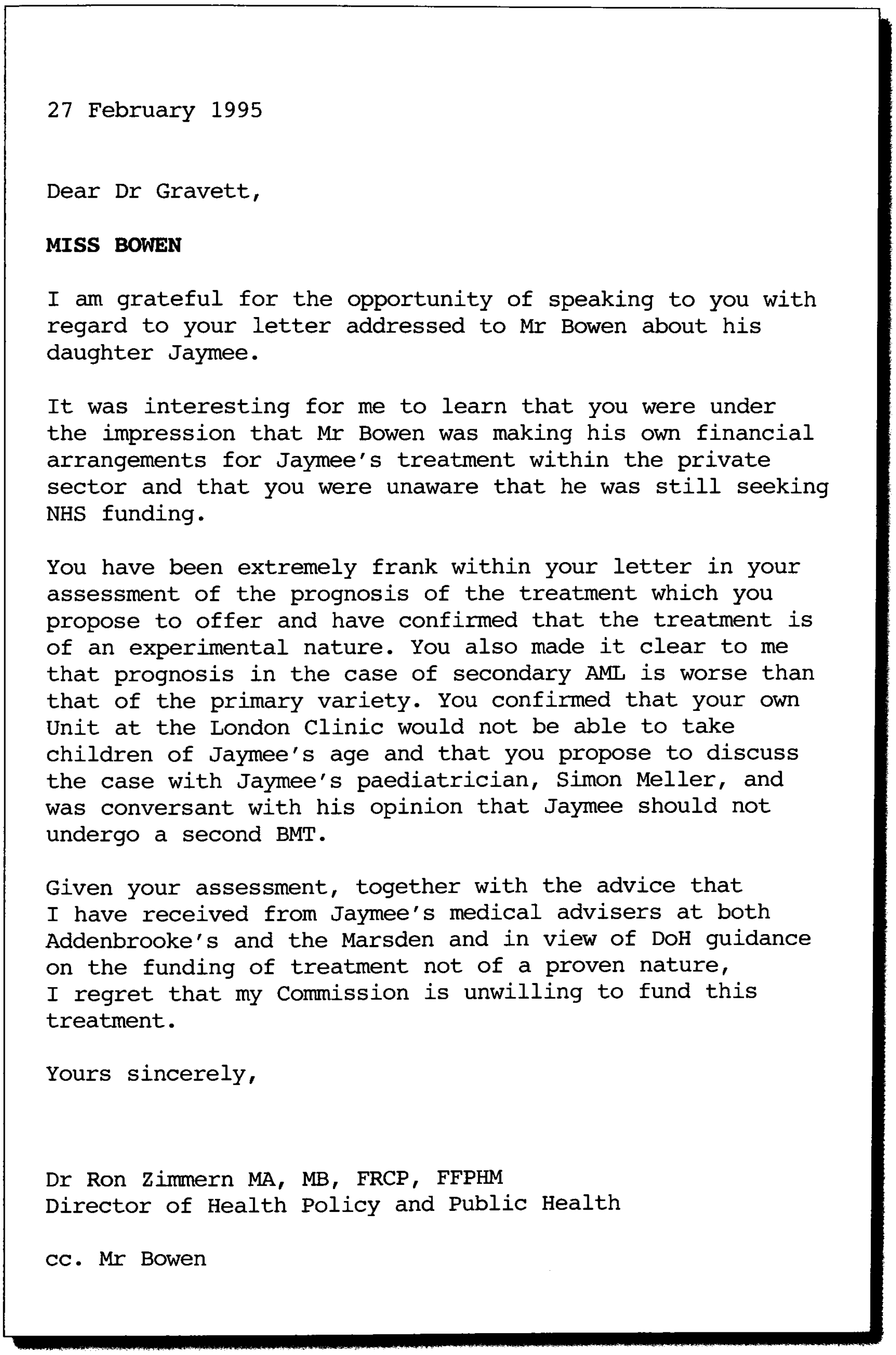
At present no formal request for funding has yet been made to the Commission from any hospital, but I would like to emphasise that any decision on this issue will be taken in the light of all the clinical advice available to it in the context of DoH guidance on the funding of unproven or experimental treatments, at all times with Jaymee's best interest in mind.

At this stage I have to say that on the evidence provided to us it is unlikely that we will authorise further intensive chemotherapy for Jaymee but will always keep under review the nature of the clinical advice that we receive.

Yours sincerely

Dr Ron Zimmern MA, MB, FRCP, FFPHM
Director of Health Policy and Public Health

One of the uncertainties that arose in making this response was whether an extra contractual referral (ECR) had in fact been made in this case, given that David Bowen had made his own arrangements to see Professor Goldman and Dr Broadbent had authorised the referral retrospectively and reluctantly. The issue was resolved when David Bowen sent a further request for funding to treat Jaymee privately under Dr Peter Gravett enclosing a detailed letter from Dr Gravett. At this point the health authority decided that an ECR request had been made and after further consideration it again declined to pay for treatment, reiterating its view that palliative care was the preferred option. Dr Zimmern's letter to Dr Gravett communicating this decision stated:



27 February 1995

Dear Dr Gravett,

MISS BOWEN

I am grateful for the opportunity of speaking to you with regard to your letter addressed to Mr Bowen about his daughter Jaymee.

It was interesting for me to learn that you were under the impression that Mr Bowen was making his own financial arrangements for Jaymee's treatment within the private sector and that you were unaware that he was still seeking NHS funding.

You have been extremely frank within your letter in your assessment of the prognosis of the treatment which you propose to offer and have confirmed that the treatment is of an experimental nature. You also made it clear to me that prognosis in the case of secondary AML is worse than that of the primary variety. You confirmed that your own Unit at the London Clinic would not be able to take children of Jaymee's age and that you propose to discuss the case with Jaymee's paediatrician, Simon Meller, and was conversant with his opinion that Jaymee should not undergo a second BMT.

Given your assessment, together with the advice that I have received from Jaymee's medical advisers at both Addenbrooke's and the Marsden and in view of DoH guidance on the funding of treatment not of a proven nature, I regret that my Commission is unwilling to fund this treatment.

Yours sincerely,

Dr Ron Zimmern MA, MB, FRCP, FFPHM
Director of Health Policy and Public Health

cc. Mr Bowen

At an early stage Dr Zimmern realised that the case could assume wider significance. He therefore took particular care to seek the views of clinicians and to involve close colleagues in the health authority. As director of public health, Dr Zimmern was responsible for cases of this kind and particularly for handling ECR requests. He explained to us that:

> 'I get two or three difficult ECRs a week'

and it was normal practice for him to make decisions on these requests using the authority delegated to him. In Jaymee Bowen's case:

> 'There was no reason in terms of our ordinary process that this should be discussed'

more widely in the health authority, but because his 'sixth sense' told him that the case was likely to be particularly difficult, Dr Zimmern made sure that other members of the health authority were aware of the situation. The colleagues concerned were Stephen Thornton, Chief Executive, Maggie Scott, Chairman, and Robert Jefford, Head of Administration. As chief executive, Stephen Thornton's involvement was particularly close.

Dr Zimmern explained that the discussions about Jaymee's case were conducted in the light of the authority's set of agreed values (see below). He also explained that initially he was more committed to the decision than his colleagues:

> 'certainly, in the first 24/48 hours it was me who was pushing for it not to be funded'.

The health authority staff involved were in general agreement with the decision that Dr Zimmern had arrived at initially, although there were various shades of opinion held among them as to certain aspects of the case, including that of the political fallout and possible implications in the local community and wider NHS. But they presented a cohesive view throughout the period of time leading up to the judicial review and beyond. This was helped by the open, informal communication style of the health authority and the fact that they had an open-plan office, for example, which encouraged the interchange of ideas and information. Only when the judicial review proceedings were brought were plans put into operation for a fuller, but still informal, health authority meeting, comprising the chairman, two non-executive directors and four executive directors. The plan was for this group to meet following the review, should they be required to come to a decision in the event that the Court of Appeal found against them, but this was not necessary.

One of the principles which guided Dr Zimmern in his approach was that of a perceived duty to take seriously the role of health authorities in priority-setting in the wake of the NHS reforms initiated in 1991. Prioritising and rationing decisions came under the remit of health authorities and were not left solely to clinicians, as in the old days. Here, Dr Zimmern's stance was informed by two distinct responsibilities, the first arising from his role as chief medical adviser to the health authority, the second from his position as an executive director of the authority. Dr Zimmern spoke of:

> 'a genuine feeling that if one's not going to turn down funding for something like this then we might as well give up and go home'.

Prioritising decisions, he explained, had always been and continued to be a routine part of clinicians' daily work. This is a necessary aspect of the contract system, which allots a finite amount of money to a hospital to carry out its work. Because the need to make a decision had arisen through unusual circumstances, it was not a proper course of action, he believed, for the health authority to duck its responsibilities as a purchasing organisation and hide behind implicit rationing decisions. Certainly it was not the way for the health authority to conduct its business. The NHS reforms and the purchaser-provider split had made rationing decisions more explicit and choices such as those involving Jaymee were unavoidable. As he commented:

> 'because it's being done in the public eye we must be just as robust about our decisions'.

The health authority recognised that its approach involved greater risks than the alternative, namely to acquiesce to the pressure exerted by David Bowen and to fund treatment, even though this would have conflicted with its values. The latter course would have been the line of least resistance and would have undoubtedly resulted in a quieter life for those most closely involved in making the decision. It would, however, have been an abrogation of the responsibility given to the health authority to use its resources in the best interests of the population as a whole and to purchase services of proven clinical effectiveness.

From this perspective, Jaymee Bowen's case epitomised the inherent tension between a concern for the interests of individuals and a desire to meet the needs of the community as a whole. As the health authority pointed out, at around the same time it did agree to fund treatment for a patient with haemophilia at a cost of over £200,000 because in this instance the advice received was that this was an effective and appropriate use of resources. Jaymee's case was different in that the clinicians who knew her well felt that further intensive treatment was likely to do more harm than good. For this reason the health authority refused to fund other than palliative care and was willing to take a stand not just on the individual case but on the wider principles involved.

The consequences for the individuals involved in the health authority were profound. Not least, they were criticised in the media and also suffered personal abuse. As Stephen Thornton commented after the event:

> 'Coping with the sometimes unbearable public pressures this creates for individuals in my position is now just part of the job. NHS management is no longer for the faint hearted'. (Thornton, 1997, p. 1839)

Thornton and his colleagues were willing to take this risk because they believed this was a decision that would benefit from public debate. In the process, the health authority attracted admirers as well as critics and while the tabloid press vilified the authority for its approach, often personalising this around those, like Stephen Thornton and Ron Zimmern, who took most responsibility for explaining the basis of their decisions, many within the NHS wrote in support of the stance that the authority was taking. Most notably, Virginia Bottomley, Secretary of State for Health, was impressed by the way in which the authority in general, and Stephen Thornton in particular, handled this case. As she told us, Thornton 'took a lot of flak', and she admired his resilience in the face of pressure.

On this aspect of the case, as on many others, opinions were sharply divided. What was not in doubt was that the health authority had a choice as to the approach it should take. By deciding not to fund treatment, it started a chain of events whose consequences were felt well beyond Cambridge.

The influence of values

Cambridge and Huntingdon Health Authority had committed itself to a set of values which it included in its 'purpose, role and values' statement, formally adopted by the health authority in January 1994. The values themselves were to a large extent culled from those adopted by the former East Anglian Regional Health Authority (RHA). They were those of effectiveness, efficiency, equity, accessibility, appropriateness and responsiveness.

Dr Zimmern considered appropriateness, effectiveness and responsiveness to be particularly apposite in formulating a decision on this case. He believed the use of such values had made his decision more rigorous and capable of standing up to scrutiny:

> 'I would say one of the most important things was the fact that we had to consider the case and deal with its pros and cons against the background of a set of values. We weren't just doing it in a vacuum with no guidance ...'

As set out in his original file notes, Dr Zimmern applied these values at the time as follows:

> 'Equity: There is an opportunity cost to funding further intensive chemotherapy and BMT. Given existing pressures on both the ECR and Oncology budgets it would be inequitable to decide in favour of Jaymee.
>
> Appropriateness: The opinion of her present expert medical advisers, paediatricians and paediatric oncologists alike, is that it would be clinically wrong for her to be submitted to further medical treatment. The contrary opinion, from John Goldman, is from an adult leukaemia specialist. It could be argued that he had not taken adequately into account the holistic perspective of Jaymee's care, nor taken into account that Jaymee had already been subjected to treatment for a prior malignancy (NHL) before she developed AML.

> Effectiveness: There is a general agreement about the experimental nature of the proposed treatment. We should have regard to EL (94) 74 on Improving the Effectiveness of the NHS, and this year's Priorities and Planning Guidance which states 'that the available resources should be devoted to measures which are known to be effective and that expenditure on programmes which are less effective should be progressively reduced' and the view from the NHS R&D Directorate (echoed by the UKCCSG) that experimental treatments should ideally be given in the context of a randomised trial.
>
> Efficiency: In this particular case, it has to be accepted that the payoff in terms of cost benefit is likely to be low.
>
> Responsiveness: In this particular instance we are dealing with a minor. We understand her father's natural concern for her to receive the best treatment possible. But in making a decision about responsiveness in a child we should adopt the same principles as underpin all forms of legislation regarding the rights of children, including the Children Act and accept that the needs of the child are 'paramount'. I am entirely convinced of the sincerity of Val Broadbent and her colleagues in acting in Jaymee's best interests and would argue strongly that to follow any other course, despite her father's frantic search for a miracle cure, would not be in Jaymee's best interest.
>
> Accessibility: Not an issue here.'

Two aspects of the application of these values are of particular note. First, as the above statement makes clear, the authority's decision was based mainly on considerations of appropriateness and effectiveness. Finance is mentioned, particularly in relation to the 'opportunity cost' of treatment and the 'cost benefit' of a second transplant, but this was felt by Dr Zimmern to be of lesser importance. As he explained in a letter sent to David Bowen on 21 February:

> 'Should there be any misunderstanding I should state quite clearly that any decision taken by the [Commission] will be made taking all clinical and other relevant matters into consideration and not on financial grounds.'

However, in the affidavit sworn by Dr Zimmern for the purpose of the judicial review, the financial strand was mentioned. He described his reasoning as follows:

> 'First and foremost I had to consider whether the proposed course of

> treatment was clinically appropriate for Jaymee. I also had to consider whether it would be an effective use of the [Commission's] limited resources, bearing in mind the present and future needs of other patients'.

Referring to the guidance of the Department of Health with regard to experimental treatments, he continues:

> 'The ethical use of resources demands that new and expensive treatments are evaluated before they are transferred to the NHS for service funding ... I also considered that the substantial expenditure on treatment with such small prospect of success would not be an effective use of resources. The amount of funds available for health care are not limitless. The respondent has a responsibility to ensure that sufficient funds are available from their limited resources for the provision of treatment for other patients which is likely to be effective'.

While the decision-making process presented by Dr Zimmern was based predominantly on clinical issues, the financial motif is an important theme weaving itself throughout the attempt to demonstrate the applicability of the values. It certainly stands out to the reader as a factor of some significance. Mr Justice Laws, in his High Court judgement, discerns two distinct strands to the health authority's decision:

> 'The respondents' decision was based upon two grounds:
>
> i) that the proposed treatment would not be in the best interests of J.; and
>
> ii) the substantial expenditure on treatment with such a small prospect of success would not be an effective use of the limited resources bearing in mind the present and future needs of other patients'.

There is no doubt, then, that the issue of funds entered into the decision-making process, although in a secondary capacity, after that of clinical considerations. This generated confusion in the public perception and media reporting of the case. It also angered the paediatricians involved who argued consistently that their decision not to recommend intensive chemotherapy followed by a second transplant was based on considerations of clinical effectiveness alone.

The judgement of the High Court acknowledged the confusion which the health authority's stance would have given rise to on the part of an onlooker. Mr Justice Laws stated:

> 'On 21 February 1995 ... Dr Zimmern said to B's father: "Should there be any misunderstanding I should state quite clearly that any decision taken by the Commission will be made taking all clinical and other relevant matters into consideration and not on financial grounds." His affidavit was sworn precisely a fortnight later. The father might, I think, be forgiven for reflecting that it amounted to something of a volte-face'.

The second key aspect was the relationship between the health authority and the Bowen family, especially given that one of the authority's values was responsiveness. Dr Zimmern's policy with respect to ECR decisions, such as Jaymee's, was to preserve an arm's length detachment from patients. This was manifested in his refusal to meet the patients or family connected with ECRs. Dr Zimmern himself described the policy as lacking in official sanction by the health authority, and one he had adopted for pragmatic reasons. He explained to us:

> 'I have always declined [to talk to patients] on the basis that I cannot make an objective judgement. I will talk to the GP, the consultants, but not the patient – to preserve myself but also because all you get is a pile of emotional baggage that detracts.'

From the father's perspective, the difficulty of obtaining access to those responsible for making decisions was a major problem. Although junior staff in the health authority were unfailingly helpful in advising on whom to contact and the procedures to be followed, David Bowen felt that the policy of not seeing patients and their relatives was 'just a waste of space', adding 'it did not go down well with me'. The real problem he encountered was finding someone to help and advise when the views of doctors conflicted. In this context, the detachment of the authority was a hindrance, simply adding to the problems faced by a father running short of time in a desperate search for a cure. Mr Justice Laws in the High Court was also critical of the detachment shown by the authority.

The involvement of clinicians

When the matter was brought to Dr Zimmern's attention, he considered the facts and talked to the consultant, Dr Valerie Broadbent, at Addenbrooke's Hospital. In the course of discussions with her, Dr Zimmern learned that the referral to Professor John Goldman at the Hammersmith Hospital had been made 'under duress'. Dr Broadbent's letter to Professor Goldman had stated that she was unhappy with the clinical decision to consider Jaymee Bowen for a second bone marrow transplant. In her letter she said:

> 'It is against my medical judgement that a second transplant is indicated and I would therefore have difficulty in recommending this within the NHS'.

Dr Zimmern further informed himself in this process with recourse to the views of two other experts in the field, both of whom had been involved in Jaymee's prior treatment. Professor Pinkerton's view was given in a note dated 24 January which stated a number of management options and records:

> 'Our current policy at the Marsden is not to re-transplant any allograft in the paediatric unit, as in my view the likelihood of long term benefit does not outweigh the early morbidity'.

Dr Simon Meller, his colleague at the Royal Marsden, concurred with this viewpoint. Dr Zimmern's file note states:

> 'It was his opinion that Jaymee should not be subjected to further treatment of this nature and, when I stated that I was minded to turn down any ECR request for intensive chemotherapy or bone marrow transplant, he stated that he felt that this was an appropriate decision'.

Dr Zimmern felt able to reach a decision which he recorded in his file. Dated 21 February 1995, it reads:

> 'I believe that the Commission should refuse to fund Jaymee's further treatment by way of an ECR. Her care has been co-ordinated by Val Broadbent for some years and any palliation and further care should be carried out at Addenbrooke's'.

Dr Zimmern did speak to Professor Goldman, after he had made his decision, on the late afternoon of 21 February. It was recorded in his file note dated 23 February. This states that Professor Goldman confirmed that he had been aware David Bowen had sought his clinical opinion without having been referred by a GP or consultant. He described the treatment proposed as 'experimental' and with a low probability of success. The file note also stated that Professor Goldman had a genuine difference of opinion with his colleagues at the Royal Marsden and at Addenbrooke's, believing that intensive chemotherapy was indeed a further option.

Dr Zimmern also corresponded with Dr Gravett following Jaymee's consultation with him. In deciding between the experts, a point which will be discussed in more depth later, Dr Zimmern felt confident that the paediatricians had more concern with the 'holistic' aspects of Jaymee's treatment and therefore that their views were in some ways more valid. The decision he made was in accordance with a prescribed set of values to which the health authority was committed. He later explained to us that this degree of rigour and robustness in setting out the reasons explicitly was exceptional:

> 'I didn't do this after the event, but there and then, which is very unusual'.

This reflected his feeling that the case would assume wider significance.

Divisions of opinion among the doctors involved were of fundamental importance in determining how the case was handled. As the paediatrician responsible for Jaymee's treatment and someone who had come to know the family well, Dr Broadbent took particular care to weigh up the available alternatives. She was aware that David Bowen would want to explore every possibility for Jaymee and so she sought the advice of colleagues, consulted the literature and sought information from the European and international bone marrow transplant registries. Having done so, Dr Broadbent's view was reinforced that not only was Jaymee's case unusual, in that her leukaemia was a second malignancy after non-Hodgkin's lymphoma and that she had relapsed quickly following the bone marrow transplant, but also that further intensive treatment was not appropriate. As she commented during interview:

> 'We do have relapse protocols for patients with AML but not for those who have AML and have relapsed as a second malignancy'.

All of her clinical experience confirmed that further intensive treatment would not be in the patient's best interests and there were no published data to suggest that such treatment was appropriate. This view was shared by both Professor Pinkerton and Dr Meller at the Royal Marsden.

Although they knew Jaymee less well than Dr Broadbent, their experience confirmed her opinion that intensive chemotherapy followed by a second transplant was likely to do more harm than good. This was reinforced by data from the bone marrow transplant registries, which, in the absence of published studies, were the best source of evidence in cases of this kind. The paediatricians involved were particularly concerned that the chemotherapy needed to get Jaymee into remission carried significant risks for a child with her medical history. Furthermore, the data they obtained from the bone marrow transplant registries showed that all patients with AML who had been re-transplanted had died. As Dr Meller commented to us:

> 'I don't intend to have any more experience of second transplants within 12 months of the first because all four or five I've seen have been a disaster and afterwards the parents wished they hadn't agreed to their child having a second transplant. That's my database, that's how I make decisions. I won't go on doing treatments that I think are wrong for children or unkind to children'.

Professor Pinkerton argued that intensive chemotherapy should be administered only if there was a clear intention to proceed to a second transplant. As this was not a realistic option in his opinion, then chemotherapy was not appropriate.

The adult specialists, on the other hand, advised further chemotherapy with the aim of giving Jaymee a second bone marrow transplant in the event of remission being achieved. The stance taken by the adult specialists derived from their view that the outcome sought was not simply a cure but involved intervention to extend Jaymee's life and improve its quality. This was acknowledged by Professor Goldman who was careful to point out the absence of any black and white definitions of successful outcome. Assessing Jaymee's extra months of life in hindsight he said:

> 'I do not believe that her life would have been equally long without the remission. If you say that just prolonging people's life for six months is futile, then for practical purposes I'm out of business. We don't cure that many people with proper cancer. We do prolong their life. That's what oncology's all about'.

Professor Goldman saw the case as revolving around competing medical ideologies, with money being a 'big red herring' of no direct relevance to decision-making in this instance. He described the whole dispute as being about:

> 'doctors' philosophies about how to treat twelve year olds [sic] with poor risk leukaemia'.

In devising a programme of care for Jaymee, the paediatricians involved were concerned with her well-being seen holistically, what they called 'the best interests of the child'. They were guided by both scientific evidence and the precepts laid down by their professional body, the United Kingdom Children's Cancer Study Group (UKCCSG), as well as government guidance on the use of evidence-based medicine. The code of conduct adopted by the UKCCSG, although lacking statutory force, advised that children should be treated in paediatric facilities and that ideally experimental treatment on children should be done in the context of clinical trials. Dr Broadbent particularly laid great store on the Good Clinical (Research) Practice guidelines adopted by the UKCCSG.

These guidelines were intended to set a standard by which clinical trials are designed, implemented and reported, and they were also intended to protect patients (Ablett, 1994). Similarly, Dr Meller at the Royal Marsden invoked the guidelines prepared by the Royal College of Paediatrics and Child Health (formerly the British Paediatric Association) for the ethical conduct of medical research involving children in support of the view that intensive chemotherapy and a second transplant were inappropriate in Jaymee's case (Royal College of Paediatrics and Child Health, 1992). As the guidelines note, research should only be done on children if comparable research on adults could not answer the same question.

The paediatricians involved had strong views on unnecessary suffering inflicted with very little prospect of cure, especially on a child. They were concerned with what Dr Broadbent called 'good death and bad death'. In this case it was the belief of the doctors who had been treating her for a long time that a good death in Jaymee's case would be one aided by palliative treatment. A bad death would be one connected with intensive chemotherapy and its likely effects. Dr Broadbent stated in her affidavit to the High Court:

> 'I took the view that it would not be right to subject Jaymee to all of this

> suffering and trauma when the prospects for success were so slight'.

In this case, Jaymee was already in poor health owing to her many years of receiving treatment, not only with the intensive chemotherapy associated with her bone marrow transplant but also with her prior malignancy. This meant that she had limited marrow reserve and there was the possibility of other organs being damaged, especially her heart given high levels of cardiac toxicity. The chair of the bone marrow transplant group of the UKCCSG, Dr Cornish, endorsed the position of Dr Broadbent and Professor Pinkerton in refusing to treat Jaymee further with toxic drugs. Moreover, as her father wanted to protect Jaymee from full knowledge of her condition, her paediatricians felt it incumbent upon them to weigh up all the facts and make a decision based on her best possible interests, taking everything into account.

The adult specialists felt that treatment, although unlikely to result in a cure, should not be ruled out, particularly in view of the father's strong wish to access further treatment for his daughter. Professor Goldman did not advocate a second bone marrow transplant, although the discussion soon polarised around whether or not she should receive one. In fact, he advocated further chemotherapy to see if the patient could be brought into remission and then if this did occur a second transplant should be considered as a further option. He told us:

> 'If you see a patient with relapsed leukaemia it is now world wide convention to give further chemotherapy. If you achieve complete remission it is likely that the person lives longer than they would have done if they had not been treated with chemotherapy'.

Moreover, he believed that death from untreated leukaemia would be no more pleasant than that associated with further treatment, taking into account the possibility of toxic side effects which the patient might experience. On top of this, Jaymee herself had responded well to previous chemotherapy and bone marrow transplantation and it was clear that she had an indomitable spirit and courageous attitude to her illness. He said:

> 'I thought she deserved further treatment'.

A criticism voiced by the paediatricians was of the willingness of Professor

Goldman to agree to give an opinion, without consulting the specialists involved in her case on a long-term basis, and without being aware of all the facts. They also took issue with his view that chemotherapy was appropriate for multiply relapsed patients. These differences reflect the individualistic values to which medicine has always subscribed, particularly in the case of clinicians who have reached the top of the hierarchy and feel they possess sufficient expertise to act on the basis of their own judgement. Codes of conduct over such matters are very hard to enforce. As one paediatrician expressed it during interview:

> 'Some specialists would feel that somebody is trying to tell them how they should or shouldn't practise medicine ... It's very classical behaviour of famous specialists. They usually have a very large private practice and whatever rules we decide are appropriate within the NHS, they won't apply to private practice'.

Another of the paediatricians' criticisms was of the willingness of the adult cancer specialists to treat a child outside the realm of paediatrics. In contrast, the adult cancer specialists referred to the 'paediatric mafia' of child cancer specialists, with their conservative and inflexible attitudes, suggesting that adult specialists were more 'open-minded'. Eden, writing in the *BMJ*, depicts the nature of the close professional allegiance, described by Jaymee's paediatricians, not only in the UK but worldwide:

> 'What the public must recognise ... is the close collaboration among specialists in childhood cancer in Britain, Europe and the United States; we all speak to each other, communicate our results, and respond if results look superior in a particular centre or country. We share our successes and failures in order to optimise patients' care'. (1996, p. 575)

Some of those interviewed spoke of Professor Goldman's 'clinical arrogance' in being willing to recommend further treatment, despite the fact that leading child cancer specialists had already been involved in Jaymee's long-term care and considerations for further treatment. They claimed that, while indisputably one of the nation's leading experts on leukaemia, his expertise was mainly in the treatment of chronic myeloid leukaemia rather than Jaymee's illness, acute myeloid leukaemia. As Dr Meller noted:

> 'I think [Professor Goldman's] reputation is for his knowledge of a particular

> disease, chronic myeloid leukaemia, and all of us would go to him for advice about a difficult case. I don't think he would be regarded as the best opinion about acute leukaemia because it's not particularly his area of expertise, especially not in children. Now he would argue that he is a professor of leukaemia and would be able to give an opinion on any leukaemia case and I wouldn't dispute that'.

Dr Cornish also acknowledged Professor Goldman's expertise, conceding that the methods of transplantation are the same for adults and children, and agreeing that it was within his capacity to offer a critical opinion on the case. Professor Goldman argued that the expertise of others, who have also offered opinions, was not enough in itself to satisfy him that their views on a particular clinical matter were necessarily 'right'. His experience with tertiary referrals, he explained, had shown him the importance of coming to decisions about diagnoses, prognoses and treatment options afresh. Moreover, it was precisely in such independence of mind that lay his claim to integrity. He said:

> 'My function as a senior member of the medical profession is not to accept other doctors' opinions. And not even to accept them when they say: there's no need for a second opinion. Often it's the ones where they say there's no need for a second opinion that *most need* a second opinion'.

The approach of the specialists in adult leukaemia is further differentiated from the paediatric specialists by dint of the close relationship between the adult specialists and the world of private practice. Dr Gravett, as a private practitioner in Harley Street, took this comparison a stage further. In contrast to the self-regulation of the paediatricians involved, he explained that in private practice people are less constrained. In the NHS, particularly within the UKCCSG, he felt that paediatricians tend to operate within guidelines and protocols which appear rigid. Dr Gravett argued that:

> 'paediatricians feel that if there is no protocol, then there should be no treatment'.

By contrast, he maintained that the private sector is more flexible – less constrained and restricted by rules, more adaptable, therefore, to the demands of the consumer and better able to practise patient-centred medicine. The cultural difference between NHS and private practice was particularly noticeable in the attitude towards carrying out Jaymee's experimental treatment outside the confines of a clinical trial, a subject which will be considered later.

Dr Gravett also argued that both he and Professor Goldman had specialist expertise by virtue of being haematologists. He maintained that paediatric oncologists had expertise primarily with solid tumours rather than the type of cancer that Jaymee was suffering. David Bowen also felt that the haematologists were better placed than the paediatricians to recommend treatment options.

Dr Gravett was particularly critical of what he saw as 'empire building' by the paediatricians and their animosity to private practice. Against this, the paediatricians responsible for Jaymee's care argued that paediatric haematologists were better placed than adult specialists to advise on cases of this kind. They felt that David Bowen should have sought their advice if he wanted a further opinion. The paediatricians also disputed the view that the UKCCSG controlled the treatment of child cancer, arguing that specialist child cancer centres varied considerably in their approaches. Not only this, but they were also critical of Dr Gravett for even contemplating, let alone administering, intensive and experimental chemotherapy on Jaymee, given her medical history. Professor Pinkerton's view, expressed unequivocally, was that this was 'entirely inappropriate' in Jaymee's case.

The health authority's dilemma was which opinion should prevail when clinicians disagreed. Dr Zimmern summarised the dilemma as follows:

> '... the opinion of the experts was that if you gave her intensive chemotherapy to put her in to remission the chances of success of that intensive chemotherapy were only 10–20 per cent and only then would a second bone marrow transplant be considered and then the chances of that working were again 10–20 per cent. So the experts all agreed on her chances – they just disagreed on what to do with this'.

In fact, there were notable differences in the probability of success given by individual doctors. The US doctors consulted by David Bowen, for example, were much more optimistic, indicating that there was a 60 per cent chance of Jaymee coming through a second transplant successfully. This provided David Bowen (with ammunition to use in his battle to secure funding for further treatment. Yet Entwistle and colleagues have noted in relation to media coverage of the case:

> 'The difficulties of extrapolating from data about the average effects of treatment among a group of people to estimate an individual's chance of a favourable outcome were largely ignored'. (1996 b, p.109)

The clinicians involved expressed anger at the way in which the debate was transformed from a consideration of medical probabilities to one bearing distinctly political and financial overtones. By bringing the question of finance onto the agenda, they believed, Dr Zimmern was distorting the case, making an issue where there hadn't been one. It was felt that Dr Zimmern should not have built his 'academic rationing discussion' around such a high profile case, in which medical criteria had been the deciding factors and indeed the only appropriate ones. Their anger was accentuated by publication of Dr Zimmern's annual public health report in 1995 which focused on the dilemmas of priority-setting and rationing and referred specifically to Jaymee's case in the course of arguing the need for there to be:

> 'an adequate understanding of the ethical, economic and clinical issues surrounding rationing'. (Zimmern, 1995)

In making this point, the reluctance of clinicians themselves to engage in public debate of the issues should be noted. Although Dr Gravett did respond to the media's requests for information when he took responsibility for Jaymee's case, and while Professor Pinkerton participated in the *Panorama* television programme broadcast in October 1995, many of the clinicians expressed a reluctance to explain to reporters the basis of their decisions. This reluctance stemmed from a perception that their views would not be reported accurately and that they would be criticised for denying a child the right to life.

Reflecting on this after the event, Professor Pinkerton wondered whether he had done the right thing. He had turned down a request to appear on the *Frost* television programme after the court case, and felt that had he accepted then the clinical arguments for not proceeding with further intensive treatment might have been better understood. His fellow paediatricians did not share these doubts, arguing that the media had ignored a press release issued by the UKCCSG pointing out that paediatricians had never denied children treatment on the basis of finance alone, and maintaining that it was naïve to expect the media to give doctors' views a fair hearing in an emotive case of this kind. We discuss the role of the media more fully below; here we simply note that the public presentation of the case as an example of rationing to some degree reflected the stance taken by clinicians and their preference for private rather than public discussion of the issues.

Experimental treatment

From the very start of the debate, the proposed use of intensive chemotherapy followed by a second bone marrow transplant was described by Dr Broadbent and the health authority as experimental, both in the sense of high risk and in the sense of not having been evaluated. In discussion with Dr Zimmern, Valerie Broadbent explained her misgivings in recommending further intervention other than palliative care. Dr Zimmern's file note records:

> 'She confirmed that she would stand by the views stated in her letter and that any further definitive treatment would be of an experimental nature. She went on to state her view that experimental treatment of this nature, carried out on children, should only be done in the context of a randomised trial ... Professor Goldman rated the chance of success as less than 20 per cent. Val's view was that most experts would put it in the 10 per cent region'.

Again, in her affidavit composed for the judicial review, Dr Broadbent described:

> '... any further definitive treatment by way of intensive chemotherapy or a second transplant as being treatment of an experimental nature rather than for the genuine therapeutic needs of [B]'.

Dr Meller expressed the same view. Dr Zimmern's file note again:

> 'He affirmed that any further definitive treatment by way of intensive chemotherapy or a second BMT would be of an experimental nature, and if carried out should be done in the context of a randomised trial'.

Dr Zimmern's affidavit, in part summing up the clinical judgements of the experts involved, observed:

> 'I noted that Professor Goldman had agreed that the proposed treatment

> could and would be described as experimental. In other words, he agreed with Dr Broadbent, Dr Pinkerton and Dr Meller that the treatment could not be justified purely on therapeutic grounds and that the fundamental justification would be experimentation'.

Discussing the situation after Jaymee's death, Professor Goldman disputed the use of the word experimental if it implied that treatment should be withheld from a needy child. If there were no trials available to enter Jaymee into, then this was not a reason, in Professor Goldman's mind, for withholding the treatment from her. Commenting on the view that the UKCCSG believed that experimental treatment should only be done in the context of a randomised controlled trial, Professor Goldman said:

> 'If they think that, then I would say that this was *not* experimental, it was trying to treat a child in a way most likely to help her'.

The term 'experimental' generated controversy during the history of the case, not least in the law courts. In the High Court, Mr Justice Laws questioned the use of the term but it was accepted by the Court of Appeal judges. Part of the difficulty is that nowhere does a definition of the term 'experimental' appear in any of the statements given by those involved in the case. While this is a difficulty for those interpreting the case, it also becomes a practical problem for managers attempting to follow government guidelines. While clinicians may use it to mean different things, there are no guidelines which managers may themselves use to interpret the status of proposed treatments. In broad terms, the Appeal Court suggested, experimental would seem to mean that:

> 'unlike many courses of medical treatment, this was not one that had a well tried track record of success. It was, on any showing, at the frontier of medical science'.

Yet definitions of whether a treatment is experimental are often subjective. As Professor Goldman said:

> 'the word "experimental" is in the eye of the beholder. It's the same with "guinea pig" – I frequently have the word "guinea pig" used in my practice. Some people say to me, "if you want to use me as a guinea pig, please do."And other people say, "you've just used my daughter as a guinea pig – it's monstrous." Experimental is in that category. It's good or bad, in the eyes of the beholder'.

While a second bone marrow transplant undertaken in a patient with Jaymee's medical history may have been at the frontier of medical science, to adopt the phrase used by the Appeal Court, the treatment that was actually used – donor lymphocyte infusion – was even more untried and untested. However, as Dr Cornish explained to us in discussing the work of paediatric oncologists:

> 'We are often prepared to offer innovative treatments if other options have been exhausted'.

This was confirmed to us by Professor Pinkerton who noted that notwithstanding the advice issued by the UKCCSG:

> 'there is almost complete freedom in treating relapsed patients'.

He added that while the aim is to include experimental work as part of clinical trials, this does not always happen in practice. As a consequence, there are variations between different centres in their approach to treatment. Furthermore, while organisations like the European Group for Blood and Marrow Transplantation (Schmitz, Gratwhol and Goldman, 1996) have sought to define the circumstances in which transplants may be considered routine or developmental (a term often used as a synonym for experimental), this implicitly rejects the notion that experimental treatment should always be carried out in the context of a randomised clinical trial (Goldman, personal communication).

Attitudes to, and definitions of, experimental treatment have important policy implications, not least of which is the question of whether or not a health authority should be using its finite budget to fund it. Because the proposed second bone marrow transplant for relapsed AML was perceived to be of an experimental nature, Dr Zimmern felt justified in recommending against funding it. As he noted in his affidavit:

> 'The ethical use of resources demands that new and expensive treatments are evaluated before they are transferred to the NHS for service funding'.

Such treatment could, on the other hand, be funded out of a research budget. This was the point made by Dr Broadbent in her letter to Professor Goldman:

> 'You may have decided that an experimental treatment, such as it would be if you plan to go ahead, is within your research repertoire and budget and for this reason you may be willing to consider a second transplant'.

This is also linked with the question of the extent to which treatment, so far as it is experimental, should be undertaken outside the context of trials.

Drs Broadbent and Meller and Professor Pinkerton spoke with conviction of the desirability of conducting any high risk intervention, such as a bone marrow transplant, within the context of a trial whenever possible. Partly, this is due to the necessity for clinicians to gauge properly the benefits of such treatment in the progression of disease. After Jaymee's death, some medical experts declared that, because of the lack of a scientific framework, they had learnt nothing. *The Independent* (23 May 1996), quoting Professor Clifford Bailey (consultant paediatric oncologist, Leeds, former chair of UKCCSG and Secretary of the International Society of Paediatric Oncologists), pointed out that Britain leads in child leukaemia treatment because all research is highly co-ordinated. However, if health authorities gave in to patient pressures and funded treatment outside trials, their money would be wasted and trials would be wrecked 'in popular stampedes with no clear outcomes'.

Professor Pinkerton, on the *Panorama* television programme, also talked of striking a balance between quality of life and the remorseless push for treatment at whatever price. He said:

> 'When you're talking about experimental treatments which are likely to do more harm than good to an individual child the priority for us is the interest of the child and we're not prepared to be involved in experimental treatments which have not been properly or fully thought out for children'.

Elaborating this point, he observed:

> 'The critical issue is the definition of good quality time and if that time is several weeks in hospital suffering the consequences of the treatment then it can't be called good quality time'.

On the other hand, there have to be cases where patients would benefit from one-off experimental treatments. As Professor Goldman told us:

> 'We should learn from clinical experience. And if we can't, we can't ... I accept, perhaps, that we didn't learn anything. But that is not an argument for not doing the treatment'.

In the event, Dr Gravett decided against treating Jaymee with a second bone marrow transplant and opted for an even more unknown and therefore experimental treatment, donor lymphocyte infusion. The pioneering nature of the treatment was such that, while there were no trials into which Jaymee could be entered, barely six months later trials were in fact begun at the Royal Marsden as part of a national project co-ordinated by the UKCCSG. At the time of Jaymee's treatment, there was no knowledge of its effects on children. While it was known to have an effect in some cases of chronic myeloid leukaemia, its effects on AML were largely unknown. Dr Gravett did, in fact, report the results of Jaymee's treatment as a case study to the Royal Marsden and also to the international and European bone marrow transplant registries. He thus sought to counter claims that nothing was learned from the case.

Dr Cornish described donor lymphocyte infusion as potentially less taxing on the patient than bone marrow transplants, with there being no need to use such highly toxic therapy. She also noted that there had been sporadic examples of one-off donor lymphocyte infusion therapy being given to children before Jaymee Bowen. In view of this, Dr Gravett's decision was perhaps less of a totally wild card than has sometimes been presented. In fact, he believed that the experiment had been worthwhile because it had given her more than a year of extra life, and in his view much of this was of reasonable quality. This was illustrated by the *Panorama* television programme which showed Jaymee enjoying her birthday and appearing to be in reasonable health. Problems only arose in the very last stages. Conventional treatment would have given her only a few weeks, he pointed out. Professor Goldman was of the same opinion. He argued:

> 'to get her into remission was a nice achievement. I do not believe that her life would have been equally long without the remission'.

Against this, Dr Broadbent maintained Jaymee would almost certainly have enjoyed an equivalent period of *good quality* life if the option of palliative care offered by the paediatricians had been pursued. Her fellow paediatricians took a similar view, arguing that the risks involved in further intensive treatment were unacceptably high, and indicating that they would act in the same way if a comparable case arose again. In taking this view, they were challenging the perception that palliative care was a second best option. The argument of the paediatricians was that palliative care was a positive choice designed to provide as good a quality of life as possible. From this perspective, duration of life was a second order consideration (Gillis, 1997).

The pressure exerted by Child B's father

When Dr Broadbent told David Bowen that there was nothing more she could do for Jaymee and recommended palliative care, he refused to accept her opinion. Nor did he accept the opinions, equally as unhopeful, of Professor Pinkerton and Dr Meller. His attitude to them was one of outrage at their refusal to treat his daughter. In his attempt to persuade Dr Broadbent to change her mind, he sought out information and collected clinical opinions from around the world. He presented this information to Dr Broadbent in a snowstorm of faxes. At one point she described how he was telephoning her with requests every thirty minutes, an intensity of demands on her which she found very difficult to manage.

When David Bowen went to see Dr Meller, the latter recalls:

> 'By the time I saw him this was a mission'.

David Bowen tried to persuade Dr Meller to carry out a second bone marrow transplant at the Royal Marsden, but he refused. Dr Meller remembered:

> 'He was very angry; he argued with me for an hour'.

The consultants involved in Jaymee's care at Addenbrooke's and the Royal Marsden described the demands made of them as taking place within an atmosphere of mistrust. When bombarding Dr Broadbent with information, one of the requests David Bowen made was that she study the literature on the trials taking place in the USA and find a treatment that would be suitable for his daughter. He had carried out the research himself in an intensive exploration of the Internet, among other sources. This request to Dr Broadbent for a referral, as she herself explained, was akin to blackmail, and she later sent a retrospective letter to Professor Goldman only under extreme pressure from David Bowen and against her professional judgement. At the point at which she was 'coerced' into making a referral to Professor Goldman, she explained to David Bowen that she considered the trust between them had broken down. David Bowen, in turn, put in a formal complaint to John Ashbourne (the chief executive of Addenbrooke's Hospital) on the basis of her 'obstructive approach'.

Other consultants involved in the long-term care of Jaymee also spoke of her father's anger and belligerence to them. Armed with information of his own, David Bowen argued with them and attempted to persuade them to carry out the treatment which he favoured at the Royal Marsden and refused to listen to their objections, despite the satisfactory nature of their treatment of her in previous years and the fund of goodwill that had grown up during that time. No structure existed, in managerial terms, to shield the clinicians from intrusive or inappropriate contact from the patient's family. This was highly problematic for Dr Broadbent until she explained her predicament to her manager who then intervened.

A colleague agreed that patients' families could abuse this delicate doctor-patient relationship based on trust and esteem. Normally this does not happen; but there is always a risk that it may. As one of Jaymee's oncologists told us:

> 'If you're an approachable paediatrician, you're a very popular paediatrician and it's actually very rewarding for the paediatrician as long as it's not abused, because you're offering a very good service to your patients and you have a very good doctor-patient relationship which is the only reward for doctoring – having an interesting life and good professional relationships with your patients. And then someone comes along and abuses it'.

The breakdown of trust is linked to an increased willingness of patients and their families to question doctors' decisions. This is not to say that all members of the public act as assertive users of health care. The inherent information asymmetry which extends beyond the characteristics of the product to the effect the product may have on the user continue to act as a barrier to consumer sovereignty in health care. Nevertheless, there are moves in this direction which include the growing popularity of information sources such as the Internet. Although David Bowen showed particular determination, the doctors interviewed for this study testified to the increased frequency with which their views were challenged by patients.

Reflecting on the changing attitudes of patients, Dr Meller noted during interview:

> 'They think that if they shout loudly or if they go private, or if they have a fundholding GP, then they'll get better treatment. And they think that they're entitled to it and so they get on the phone and they talk to doctors'.

David Bowen's behaviour could be interpreted as following this current of opinion. Although he did not stray outside the realms of orthodox medicine and consider alternative remedies for his daughter, his willingness for her to be treated in the private sector – using something other than evidence-based treatment (donor lymphocyte infusion) – is consistent with this consumerist challenge to medicine as a profession. The specialists recognised that David Bowen was disenchanted with doctors and felt that he believed that financial reasons were at the root of their medical judgements. As Dr Meller explained:

> 'I think in that sense the public are very suspicious that treatment is being withheld for financial reasons. They find it very difficult to accept that a doctor might genuinely not recommend a treatment because it might do more harm than good'.

On the other hand, David Bowen's refusal to accept that orthodox medicine could not cure his daughter also demonstrates tremendous faith in the medical profession which was rewarded when he found a doctor who was prepared to stretch medicine science to its limits in the pursuit of such a cure.

David Bowen was unrelenting in his search. He recalled how on first learning that Jaymee had cancer he wanted to do everything possible to help:

> 'I wanted to be able to sleep for the rest of my life'.

He also had enough insight to recognise the difficulties he was causing the doctors responsible for Jaymee's care. That he was prepared to persist reflected a rare single-mindedness and an unwillingness to accept that doctor always knows best. While the energy he put into researching innovations in treatment may have been unusual, his behaviour nevertheless illustrates an important shift in attitudes on the part of patients and their families. Not least, it suggests that those working in the NHS need to find ways of coping with these pressures in the future and of communicating more effectively with service users.

A recurring theme in David Bowen's own reflections on his experience is the inadequacy of communication between doctors and nurses on the one hand and patients and their families on the other. This is linked to the lack of advice and counselling, particularly when medical opinions are divided and when patients want to seek further information.

Virginia Bottomley, Secretary of State for Health at the time, felt that the one aspect of the case on which the health authority was vulnerable was its relationship with David Bowen. As she recalled during interview:

> 'A more sensitive approach to the family with counselling and advice might have left the treatment in the NHS'.

Against this, some of the doctors felt that David Bowen's personality was a particularly important factor and that even the most sensitive approach would not have prevented him following the course he did. This was certainly the view of Dr Broadbent who argued that his single-minded approach was exceptional and not necessarily in the best interests of Jaymee.

The interests of the child

A central feature of this case is that David Bowen was prepared to take his dissatisfaction with the clinicians and with the health authority to the courts. Price, commenting on the case, observed:

> '... the affair reached the courts only because a doctor and a patient's parents failed to agree over the right course of action to take in a particular case'. (1996, p.168)

The paediatricians involved in Jaymee's care spoke of making their decision not to continue with treatment following a consideration of her 'best interests'. The conviction with which they made such statements is connected with their special position which might lead them to act as if, at least in part, they are custodians of the child's best interests. This issue is bound up with considerations around the rights of children and the point at which they are capable of taking some responsibility for decisions that affect them.

Dr Broadbent and Professor Pinkerton concurred with each other's viewpoints. Dr Broadbent, in her affidavit, commented:

> 'I took the view that it would not be right to subject B to all this suffering and trauma when the prospects of success were so slight'.

In his interview for the *Panorama* television programme, Professor Pinkerton went further. He explained:

> 'We're not going to be right all the time but the decisions that we take, the advice that we give, is based on that primary goal which is not to harm the child simply because we all find it so difficult to let go'.

The consultants explained that usually, after a period of initial shock and denial, parents came round to acquiescing with the viewpoint of the doctor. In this instance, David Bowen's unwillingness to accept the advice of paediatricians was a direct challenge to the authority of the doctors who had been responsible for Jaymee's treatment.

The rise of consumerism leads increasingly to medical decisions becoming a negotiation between the views of the doctor and the wishes of the patient. Professor Goldman, as an adult specialist, and one who had much experience with patients who had already seen a variety of doctors, was more at ease with this concept. From the very start of his involvement, he placed the onus of decision-making firmly on the shoulders of the family. After writing to Professor Pinkerton concerning his initial evaluation of Jaymee, Professor Goldman ended his letter:

> 'I do not know what course of action the family will select'.

He also took exception to the 'paternalistic' attitude of the paediatricians, seeing their patient as a small child 'to whom they dictate the rules' and generally behave inflexibly. Professor Goldman suggested:

> 'My own view is that one has to sit round a table and consider all interested parties – the doctors, the family and the child herself if she appears to be competent to make a decision ... [The decision] required a synthesis and to ignore and overrule the father's view was already unwise'.

However, if the paediatricians' approach with regard to Jaymee was felt by the adult specialists to be paternalistic, then certainly the approach of Jaymee's father can be described likewise. As David Bowen explained to the *Panorama* television programme:

> 'On what she's gone through and what she's done and the response to drugs and her just zest and appetite for life this is the child and I will at least honour her by giving her the chance that I feel she really needs'.*(sic)*

Again, Jaymee's case departs somewhat from the norm in terms of child cancer. With a child of her age and maturity, the usual procedure would be for the doctors to discuss certain things privately with the parents, but then involve the child in the discussion where appropriate, thereby hoping to secure the child's assent. This was not possible in Jaymee's case as her father wanted her shielded from knowing how seriously ill she actually was. In the early stages of the case, when David Bowen was challenging the health authority's refusal to fund further treatment, he applied for a court order to protect her anonymity so that she would not recognise herself in the news reports. His protective approach was a concern to the paediatricians who cared for Jaymee as they believed that a child of her maturity should be involved in deciding on treatment options.

David Bowen explained that Jaymee was involved in considering treatment options at the time she received her first bone marrow transplant. When her leukaemia was diagnosed, he went through things with her and talked about the likely consequences. She was happy to proceed on that basis. After her relapse in 1995, he felt unable to do the same because she had been given only six to eight weeks to live. As he explained to us:

> 'It would have tortured her'.

His main concern was not to upset Jaymee and thereby undermine her chances of recovery. He was prepared to take the decision on her behalf because:

> 'I knew her well enough to know that she would be happy to take the chances I had taken'.

Having read the literature on cancer treatment he knew that the patient's mental attitude had a bearing on the outcome. He wanted to keep Jaymee happy and smiling 'even if it meant keeping the truth from her', adding:

> 'My sole reason for not telling her was that the chances were best supported by keeping her happy at that point'.

This was not something that came easily. He emphasised during interview:

> 'I weighed up very carefully, because I was gambling with something very precious'.

This judgement was based on an intimate understanding of Jaymee and her personality. If the child concerned had been her sister, Charlotte, David Bowen explained that 'I would have told her'. It was because of Jaymee's likely reaction that he chose not to involve her in the decision.

An anecdote reported by Sarah Barclay, the BBC reporter responsible for the *Panorama* television interview, had Jaymee hearing about the case of 'Little B' on the news and exclaiming that the poor child should definitely get the treatment. Later, when the anonymity order was lifted, Jaymee expressed herself eager to go on fighting and receive the treatment to get well again. Conceding that many children would shrink from more pain and discomfort she said, 'I'm not one of them'. As she said:

> 'I would have gone to Court and stood there right in front of them and said that no matter what it takes I'm going to go through this and I'm going to get better.'

Dr Meller was troubled by the refusal of her father to let her share in decisions that were made about her treatment along the way. He explained to us:

> 'This case is unusual because David Bowen was not involving what he called a very grown up nine year old from taking part in the discussions when she had always been included prior to her relapse. He assumed that because she was his daughter she would have the same views as him, that she wanted treatment even though it only had a small chance of a cure. And that was an assumption that a father is not entitled to make'.

But the same consultant also made it clear that Jaymee was probably not capable of making her own decision on her future.

Differences between approaches to childhood and adult leukaemia revolve in part around the fact that children cannot always give their consent to treatment and so must have their interests assessed by others. The point of friction in this case lay in Jaymee's position as a very mature and intelligent child. If they had met me, she says in the *Panorama* television interview, they would have seen what I was like. Jaymee's personality and competence, indeed, were not lost on any of the clinicians who did meet her. Professor Goldman said he approached her as a young adult, rather than a child. Drawing a contrast between himself and the paediatricians, he reflected:

> 'They were treating her as a small child and I was treating her as a young adult. I think there is a difference in style between paediatricians and adult haematologists. I saw her as a young lady who had a life to live and who had got enjoyment out of her current life. They were seeing her as a small child ...'

However, it should also be noted that David Bowen's protective attitude towards Jaymee made it particularly difficult for the clinicians to involve her in the decision.

The health authority was concerned about the welfare of Jaymee and the child protection issues involved. The treatment that they were refusing to recommend and fund was not a 'hands-on' experience, involving the laying of warm hands on the patient's head, as the public might have thought, but, as the chair of the health authority pointed out, a painful regime with a low probability of success. Linked with this was the issue of the rights of another minor – Jaymee's sister Charlotte, aged eight. While Charlotte had served as the donor for Jaymee's bone marrow transplant, the use of her in the donor lymphocyte infusion procedure was a lot more problematic, and, as well as being very uncomfortable, involved her submitting to a general anaesthetic. Certainly, Charlotte was persuaded to give her assent with much encouragement from her father but there appeared to be only the loosest of guidelines or procedures around her role as donor.

As with Jaymee, David Bowen chose not to involve Charlotte in the process of deciding whether or not to act as donor for the treatment that was eventually administered. He explained how he had considered this but 'it lasted for a blink of an eyelid'. He argued that he knew Charlotte would never say no and could not conceive of her refusing to help her sister: she said had enjoyed being in the limelight and contributing to Jaymee's recovery. Her involvement had 'made the family unit stronger' and this in itself he felt had justified her role.

As these comments indicate, Jaymee's case throws up significant and complex issues concerning assent and consent to treatment affecting both children and siblings (Delany, 1996; Month, 1996). The conflict that emerged between paediatricians and David Bowen epitomised the dilemmas involved. In the case of a mature ten-year-old such as Jaymee, respect for the autonomy of individuals would seem to indicate fuller involvement in treatment decisions than actually happened. The fact that this did not occur resulted in conflicting interpretations of what was in her best interests and who was best placed to judge these interests, an issue on which the courts were to comment at some length. In the process, the principle of autonomy was juxtaposed with considerations of both beneficence and non-maleficence (Gillon, 1985 and 1994), even though the debate was not structured in these terms.

The willingness of patients and their families to seek multiple opinions

When David Bowen set about challenging the decision of the doctors and of the health authority, he armed himself with information often inaccessible to the lay person. As the consultants in the case pointed out, they have been required increasingly to supply their patients or patients' families with detailed information about the rationale for choosing certain courses of treatment and this demand had risen steadily over the last ten years. The consequences were not always welcomed by the patient, particularly in the case of 'bad news' diagnoses, where the patient did not always want to be told 'the truth' and where it could also be considered unethical to tell the patient the truth.

However, paediatrics has a different patient-doctor relationship, with the parents serving as the channel through which the child receives treatment, and increasingly parents of the children in their care want to be presented with the facts and want to be won over to certain viewpoints. As one paediatrician told us:

> 'When I was 40 and I was a consultant and people actually accepted my judgement I was pretty amazed. I didn't tell them that. But I never felt very god-like as a doctor. Now, the trouble is if you're not a little bit god-like as a doctor you spend hours and hours and hours discussing things with patients, so ultimately you have to say: look, you either accept my opinion or you don't. And if you don't like my opinion, go somewhere else'.

Professor Goldman explained that he welcomed this challenge from the public. In place of god-like, he claimed 'Socratic' to be more accurate a description of the doctor's role, saying:

> 'Your 'divine' capacity comes, if at all, from your honesty and your integrity and your willingness to consider every possibility ... it comes from not feeling threatened by those who express dissenting views'.

He understood why patients should want to question and challenge doctors and commented:

> 'If I had cancer or leukaemia I'd jolly well want to make sure that my doctor was doing a good job or doing the best job he could'.

This view was not shared by others. Dr Meller explained:

> '... we are frequently asked for second opinions and the first question I will ask is: does your GP know that you're coming? And if I have any doubt about that I actually ask the GP to ring or write to me. Because every patient in this country has a GP and the GP should know what's going on, I think all specialist opinion should be routed via the GP'.

The ease of direct access to specialists that parents in the position of David Bowen are able to achieve is potentially problematic to doctors and indeed did sometimes prove difficult for the individuals involved in Jaymee's care. If patients or the family of patients are able to pick up the telephone and come through to the specialist, then this has implications for the way in which consultants carry out their work and the relationships they have with patients and GPs.

In the course of interviewing one of the paediatricians involved in Jaymee's care, we were in fact interrupted on a couple of occasions by telephone calls from anxious parents up and down the country seeking a second or third opinion. As the paediatrician said:

> 'I would like to suggest that a patient should only have access to a specialist via the GP ... I think they should ... always go through GPs to see the first specialist, the second specialist, the third specialist and if the GP is feeling this is getting beyond a joke because you're just about to see your eighth specialist then he should say: "Hey, come on"'.

In other words, while the health service is gearing itself to be responsive to the wishes of patients, there have to be some checks and balances. Dr Graham Winyard, Medical Director of the NHS Executive, concurred with this, telling us that:

> 'patient self referral is very problematic with all sorts of potential adverse consequences both for individuals and the overall system'.

He pointed out that such requests have to be channelled through one's GP:

> 'So if a patient goes back to their GP and says "I really want to see this consultant", the GP might say, "Well why? There is somebody equally good locally". But if the patient is really passionately committed to seeing that particular consultant, the GP would be likely to refer them'.

In this case, the fact that the Bowen family did not seek access to specialist advice through a GP meant that this control mechanism was not in place. This partly reflected the fact that Jaymee was by this stage under the care of specialists but it also resulted from David Bowen's willingness to short-circuit established procedures because of the limited time Jaymee had been given to live.

The question this raises is whether patients should have to pass through a gatekeeper to arrive at the specialist of their choice? Professor Goldman vigorously dismissed the notion of patients being forced to seek access through their GPs. Despite all the rhetoric surrounding the concept of a primary care-led NHS, he rejected this as an 'old-fashioned' notion, which is not consistent with the increasingly assertive behaviour of patients:

> 'The idea that GPs should monitor access to specialists was well embodied in the British medical profession in the twentieth century – the world is not going like that'.

A contrary view was expressed by Dr Winyard who believed there had to be some sort of control:

> 'Because it's sensible ... It certainly would be expensive on resources to have endless consulting. Provided it's been done properly and patients have been seen by a reasonably competent group. I'm not sure there could be a right to endlessly hawk yourself around the NHS until you got the answer you wanted'.

Against this, Professor Goldman recognised that there may well be a justified need to go on consulting experts:

> 'I think a patient must be entitled to seek other opinions... assuming the patient and his family to be sane. Because they're going to doctor number ten means they're not satisfied with the first nine. The fact that they're not satisfied ... must denote some controversy or unease ... and their optimism that the tenth can solve the problem that the first nine cannot'.

The dissent among paediatricians and adult specialists over the treatment options available for Jaymee in itself would appear to validate David Bowen's search for advice from other sources and further clinical opinions. The unanswered question is whether *multiple* opinions should be sought and the effect this has on an already overloaded health care system. The related question – whose opinion should prevail when doctors disagree – is one we return to in Chapter 2.

The judgement of the courts

When the health authority decided against funding Jaymee's second bone marrow transplant, David Bowen initiated legal proceedings. Under the NHS Act 1977, the Secretary of State for Health has a duty:

> 'to continue the promotion in England and Wales of a comprehensive health service designed to secure improvement:
>
> a) in the physical and mental health of the people of these countries; and
> b) in the prevention, diagnosis and treatment of illness,
>
> and for the purpose to provide or secure the effective provision of services in accordance with this Act'

Section 3 of the Act continues:

> 'It is the Secretary of State's duty to provide throughout England and Wales, to such an extent as he considers necessary to meet all reasonable requirements:
>
> a) hospital accommodation;
> b) other accommodation for the purpose of any service provided under this Act;
> c) medical, dental, nursing and ambulance services;
> d) such other facilities for the care of expectant and nursing mothers and young children as he considers are appropriate as part of the health service;
> e) such facilities for the prevention of illness, the care of persons suffering from illness and after-care of persons who have suffered from illness as he considers are appropriate as part of the health service;
> f) such other services as are required for the diagnosis and treatment of illness.'

The functions of health authorities are delegated to them and they act as agents of the Secretary of State in carrying out their responsibilities. The role of the courts in enforcing the duty to provide health care contained in the 1977 Act may involve a claim for compensation or a public law action for judicial review (McHale and others, 1997). In this case, the latter route was taken. Given the history of cases of this kind, in which the courts had consistently declined to support aggrieved patients and their families seeking to challenge health authority decisions, David Bowen's action in initiating a judicial review was in many ways as much of a gamble as his search for a cure. Yet as with other aspects of this story, events were to take an unexpected turn.

As soon as legal proceedings were started, the health authority contacted its solicitors who in turn instructed counsel. The lawyers analysed the papers relating to the case and affidavits were sworn by the doctors most closely involved. The health authority maintained close contact with the lawyers through Robert Jefford, Head of Administration, but the authority's officers did not themselves attend the court hearings. At this stage, control of the case effectively passed from the authority to the lawyers who advised on how the arguments should be presented and the options available if the decision went against the authority. As we shall see, this led to the arguments being presented in a particular way.

In the High Court, Mr Justice Laws instructed the health authority to reconsider its decision. On the advice of its lawyers, the authority appealed immediately. The Court of Appeal overturned Laws' decision and supported the reasoning behind the authority's original decision. The judicial review was about procedure, form and due process. The court's role was not to question the decision itself but rather to scrutinise the manner in which the decision was reached. In so doing the judges in the High Court and the Appeal Court took very different approaches.

Mr Justice Laws in the High Court stated:

> 'It is of course no part of my function to make medical judgements: not only because I have not the competence, but because the judicial review court does not generally redecide the merits of administrative decisions, since to do so would be to usurp the role of the decision-maker which has been confided to him by or under Act of Parliament. What I must do, however, is ... determine whether there has been an error of law in the decision-making process under review'.

As one of the lawyers involved in the case explained, in these kinds of cases courts look at how public bodies make their decision and the policies that they follow, both how they carry out their policies and how they deal with the exceptions. As Rose Sunter, acting on behalf of David Bowen, told us:

> 'In this case it looked like Cambridge and Huntingdon might be vulnerable because it had not dealt adequately with the exceptions'.

Mr Justice Laws in the High Court took a very different approach to that of the judges in the Appeal Court, reputedly because of a particular personal interest in the European Convention on Human Rights. His view hinged on the overriding importance of the right to life contained within the European Convention. His starting point was:

> 'Of all human rights, most people would accord the most precious place to the right to life itself. Sometimes public authorities, who are subject to the jurisdiction of this court, have the power of life and death – or at least to decide, as I find is the case here, whether a person otherwise facing certain death should, by reason of the resources at the public body's disposal, be given the chance of life'.

Later in his judgement he added:

> '... if the necessary funds are made available for Dr Gravett to embark on B's treatment, she would enjoy what I will call a worthwhile chance of life. It may be very modest. It may be less than 10 per cent. But to anyone confronting the prospect of extinction in a few weeks such a chance of longer, perhaps much longer, survival, must be unimaginably precious.'

Referring specifically to the European Convention he noted:

> '... certain rights, broadly those occupying a central place in the European Convention on Human Rights and obviously including the right to life, are not to be perceived merely as moral or political aspirations nor as enjoying a legal status only upon the international plane of the country's Convention obligations. They are to be vindicated as sharing with other principles the substance of the English common law. Concretely, the law requires that where a public body enjoys a discretion whose exercise may infringe such a right, it is not to be permitted to perpetrate any such infringement unless it can show a substantial objective justification on public interest grounds'.

Mr Justice Laws emphasised that this did not involve promoting the incorporation into law of the European Convention. Rather the Convention:

> 'may be deployed by the judges, not as a statutory text (a status which manifestly it does not possess), but as a persuasive legal authority to resolve outstanding uncertainties in the common law'.

Against this background, he went on to consider whether the health authority had taken a decision which interfered with Jaymee's right to life, and if they had whether they had offered 'a substantial public interest justification'. On the first question he observed that:

> 'without funding for Dr Gravett's treatment, the applicant will soon certainly die'.

He added:

> 'The decision in this case has, to the knowledge of the decision-maker, materially affected for the worse the applicant's chances of life. I hold that the applicant's right to life is assaulted by it, and accordingly the decision can only be justified on substantial public interest grounds'.

On the question of public interest, he examined the argument that the proposed treatment was not in Jaymee's best interests, focusing particularly on who should judge her best interests. Mr Justice Laws argued that doctors did not 'possess an authoritative voice' on this matter, at the same time acknowledging that:

> 'a ten-year-old child, in circumstances like those of this case, cannot make for herself an informed decision upon the question which course of action is in her best interests'.

This led him to conclude that her father was the person who should decide because:

> 'He has duties and responsibilities to her shared by no one else. The doctors' obligation is to ascertain and explain all the medical facts, and in the light of them articulate the choice that must be faced'.

In this case, the health authority had not respected the father's views. Specifically, Mr Justice Laws referred to Dr Zimmern's policy of not speaking or corresponding directly with patients or their relatives, commenting:

> 'I am at a loss to understand what rational justification might exist for such a policy'.

He added that Dr Zimmern:

> '... had no regard to the father's views as a material factor concerning the question of B's best interests. He supposed, wrongly, that the child's best interest engaged only a medical question'.

He also noted that the Wednesbury principle, which states that a decision is unreasonable if no reasonable public body could have reached such a decision, could also be invoked to demonstrate that the health authority had failed to have regard to the family's views, and should therefore reconsider its decision. In summary, while acknowledging that:

> 'the courts should not make orders with consequences for the use of Health Service funds in ignorance of the knock-on effect on other patients',

he concluded:

> 'But where the question is whether the life of a ten-year-old child might be saved, by however slim a chance, the responsible authority must in my

> judgement do more than toll the bell of tight resources. They must explain the priorities that have led them to decline to fund the treatment. They have not adequately done so here'.

And while requiring the health authority to reconsider its decision, Mr Justice Laws noted:

> '... I cannot say that they are bound to fund the treatment. It is possible for all I know that the financial constraints, and other deserving cases, are more pressing than at present appears'.

The judges in the Court of Appeal also emphasised the importance of the case and its seriousness given the high value placed by society on human life. At the same time, they reiterated that the role of the courts was not to take decisions in these types of cases:

> 'The courts are not, contrary to what is sometimes believed, arbiters as to the merits of cases of this kind. Were we to express opinions as to the likelihood of the effectiveness of medical treatment, or as to the merits of medical judgement, then we would be straying far from the sphere which under our constitution is accorded to us. We have one function only, which is to rule upon the lawfulness of decisions. That is a function to which we should strictly confine ourselves'.

The Appeal Court judges then considered the criticisms made by Mr Justice Laws of the health authority's decision. On the argument that the views of the patient and the family had not been taken into account, the Master of the Rolls, Sir Thomas Bingham, commented:

> 'I feel bound for my part to differ from the judge... At all times Dr Zimmern was as vividly aware as he could have been of the fact that the family, represented by B's father, were urgently wishing the Authority to undertake this treatment'.

The Appeal Court also supported the health authority rather than Mr Justice Laws in describing the proposed treatment as experimental.

More significantly, the Appeal Court felt that the health authority had adequately taken into account the question of resources in arriving at its decision. Whereas Mr Justice Laws had argued that there was a need to 'do more than toll the bell of tight resources', the Court of Appeal ruled:

> 'in a perfect world any treatment which a patient, or a patient's family, sought would be provided if doctors were willing to give it, no matter how much it cost, particularly when a life was potentially at stake. It would, however ... be shutting one's eyes to the real world if the court were to proceed on the basis that we do live in such a world. It is common knowledge that health authorities of all kinds are constantly pressed to make ends meet ... Difficult and agonising decisions have to be made as to how a limited budget is best allocated to the maximum advantage of the maximum number of patients. That is not a judgement which the court can make. In my judgement, it is not something that a health authority such as this authority can be fairly criticised for not advancing before the court'.

Notwithstanding this, Sir Thomas Bingham concluded:

> 'Such is my sympathy with the father and B herself that I have been tempted, although disagreeing with the judge's reasoning, to leave the order which he made in being and invite the Authority to reconsider the matter in the light of the judge's conclusions. I have, however, concluded that that would be a cruel deception since I would be bound to make clear that, in my judgement, the authority could, on a proper review of all the relevant material, reach the same decision that they had already reached and I would feel obliged, expressly, to dissociate myself from the learned judge's opinion that it would be hard to imagine a proper basis upon which this treatment, at least in its initial stage, could reasonably be withheld'.

He added:

> 'While I have, as I hope is clear, every possible sympathy with B, I feel bound to regard this as an attempt, wholly understandable but nonetheless misguided, to involve the court in a field of activity where it is not fitted to make any decision favourable to the patient'.

This was reiterated by the President of the Family Division who noted:

> 'The powers of this court are not such as to enable it to substitute its own decision in a matter of this kind for that of the Authority which is legally charged with making the decision'.

Yet if the Court of Appeal's decision vindicated the health authority's approach – as Dr Zimmern argued during interview, 'the Court of Appeal prised the whole process open like a can of sardines and we were found to be absolutely flawless' – there was nevertheless a sense among some commentators that the High Court had raised important issues worthy of wider debate. These included less the importance attached by Justice Laws to the European Convention on Human Rights and the right to life than the way in which the health authority arrived at its decision and the explanation it offered. These are views which we return to in our analysis of the case.

The reporting of the case by the media

The media handling of Jaymee Bowen's case has been analysed in depth by researchers at the University of York whose work is drawn on in this section. They note the extensive reporting of the issue and the intense interest shown by the press. As they observe:

> 'A child with cancer is a very emotive cause, highly likely to attract public sympathy and to affect people's perceptions of health care priorities. The emotive appeal of Child B was enhanced by the way the media portrayed her personality and built up her status to that of a major celebrity'. (Watt and Entwistle, 1996, pp. 155–6)

The media interest began with the court case. As David Bowen recalled, the first time he went to court there was one reporter present. On the second occasion, he couldn't find a seat. The High Court hearing made front page news and was the subject of editorial comment in all the national newspapers (Entwistle and others, 1996b). It also inspired in-depth coverage including several page spreads in some newspapers that dealt with various aspects of the case.

When the anonymity order was lifted in October 1995, Jaymee's story again made front page news in most newspapers, as it did in May 1996 when her death was announced. The case also gained prominent coverage on television. In particular, an edition of *Panorama* on 26 October 1995 was devoted to Jaymee and her father's quest for a cure. As Entwistle and colleagues comment, this programme:

> 'became a source for many newspaper articles and arguably played a crucial role in promoting Child B to celebrity status'. (Entwistle and colleagues, 1996b, p.131)

The same authors note that the press varied greatly in the way it covered the case. There was a particular difference between the tabloids and the broadsheets. Leaders in the *Daily Mirror* and *The Sun* started from the position that Child B 'needed' the treatment and found it wholly unacceptable that she should not be given it by the NHS. They implied the decision was reached because financial considerations had been allowed to dominate. They identified themselves with this opinion to such an extent that they both ran appeals on behalf of leukaemia research.

The *Daily Mirror* expressed the view that the decision was wrong and saw it as one based purely on money. In a passionate tirade published after the court hearings it exploded:

> 'Only parents who have suffered a child facing a life-threatening illness can know the full agony of that situation ... What they should never have to think about is *money*. Yet that is what the health service has been reduced to. Yesterday the Appeal Court made that official. It ruled that Cambridge Health Authority could legally refuse to pay for more treatment for a ten-year-old girl, dying of leukaemia ... money is everything in health care today. The people who matter most are not medical staff, not patients, but those who control the purse. A child's life now is worth only what a health authority's accountants are willing to pay for it'. (11 March 1995)

Among the broadsheets, *The Guardian*, the *Independent* and *The Times* acknowledged the complexity of the issue, and looked at such factors as whether or not it was in her best interests to receive further treatment. *The Daily Telegraph* believed that the health authority's decision was sound and the Appeal Court judges were consequently correct to uphold it. However, the decision would have been better understood if the NHS did not waste so much money. In contrast, the *Sunday Telegraph* implied that the decision was wrong. It caused great anguish and pointed to the fact that less NHS money should be spent on abortions (death) and more on last chances of life. *The Guardian*, on the other hand, implied that the decision was right. The case aroused emotion but 'a rational health service is as important as a national health service'. (11 March 1995)

The *Independent* and the *Independent on Sunday* admitted that the decision was difficult. The viewpoint here was that sometimes it will not be appropriate to give last chance treatments which cause suffering to children. *The Observer* implied the decision was wrong. Parents' views should dominate. Although hard decisions must be made, people want them to be made with sympathy and understanding, not on the 'crude market principle.'

The coverage of Jaymee's death in May 1996 demonstrated that the various interpretations of the case had remained consistent over time. However, as Entwistle and Watt (1996) point out, the broadsheets were more likely to mention the part that expert medical advice had played in influencing the health authority's decision than they did at an earlier period. *The Daily Telegraph* suggested that the first question Jaymee's death left behind was whether the NHS should pay for experimental treatment. The second question was who should make the decision. It focused on Stephen Thornton's view that this should be a national responsibility with the production of national guidelines, not one that falls to local managers. *The Guardian* echoed Thornton's viewpoint, saying that while explicit rationing is commendable, this should not take place outside the context of a national framework. In an editorial, it commented:

> 'Ministers have pushed rationing down to local health authorities – so that they take the blame for unpopular decisions – but then intervene when local services begin to diverge to insist there must be national minimum standards. There must, but the only people able to set them are the very same ministers who are refusing to do so. It is no use the Health Secretary interfering in an ad hoc manner ... What is needed is a coherent and comprehensive framework'. (23 May 1996)

Entwistle and colleagues (1996 a, b) saw the newspapers as varying quite considerably both in the way they reported the Child B case and what they felt it signified. An overview of what the case represented was more likely to be found in the broadsheets; the focus generally was more on the rationing of health care and the personality and charisma of Jaymee. Issues such as the ambiguity around treatment options, especially in children, and issues concerned with experimental treatment were not highlighted, nor was consideration given as to whether the treatment was in Jaymee's best interests or not. As they note:

> 'Although there were serious doubts about the clinical appropriateness of the treatment that Child B's father fought for, her case was presented in the newspapers primarily as an example of health care rationing, and it triggered some discussion of the general issue of health care funding, particularly in the broadsheet newspapers'. (Entwistle and others, 1996b, pp. 117–8)

In studying the issues covered by the media, and particularly the newspapers, Entwistle and colleagues have made it possible to see the issues deemed important enough to highlight and those that were not. Issues they felt were rarely covered in the media included the nature and status of evidence about the effectiveness of further intensive chemotherapy and a second bone marrow transplant in cases of relapsed AML, and the likelihood of Child B surviving. For example, it was never stated that there had been no instances in which children with relapsed AML had survived, with or without treatment.

Clinical arguments as a reason not to treat Jaymee may have been overlooked by the media, they suggest, for several reasons. These include the fact that the rationing angle made for a 'stronger' story; also the balance of the reporting may have been affected by the reluctance of the doctors involved to speak to the press, especially when contrasted with the willingness of the managers to do so.

The reporting emphasised other issues significantly. For example, the coverage raised important questions around the extent to which people should have confidence in doctors' advice. The tendency of the press, also, was to criticise health authorities and managers for their role in issues like this. The tabloids in particular personalised the debate to an intense degree, publishing accounts of the characters of everyone involved and again generally portraying the managers in a negative light. There was, however, some movement over time, with greater understanding of the role of managers and health authorities as the issue unfolded. This is illustrated by an editorial that appeared in *The Times* in October 1995 following the *Panorama* television programme which noted:

> 'The grim contrast between the health authority's decision and the subsequent success of the treatment it refused to fund'. (27 October 1995)

adding that the programme 'shed unflattering light upon the decision taken by the health authority on the basis of clinical advice'. In contrast, following her death eight months later, an editorial in *The Guardian* commented:

> 'Tributes, rather than brickbats, also need to be paid to the Cambridge and Huntingdon Health Commission, the authority which took the decision to stop further treatment'. (23 May 1996)

This sentiment was echoed in an editorial in *The Daily Telegraph* (23 May 1996) which praised Stephen Thornton whose 'compassion and composure throughout this exceptionally painful affair rightly won widespread respect'.

As Entwistle and colleagues point out, the selective presentations of the press, with newspapers in particular exhibiting widely differing stances, and indeed covering very little common ground:

> 'meant that anyone reading just one newspaper would have received only limited and partial information. If members of the public are to participate in debates about treatment decisions and health care rationing, means other than the media will need to be found to inform and involve them'. (Entwistle and others, 1996a, p.1587)

As these authors conclude:

> 'Our study suggests that while the media may raise awareness of the issues which need debating, and may influence people's perceptions of these issues they do not provide the solid base of information which would allow people to participate in debates in a particularly informed way, and their coverage itself does not constitute a full public debate'. (1996b, p.157)

Turning to the role of the health authority, staff of the authority were willing to talk to the public and the media throughout the case. Newspaper, TV and radio journalists in contact with the key decision-makers at the health authority testified to their integrity and willingness to communicate. One of the reasons for this was that Cambridge and Huntingdon Health Authority had a PR officer (Diana Jakubowska) whose job included responsibility for a co-ordinated approach to the task of facing the media. The health authority was in fact highly co-ordinated, with members of the team fully briefed so that they would all be 'singing from the same hymn sheet' as the chair, Maggie Scott, put it. At the same time individuals were allotted specific roles, with Stephen Thornton and Ron Zimmern speaking to television, and Robert Jefford on radio.

The health authority's handling of the press was widely praised, not least by the local journalists who were well acquainted with their style which they described as honest and straightforward. The reasons for this, they believed, were diverse: the authority favoured openness and public accountability, knowing that the media was the only means to inform public perception, which was coupled with their fear of being misrepresented if they refused to speak for themselves. The people involved were flexible and obliging (one journalist said that Dr Zimmern agreed to do an interview within fifteen minutes, even though telephoned at 6 am) and the two key figures of Stephen Thornton and Ron Zimmern were at ease in the glare of publicity.

The health authority's PR officer held the honesty of the senior officers at the authority directly accountable for the fact that the press was quick to select the financial aspect of the case and thereby 'distort' the message. Diana Jakubowska expressed the idea that the – in her view, mistaken – importance that was put on the financial aspect of the decision was a matter of presentation not substance. She had counselled Dr Zimmern not to mention finance in explaining his decision-making, her experience with the press and PR warning her that this would be fastened onto and retained in public consciousness. However, Dr Zimmern, driven by a need to be scrupulously honest and unequivocal, had decided to refer to it as a factor which, while not particularly significant, was nevertheless one worthy of mention. Referring to his interviews she explained to us:

> 'Right at the beginning my advice to Ron was not to mention money. He said it was something like the sixth of six reasons – he said we've always said we are an open, honest, upfront organisation and even though it wasn't a deciding factor, it's nevertheless one of the factors in the pot'.

The Daily Telegraph and *The Times* picked up on the ambiguity connected to the financial motif and *The Telegraph* commented:

> 'In the case of Child B, doctors felt that the suffering she would undergo in the course of further treatment and the unlikelihood of her surviving it, made the expenditure unwise'. (13 March 1995)

The Times reported that the precise grounds for the health authority's decision were not clear and said :

> 'While subjecting a dying child to needless futile suffering would strike most people as undesirable, refusing treatment on the ground of cost is more difficult to accept'. (11 March 1995)

The health authority's communication strategy, though commendable in many ways, also contributed to the later difficulties it experienced explaining the reasons for its decision. In particular, there were difficulties in communicating effectively a decision based on a range of considerations that were not easily simplified in headlines and soundbites. The subtlety of this stance sometimes became lost in the reporting of the story, demonstrating the challenge for even a well organised authority in getting its message across. And as our account has shown, there were incipient tensions within the authority between those seeking to offer a full and honest explanation of the issues, and those concerned to ensure that the media coverage of the case was as positive as possible.

Relationship with the Department of Health

While much of the responsibility for decision-making in this case rested with the health authority and its advisers, in a national health service it is the Secretary of State for Health who has a duty to secure the provision of health services. And while action in the courts was brought against the health authority acting as the agent of the Secretary of State, the influence of politicians was never far away. What, then, was the role of Virginia Bottomley, Secretary of State at the time, and of her officials?

During interview for this research, Mrs Bottomley recalled how at any one time there were between 20 and 30 issues on which she would be briefed in case she was asked to comment by the press. In the case of Jaymee Bowen, she had a particular interest because of the significance she attached to the evolving debate on priority-setting in health care. She illustrated this by referring to a major conference on priority-setting she had addressed in London, an invitation she had accepted 'in the face of universal advice from officials to reject'. Mrs Bottomley explained to us that as a result of the briefing on Jaymee:

> 'In spite of the tragic situation in which Jaymee and her father found themselves, and my sympathy for them, the more I heard about the case, the more I understood the doctors' and health authority's position'.

Mrs Bottomley felt that it was particularly important that respected clinicians at Addenbrooke's and the Royal Marsden had advised against further heroic intervention. As she recalled, the decision was based on clinical rather than financial considerations and she felt it was her job as

Secretary of State to support the doctors and paediatricians and the health authority. In view of the intense interest shown by the media:

> 'The easiest thing in the world would have been to have stepped in to ensure that she was treated'.

She felt this would have been the wrong thing to do and was therefore inclined to endorse the position taken by the health authority. If the government was not prepared to take a stand on this kind of issue, it would be difficult to preserve the principles of a health service available to all on the basis of need. Furthermore, at a time when the government was saying that health authorities were in the best position to determine priorities, it would have been inconsistent to have overruled the decision. In short:

> 'If we had said "yes", we'd have got a round of applause today, but it would have been wrong'.

The Secretary of State was briefed on the case by officials within the Department of Health. She attached particular importance to the views of the Chief Medical Officer, Sir Kenneth Calman, who was himself a cancer specialist. The advice she received was that Jaymee Bowen's case was not a rationing decision but was based on a concern for the child's welfare and well-being. As well as advice from her own officials, Mrs Bottomley recalled meeting Stephen Thornton and Dr Zimmern during a visit to Cambridge to hear directly from them the details of the case. For her part, she briefed the Prime Minister in anticipation that the issue might be raised during Prime Minister's questions in the House of Commons. The fact that the Prime Minister's constituency was in the area covered by the health authority (although he was not the family's MP) was another relevant consideration.

Within the Department of Health, the NHS Executive was alerted to the case early on for two reasons. Firstly, as Dr Winyard, Medical Director of the NHS Executive, pointed out, because 'the better health authorities in general alert us to difficult issues'; and secondly because Stephen Thornton and Dr Zimmern were well known to Alan Langlands, Chief Executive of the NHS, and other NHS Executive directors. As a result of their personal acquaintance with these two health authority officers, together with the confidence they had in their abilities and skill in their roles, the attitude of the NHS Executive towards the authority was described as 'supportive' but non-intervening, what Dr Winyard described as a combination of 'advising, listening and supporting' with the Department remaining removed from the fray. Alasdair Liddell, Director of Planning of the NHS Executive, commented that, in view of the fact that they had confidence in the health authority and its staff and felt that they were approaching the issue systematically using values, and had taken clinical advice, there was no reason for the Executive to intervene.

Would things have been different if there had been no personal acquaintance and therefore no immediate confidence in the health authority and its capabilities? As Dr Zimmern said during interview:

> 'It does make it much easier when you have that personal contact. If we were Puddleton-on-the-Marsh Health Authority – and no one had seen the inside of the Department – you couldn't have had the sort of conversations that I think Stephen had with Alan or I with Graham because there were one or two occasions where telephone calls had to be made at twelve midnight or that sort of thing ...'

The procedure in the NHS Executive was clearly established for cases of this kind. When the health authority recognised this as an emerging high profile issue, it would have informed the regional office of the NHS Executive and also the Corporate Affairs Intelligence Unit at the NHS Executive in Leeds in case there was press and media interest. The Unit would then have composed a note to ministers and high ranking officials at the NHS Executive, which would provide facts on the case and on the line they should take. The role of the NHS Executive, as Alasdair Liddell explained, was to satisfy itself that the issues were being properly tackled, and on this basis to support ministers in resisting the pressures to intervene directly, in order to create the space for the health authority to deal with the matter in accordance with the principle of local decision-making.

The NHS Executive was keen to draw lessons from Jaymee Bowen's case which could then be used to guide other health authorities in similar situations. As Dr Winyard explained, he drafted a letter following this case, which he knew would soon enter the public domain, to another director of public health dealing with a similar issue:

> 'drawing his attention to the process that Cambridge and Huntingdon had followed ... saying, provided you've gone through a proper process and it can be seen that the decisions rest on principles and priorities you've already determined, you're very likely to get central support'.

It was clear from the letter that health authorities themselves would remain responsible for making decisions of this type and that government was unlikely to intervene or at least, where it could be said to involve priority-setting issues, to take a central lead. The letter stated:

> 'Responsibility for making this difficult decision must lie with the authority itself, informed by appropriate clinical and other professional advice. Nationally, we are concerned that the public can be assured that there is a clear process for considering cases of this kind, founded on values and principles which have been shared with the public, and which your authority would be prepared to see applied to other cases'.

One of the indirect consequences was the setting up of a Department of Health Working Group on Priority-Setting which was established partly as a result of the publicity arising from the Child B case. Its terms of reference were to review existing work in priority-setting; to develop a framework for making decisions regarding values and principles; to identify approaches to priority-setting that command the respect of professionals; and finally to make recommendations on best practice.

The issue that arises out of this is whether it was appropriate, in the context of a *national* health service, for Ministers to stand back and allow health authorities to take local decisions, especially when these decisions might be inconsistent and result in inequities between areas. Reflecting on the experience, Stephen Thornton has argued that:

> 'making difficult choices in a setting of limited resources and within a nationally agreed framework is the raison d'être of health authorities'. (Thornton, 1997, p. 1839)

He added:

> 'What we still lack is an agreed approach within the NHS as to respective responsibilities for setting priorities. My experience leads me to believe that it is not sustainable for health authorities to be left to make such sweeping decisions as to fund or not fund whole categories of care – for example infertility treatment. Making decisions on issues of such profound

> importance to citizens is a matter for government, indeed a matter for national debate and resolution'. *(ibid)*

The respective responsibilities of the NHS Executive and health authorities in priority-setting is a contested issue and one which we analyse in more detail below.

Chapter 2

Analysis of the issues

The story of Child B illustrates the inherent complexity of priority-setting decisions and the many practical and philosophical issues which arise when choices have to be made on whether or not to treat patients with life-threatening conditions. This chapter explores these issues in more detail and offers a commentary on the role of different actors in the child B case as well as analysing the implications for the NHS. The material in this chapter then provides the basis for the recommendations we make in the conclusion. In seeking to analyse and make sense of the Child B case, our aim has been to draw out the implications for health authorities and others who are faced with the dilemma of deciding on priorities, and to locate it within the context of current debates on priority-setting in health care.

The role of the family

The research reported here has demonstrated the importance of both Jaymee and particularly her father, David, in the sequence of events. As other accounts have shown (see, for example, Barclay, 1996), it was Jaymee's resilient and charismatic character and David's dogged persistence that led to the case becoming a *cause célèbre*. In particular, David Bowen's unwillingness to accept the advice of the doctors at Addenbrooke's and the Royal Marsden and his relentless pursuit of further opinions explains how it became a focus of public attention as well as private anguish. Yet in making this point, and in emphasising that David Bowen was driven by a concern to do the best for his daughter, it is important to acknowledge the existence of other interpretations of the events.

Most obviously, the Bowen family had a complex history, a point emphasised by many of those outside the family who commented on earlier drafts of this report. David Bowen separated from Jaymee's mother, Alyson, in 1986 and they were divorced in 1988. David then married his new partner, Debbie, with whom he had been living since separating from

Alyson, taking Jaymee and Charlotte with him. To Jaymee and Charlotte, Debbie was the woman they knew as 'mummy', and only later did they realise that Alyson was in fact their natural mother. David and Debbie had two sons before they in turn separated in 1991. David then went to live with Susan who was to become his third wife. David and Susan added a fifth child, Phoebe, to the family soon afterwards. Jaymee and her sister, Charlotte, moved homes frequently during this time.

One of the consequences was that Jaymee's mother, Alyson, had little involvement in her care. David's second and third wives played a bigger part but he was undoubtedly the central figure in Jaymee's life. It was David who took responsibility for arranging her treatment and for accompanying Jaymee to hospital for her appointments. The pressures this gave rise to were considerable, to the extent that the care he showed to his children was matched by behaviour which attracted criticism from those with whom he came into contact. This applied particularly to NHS staff. The doctors responsible for Jaymee's care at both Addenbrooke's and the Royal Marsden found him very difficult to deal with in the latter stages of her illness to the extent that the core element of trust that underpins the doctor-patient relationship ultimately broke down.

Equally important, it can be argued that David Bowen's desire to be 'in control' of events also affected Jaymee and Charlotte. At all stages he was responsible for taking decisions on treatment in discussion with medical staff. As he acknowledged during interview, in the later stages of Jaymee's illness he did not involve his daughters in the process of deciding what to do, nor did he discuss with them the risks associated with treatment. This was because of his belief that Jaymee in particular would respond more positively if she were shielded from the full facts. While David Bowen justified his actions by pointing to the extra months of life gained, was he correct to have acted in this way?

The law on consent to treatment by children gives parents the responsibility to decide what should be done, except where children are of the age or maturity to understand the options and arrive at decisions. The latter cases include children who are so-called 'Gillick competent', that is minors who are able to decide for themselves to proceed with treatment.* As a ten-year-old widely recognised as mature at the time she relapsed, Jaymee was on the borderline in this respect. And even accepting that in practice:

> 'the solution has been to allow parents or guardians to supply the requisite consent'. (McHale and others, 1997, p. 374)

it has been argued that:

> 'this still leaves open the crucial question of how the best interests of the child are to be determined, particularly where parents want to make risky choices for their children, or include them in research'. (McHale and others, 1997, p. 375)

Jaymee's case fell into precisely this category. The Children Act 1989 does not give children rights to make independent decisions about medical treatment and under the law it is a matter for parents to decide. Children are involved only to the degree that parents and doctors determine. The question of who should decide Jaymee's best interests was discussed in the High Court where Mr Justice Laws confirmed the role of David Bowen as the best judge of Jaymee's interests. In so doing, he can be said to have accepted that:

> 'much of the case-law justifies paternalistic decisions by determining that the young person lacks capacity'. (McHale and others, 1997, p. 374).

Those who have analysed consent from an ethical perspective also underline the role of parents in determining the best interests of children but tend to place greater emphasis than many legal analysts on the rights of children. Graham, for instance, argues that:

> 'it would seem reasonable for health care professionals to seek assent from children of 10 years and above' (Graham, 1994, p. 658),

adding that in individual cases much hinges on the level of understanding of children. Further complexities arose in Jaymee's case because of the experimental nature of the treatment she received and the argument of some of the clinicians that such treatment involved research. In its

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*In the *Gillick* case the courts ruled that young people under the age of 16 are competent to consent to contraceptive treatment without having the permission of parents if they are of sufficient maturity guidelines for the ethical conduct of medical research involving children, the Royal College of Paediatrics and Child Health has reviewed the difficulties involved in this area and noted that:

> 'Parental consent will probably not be valid if it is given against the child's interests. This means that parents can consent to research procedures which are intended directly to benefit the child, but that research that does not come into this category can only be validly consented to if the risks are sufficiently small to mean that the research can be reasonably said not to go against the child's interests'. (Royal College of Paediatrics and Child Health, 1992, p.12)

The guidelines also note that:

> 'Children's ability to consent develops as they learn to make increasingly complex and serious decisions. Ability may relate to experience rather than to age, and even very young children appear to understand complex issues. They should therefore be informed as fully as possible about the research in terms they can understand'. (*ibid*, p.13)

More recent guidance issued by the College suggests a number of axioms to govern practice in the case of the treatment of children with life-threatening conditions. These emphasise the need for open and timely communication between members of the health care team, the child and the family. Specifically, it is suggested that:

> 'The wishes of a child who has obtained sufficient understanding and experience in the evaluation of treatment options should be given substantial consideration in the decision-making process'. (Royal College of Paediatrics and Child Health, 1997, p.12).

While acknowledging the complexities that arise in this area, it does appear that David Bowen, while exercising the rights ascribed to him in the High Court and by many of those who have written about the law surrounding consent, did not involve Jaymee or Charlotte as much as he might have done, especially given their level of development and understanding (particularly in Jaymee's case) and the nature of the treatment. This was a concern to some of the doctors responsible for Jaymee's treatment who felt that it was they who should assess her best interests – in part because David Bowen had chosen not to involve his daughters in thinking about the options available. This was reinforced by their experience of treating similar cases in the past and the adverse effects they observed on the children concerned. And while not doubting that David was doing what he believed was in Jaymee's best interests, they argued that their own duty to do no harm was a particularly important consideration when the chances of doing good were extremely limited and when the person most directly affected had not been fully informed about the available options, nor given the opportunity to express a preference. Against this, the adult specialists involved in the case may have harboured doubts about the failure to involve Jaymee and Charlotte in decision-making, but were nevertheless prepared to accept David Bowen's judgement as proxy consent. The views expressed by Jaymee after the anonymity order was lifted and when she realised she was Child B lent support to the stance taken by David Bowen and the adult specialists.

This demonstrates not only that there were differences of opinion on Jaymee's best interests but also that the current position on obtaining children's consent to treatment needs to be reviewed. While professional self-regulation through the guidelines adopted by bodies such as the UKCCSG (Ablett, 1994) and the medical colleges (Royal College of Paediatrics and Child Health, 1992 and 1997) offers some safeguards in these circumstances, Jaymee's case raised doubts even in the minds of the medical profession itself as to whether these were sufficient. The law is of little help in such cases because it places the onus on parents to judge the best interests of their children. In the context of a more consumerist approach by patients and their families and an unwillingness to accept that 'doctor always knows best', there is a need for greater clarity to guide future practice.

This point is emphasised by Alderson and Montgomery (1996) in their analysis of the issues involved in health care decisions affecting children. They argue that, while the Gillick case did appear to represent 'a clear commitment to young people's autonomy in the health care context' (p.31) subsequent cases have watered down that commitment. Notwithstanding both the Gillick case and the Children Act, decisions about children rest on 'a framework based on trust in health professionals and parents' (p.37). This framework may work well when parents and doctors agree but it comes under strain when they do not. Reflecting on the difficulties of obtaining consent, Alderson and Montgomery propose a code of practice for children's health care rights, including a right to withhold consent to proposed treatment if children are competent to do so.

These proposals are as relevant to a sibling like Charlotte Bowen, who faced risks in acting as a donor for both the bone marrow transplant and donor lymphocyte infusion, as they are to the child undergoing treatment. As McHale and colleagues (1997) have noted, the position on the consent of children who act as donors is problematic. The Medical Ethics Committee at the Royal Marsden has recently established a requirement that children should be fully informed and give assent when involved as donors for donor lymphocyte infusion. The committee has also stipulated that general anaesthesia should not be employed for the collection of donor lymphocytes (Meller, personal communication). This reflects increasing concern at the lack of protection for child donors (Delany, 1996) and debates about who should judge their best interests (Month, 1996; Savulescu, 1996; Browett and Palmer, 1996).

The code of practice proposed by Alderson and Montgomery would build on the UN Convention on the Rights of the Child and would include a presumption that children were competent to give consent to treatment unless it could be shown otherwise. Their suggestion is that children should be considered competent at an age when they are ready for formal education. They indicate how competence could be assessed, noting that parents would give consent when children are not competent, and point out that health care professionals could decide not to administer treatment that is clinically inappropriate even if children desired such treatment. Alderson and Montgomery also indicate that respect for the autonomy of children might be overridden in certain cases where children refuse potentially life-saving treatment, although they caution against extending the rules that govern such cases to treatment decisions in the round. In a similar vein, the Royal College of Paediatrics and Child Health (1997) has argued that there should be a presumption of competence among children unless a child is obviously incompetent. In emphasising the autonomy of children and the presumption of competence to consent to treatment, these approaches turn the current position on its head and, if accepted, would have major implications for health care decision-making.

The role of the health authority

The Cambridge and Huntingdon Health Authority found itself catapulted into the limelight by the Child B case. Just as the media latched onto

Jaymee's personality in reporting the case, so too they focused on the role of Stephen Thornton, chief executive, and Ron Zimmern, director of public health, in analysing the health authority's response. These two men took the principal responsibility for answering requests for interviews from television, radio and newspapers and they came to personify the health authority in reports of the case.

The legal challenge to the authority focused particularly on the way it reached its decision not to fund a second bone marrow transplant. The role of the courts was not to question whether the decision was correct but to examine whether it had been reached taking into account relevant considerations. The ruling of the Court of Appeal, overturning what many perceived as an unexpected and idiosyncratic judgement in the High Court, concluded that the authority had indeed followed appropriate procedures in making its decision. To this extent, the health authority felt that the Court of Appeal had vindicated its approach, even though the media then turned the spotlight on its actions and in effect put it through a second 'trial'.

Three aspects of the health authority's approach were particularly important in enabling it to justify its decision in the courts and to explain the basis of this decision: first, the use of a set of values to help inform the decision; second, the discussions which took place between Stephen Thornton, Dr Zimmern and their colleagues in weighing up the alternatives; and third, the relationship that was established with the media. In analysing the case after the event for the benefit of the NHS Executive, the health authority laid particular stress on its use of values (Cambridge and Huntingdon Health Commission, 1995). It argued that the existence of these values and their adoption before the case arose meant that it was prepared for this kind of eventuality and was in a position to arrive at a decision against a backcloth that had been agreed at a corporate level and which helped to ensure a degree of consistency in priority-setting decisions.

While this point has considerable force, it should be noted that the judgements in the High Court and the Court of Appeal did not lay particular stress on the role of values, suggesting that their actual significance may have been more limited than the health authority supposed. Furthermore, the way in which the values were applied is open to question. At one level, this concerns the use of financial arguments in the decision not to support further intensive treatment. At another, it could be argued that the value of responsiveness might have been invoked in favour of the course of action David Bowen was seeking rather than to reject it.

Second, the health authority also stressed the robustness of its decision-making process. As director of public health, Dr Zimmern had delegated authority for dealing with requests for funding outside existing contracts and outside the published extra contractual referrals policy. When the case arose, he discussed it with Stephen Thornton who in turn informed the chairman. These three individuals together with Robert Jefford, Head of Administration, then subjected the matter to vigorous internal debate using the authority's values as the basis for argument. As a result of this discussion, agreement was eventually reached. The full health authority was not involved but this was consistent with the authority's procedures in this type of case. Thus the authority was able to demonstrate that it had considered the case carefully and that the decision was not simply the result of one individual's judgement. It was also able to show that it had kept careful records of the case and the advice sought from clinicians.

A third aspect of the health authority's approach relevant to this analysis is its relationship with the press. At an early stage, recognising that media interest was likely to be considerable, the authority decided to adopt an open approach, providing as much information as possible while respecting patient confidentiality. The PR officer was instrumental in co-ordinating this work and the staff who dealt with the press and gave interviews were fully briefed and sought to respond positively to requests. An emergency office was set up with separate telephone lines to log media calls, and enquiries were dealt with quickly and personally by designated staff. Thus an attempt was made to explore the wider ethical issues as well as to answer specific queries about the Child B case.

The only occasions when the authority refused to speak to the media was when staff were asked to appear on programmes considered to be of entertainment value only, such as the *Kilroy* television programme. By contrast, a major effort was made to co-operate with the *Panorama* television programme broadcast in October 1995 and it was felt that this was worthwhile in enabling the authority's case to be explained to a wide audience.

Although the health authority gained credit for its role in these aspects of the case, in two areas its approach is open to criticism. First, there was confusion over the role that financial considerations played in the decision not to fund a second bone marrow transplant. This was highlighted in the High Court where Mr Justice Laws criticised Dr Zimmern for a 'volte face' in telling David Bowen that the decision was based on clinical considerations but a fortnight later in his affidavit argued that a substantial expenditure on a treatment with a small prospect of success would not be an effective use of limited resources. In practice, the health authority recognised that cost could not be ignored, particularly if it meant that other treatments would have to be foregone. In this case, the substantial expenditure and low probability of success combined to produce the decision not to fund treatment. And while the advice of clinicians on appropriateness and effectiveness was seen to be the main influence on this decision, the authority acknowledged that it would have been naïve to argue that the decision would not have been any different if the cost of treatment had been negligible (Cambridge and Huntingdon Health Commission, 1995).

The subtlety of this position proved difficult to communicate effectively. Reflecting after the event, Stephen Thornton observed that the emphasis given to financial considerations in court, and subsequently in the media, may have resulted partly from the way the lawyers took control of the case. By the time the High Court became involved, the issue was, in his words, 'out of our hands'. The affidavits sworn by Dr Zimmern and others were of course agreed by them but they were also shaped by the lawyer's assessment of how the case should best be presented.

Howard Weston, the solicitor representing the health authority, explained that the arguments advanced in court were 'a joint effort' between the lawyers and the authority, and at no stage was the authority's position misrepresented. Against this, Stephen Thornton felt that the lawyers were willing to use whatever arguments were needed to win the case and he was 'horrified' at the emphasis put on finance in the court judgements. The stress laid on finance meant that it was difficult to maintain the position that Jaymee's case was about clinically appropriate care rather than rationing.

Second, and more importantly, the policy adopted by Dr Zimmern of not personally meeting patients and their families in this kind of case can be questioned. The rationale for this was to enable difficult decisions to be made objectively. In addition, Dr Zimmern was usually able to rely on GPs to communicate the outcome of ECR decisions to patients but the absence of a GP in Jaymee's case made this impossible. Coupled with the singular and unusual determination of David Bowen to press his arguments to the limits, the result was a collision between an irresistible force and an immovable object.

In these circumstances, it was perhaps not surprising that David Bowen felt frustrated, particularly when there was no form of appeal against the authority's decision other than through the courts. It was this impersonal detachment that Mr Justice Laws criticised in the High Court and that was commented on by Virginia Bottomley when she said that better communication between the Bowen family and the health authority might have prevented matters escalating in the way they did. Furthermore, as David Bowen observed, the NHS does not offer help and advice in these circumstances to patients and their families and the absence of practical support made a difficult situation even worse.

For a busy health service manager, confronted with cases which did not qualify for authority funding, Dr Zimmern's policy may have seemed entirely logical, but in the Child B case it merely added fuel to an already raging fire. In addition, Dr Zimmern's failure to meet the family when he had spoken directly to the clinicians in the case made it difficult for him to act objectively because information from one crucial source had become available to him only through others. The application of a standard policy did not allow for exceptions to the rule and it was here that the authority was particularly vulnerable to criticism, even though it eventually won the legal arguments.

The role of clinicians

Clinical dissent is a central feature of this case. There were fundamental differences between the child cancer specialists involved in Jaymee's treatment and those who were concerned with adults. There were also differences between the specialists in the USA contacted by David Bowen and their peers in the UK. A further source of difference was between those working in the NHS and doctors like Dr Gravett who were in private practice. Each will be considered in turn.

Until Jaymee's leukaemia reappeared early in 1995, her care within the NHS had been the responsibility of child cancer specialists at Addenbrooke's Hospital and the Royal Marsden. David Bowen acknowledged the high quality of care provided at these hospitals and the value he attached to it. It was only when the doctors responsible for Jaymee's care advised him that further intensive chemotherapy followed by a second bone marrow transplant were not appropriate given Jaymee's medical history, and that palliative care was the preferred option, that he sought further opinions. This eventually resulted in his visit to Professor Goldman at the Hammersmith Hospital. As a specialist in the treatment of leukaemia in adults, Professor Goldman took a different view from his paediatric colleagues and was prepared to recommend further chemotherapy with a view to a second transplant if the chemotherapy were successful. This was also the view of Dr Gravett.

The difference between Goldman and Gravett on the one hand, and Drs Broadbent and Meller and Professor Pinkerton on the other, revolves around the philosophy adopted by child cancer specialists. These specialists operate within the framework laid down by the United Kingdom Children's Cancer Study Group (UKCCSG), and their work is based on a belief that children should be treated in paediatric facilities and that, whenever possible, treatment should be protocol driven. Child cancer specialists also believe that experimental treatment should be done ideally in the context of clinical trials. This philosophy stems from a desire to use treatments of proven effectiveness and to experiment only when the benefits are likely to outweigh the risks and when lessons can be learned.

By contrast, both Professor Goldman and Dr Gravett were willing to depart from the guidelines adopted by their paediatric colleagues to find a treatment for Jaymee other than palliative care. While they were not over-optimistic about the chances of success, they were prepared to contemplate alternatives which the child cancer specialists had ruled out. The latter were critical of Professor Goldman and Dr Gravett for their willingness to practise what one of the paediatricians described as 'maverick medicine' in the same way that Goldman and Gravett were unhappy at the inflexibility of what they saw as the 'paediatric mafia'. In these circumstances, particularly when direct contact between the paediatricians and adult specialists was limited, the advice issued by bodies like the UKCCSG carried little weight.

The second source of difference was between specialists in the USA and their peers in the UK. Having reached the end of a cul de sac in the UK, David Bowen used his family contacts and his library research to track down two specialists in California who took a more optimistic view than the doctors at Addenbrooke's and the Royal Marsden. By doing so, he acknowledged that if he was going to find a doctor anywhere who would help it would be in the USA where the 'can do' culture was likely to produce clinicians willing to intervene and experiment even in relatively hopeless cases. He was not disappointed, and the advice he received from Drs Zeltzer and Cairo was used as ammunition in discussion with doctors in the UK.

In the event, neither Dr Broadbent nor Professor Pinkerton was persuaded by the information David Bowen had obtained from the USA. For them the entrepreneurial spirit that made US doctors willing to innovate carried unacceptable risks for patients. These cultural differences in medicine on opposite sides of the Atlantic in some ways mirrored those between doctors treating children and those treating adults in the UK, although both Professor Goldman and Dr Gravett were more cautious in their assessment of a successful outcome than their US counterparts. Reports of experimental treatment on British children with life-threatening brain tumours by a US surgeon who has achieved poor outcomes reinforces the argument of those who have urged caution in such treatment (Calvert and Conett, 1997). This supports the views of organisations such as the UKCCSG for clear guidelines to govern treatment and protect patients.

Partly in response to these concerns, the Royal College of Paediatrics and Child Health has put forward proposals setting out situations in which doctors should consider withholding or withdrawing life-saving treatment from children. These proposals identify five situations where the withholding or withdrawal of treatment might be considered. These include the so-called 'no-chance' situation in which a child has such severe disease that life-sustaining treatment simply delays death without significant alleviation of suffering. The paediatricians involved in Jaymee's case felt that her case fell precisely into this category.

The third source of difference concerns doctors working in the NHS and those practising privately. The failure by David Bowen to persuade the Cambridge and Huntingdon Health Authority to pay for NHS treatment and the willingness of an anonymous donor to fund it privately after the Court of Appeal judgement added a further layer of complexity to the case. In the event, Dr Gravett took responsibility for Jaymee's care in the private sector, administering chemotherapy and then donor lymphocyte infusion, thereby extending her life by over a year when she had been given between six and eight weeks to live by her NHS doctors. While there were suspicions initially that Dr Gravett, like his colleagues in the USA, might be motivated by considerations of financial gain, Dr Gravett's expertise in the treatment of leukaemia was accepted not only by the Bowen family but also by many of his peers.

There were, nevertheless, doubts about the wisdom of carrying out this type of experimental treatment in the private sector and outside the framework recommended by the UKCCSG, leading Dr Gravett's critics to argue that nothing had been learnt from Jaymee's treatment. For his part, Dr Gravett maintained that the private sector was more flexible than the public, offering patient-centred care, less constrained by the protocols and guidelines governing mainstream treatment. As such, it offered an important safety valve in a system where treatment options were otherwise strongly influenced by the UKCCSG. The dilemma here is whether limits should be placed on experimental treatment in the private sector, especially for children.

A key difficulty in resolving this dilemma is the definition of 'experimental' treatment. In practice, this centred on the treatment that Dr Gravett ultimately administered, namely donor lymphocyte infusion, but it arose originally in relation to whether to proceed with chemotherapy followed by a second bone marrow transplant. Dr Broadbent and the health authority felt that further intensive treatment was best described as experimental, a view shared by Dr Meller and Professor Pinkerton. This was also the opinion of the Court of Appeal. Professor Goldman begged to differ, arguing that there was no agreed definition of experimental and using this in part to justify his decision to recommend further treatment.

In practice, as the paediatricians involved in Jaymee's case acknowledged, when routine treatment options had been exhausted, there was considerable latitude to try alternatives. Decisions on whether to proceed with these alternatives rest with clinicians and may either involve treatments in the context of clinical trials or 'developmental' procedures undertaken as single cases or small pilot series by transplant units with acknowledged expertise (Schmitz, Bratwohl and Goldman, 1996). To this extent, the differences between the paediatricians and the adult cancer specialists were somewhat narrower than at first appeared, although opinions remained deeply divided about the wisdom of allowing innovative treatments to be undertaken in the private sector rather than in established NHS units.

Whose views should count when clinicians disagree? In this case, the health authority preferred to act on the advice received from the doctors who had been responsible for Jaymee's care, rather than those from whom further opinions were sought. This was justified principally because these doctors were paediatricians who were best placed to take a holistic view of her care, having known the patient over a period of years. Dr Zimmern did seek the views of Professor Goldman but he attached greater weight to the advice from the paediatricians. Given their expertise and knowledge of the family over a number of years, it is difficult to find fault with this approach, although it did not satisfy a father who was prepared to continue seeking opinions until he found a doctor willing to provide more intensive treatment.

How many opinions then should a patient be able to seek? Under the *Patient's Charter*, patients can request a second opinion but there is no right to more than this. GPs often play a key role in avoiding multiple opinion seeking but, in the case of the Bowen family, frequent moves of house meant that there was no GP who knew the family well enough to act in this way. It was this that Dr Winyard of the NHS Executive was referring to when he argued that patients who made too many demands on the NHS would overload a system already under great pressure and that limits had to be set to the new consumerist, 'shopping around' approach by patients and their families. The conflict that emerges here is between an NHS committed to evidence-based medicine and one in which patient empowerment and choice are given priority – a conflict that remains unresolved. Commenting on second opinions for patients with cancer, Sikora argues that:

> 'Second opinions can give much greater peace of mind for patients with cancer and their doctors. But it is vital that they are used wisely'. (Sikora, 1995, p. 1180)

Finally, what of the relationship of clinicians with the media? For the most part, the doctors involved in this case were reluctant to explain the clinical reasons behind their decisions. This meant that the case was presented mainly as an example of rationing rather than a question of what was clinically appropriate. While the reluctance of busy clinicians to engage in public discussion is understandable, the effect was to skew the debate and to present a partial picture of the complex arguments that arose. As Professor Pinkerton noted, with the benefit of hindsight, a greater willingness on the part of clinicians to communicate the basis of their decisions might have led to greater public understanding of the case.

The role of the courts

The English courts have traditionally been reluctant to become involved in cases such as that of Child B. When judicial reviews are instituted, the courts do not, in the words of Mr Justice Laws, 'redecide the merits of administrative decisions'. Rather, their role is to examine the process of decision-making and to determine whether this was reasonable. It was for this reason that the health authority laid great stress on the robustness of the process it had followed and the use of a set of values to guide decisions. And because the decision-making process was robust and informed by values, the authority believed its decision was upheld in the Court of Appeal.

There are, however, two aspects of this case which deserve comment. First, there is the argument advanced by Mr Justice Laws in the High Court on the right to life. By invoking the European Convention on Human Rights, Mr Justice Laws sought to make a case in support of the Bowen family. While recognising that the European Convention did not form part of English law, he maintained it was 'a persuasive legal authority' that could help to resolve uncertainties in the common law. It was this line of argument that led some observers to argue that the High Court judgement was idiosyncratic and therefore out of line with previous rulings. Accordingly, it came as little surprise that the Court of Appeal reached a different judgement.

The reluctance of the Appeal Court to demand an explanation as to the allocation of resources has several precedents in English courts. In R *v* Central Birmingham Health Authority *ex parte* Collier 1988, in which a child's heart operation had been cancelled on three occasions as a result of shortage of adequate facilities, Gibson LJ said that the court:

> 'has no role of general investigator of social policy and of allocation of resources. Its jurisdiction ... is limited to dealing with breach of duties under the law, including decisions made by authorities which are shown to be unreasonable'. (quoted in Longley, 1993, p. 81)

Ex parte Collier followed R *v* Central Birmingham Health Authority *ex parte* Walker 1987. Macpherson J had held that the court had no jurisdiction to investigate:

> 'any case where the balance of available money and its distribution and use are concerned. Those are of course questions which are of enormous public interest and concern ... but they are questions to be raised, answered and dealt with outside the court'. (*ibid*)

Longley comments:

> 'The above cases are important not only because they indicate the limited role which the courts see themselves as having in relation to the provision of health services to individuals but because they are instructive about the reality of challenging policy decisions in the British courts'. (Longley, 1993, p.81)

She points out that the response of the court in these cases was the assertion of the traditional role of ministerial responsibility and a restrictive interpretation of judicial review. As Feldman (1993) has commented, the fundamental reason for this is that:

> 'The right to receive treatment, or any particular standard of health service provision, is not a legal right under English or Scottish law. Health service managers have certain duties under the legislation which established the National Health Service, including a duty on health authorities to balance their budgets, but such provisions do not confer legally enforceable rights on patients'. (Feldman, 1993, p. 903)

Given the nature of health service decision-making:

> '... judges have understandably taken the view that it would be inappropriate to grant remedies for failure to provide particular services or therapies, as this would in effect put the courts in the position of specifying to health providers and managers, health authorities, and indirectly central government, what services should be provided for whom, where they should be based, and how much money should be made available for them. There would be a risk that the courts would have to take over policy making for the health service'. (Feldman, 1993, p. 904)

Feldman continues:

> 'The conclusion which seems to flow from this is that rights to health care are principally political, subject to politico-economic and moral considerations ... To give a right to particular types or levels of health care through the NHS would reduce both the government's control over the provision of public programmes and public expenditure, and, to some extent, also to the health professionals' power. The law can offer little substantive assistance to individuals'. (Feldman, 1993, p. 907)

The second aspect worthy of comment is the expectation contained within Mr Justice Laws ruling that health authorities should explain why they are not prepared to fund treatment. While the traditional and acceptable reason has been that resources are limited, James and Longley (1995) note that the High Court was implicitly requiring health authorities to go beyond this explanation to give reasons for their decisions. The Court of Appeal may not have accepted this argument but the point still stands.

Other writers who have analysed the legal aspects of the Jaymee Bowen case have drawn attention to the restrictive nature of the Appeal Court's judgement and its reluctance to engage with the issues raised by Mr Justice Laws. Parkin, for example, comments that:

> 'The approach taken by the Court of Appeal risks making it unacceptable that the general debate on these and similar issues will remain either unstructured or behind closed doors, except insofar as the media take an interest in it. The approach also risks failing to reassure those directly affected by the results of such policies as are developed that their individual cases are receiving properly worked out and consistently applied consideration'. (1995, p.877)

Echoing this argument, James and Longley state:

> 'Rationing and prioritising is an integral part of the function of a health authority ... by highlighting the essentially moral nature of choices inherent in much public administration the quality of decision-making may be improved. The courts have a part to play in structuring decision-making and ensuring that the policy choice made, even if reasonable, is explained and justified'. (1995, p.373)

The common point in these analyses is not that the courts should interfere in priority-setting decisions but rather that their role should be to strengthen the way in which decisions are made. In particular, it is argued that the reasons behind decisions should be made clear and open to challenge. This argument is echoed by Nedwick who maintains that the Child B case:

> 'demonstrates that it is entirely possible for health authorities to present evidence on which individual decisions have been based. For the court to review the reasons for such a decision does not require it to substitute its own decision ... the very fact that such clinical evidence were required would focus minds on ensuring that these unenviable decisions are reasonable and defensible, and would help to satisfy patients and the public that the question has been properly addressed'. (Nedwick, 1995, pp. 132–3)

It is this point that, in a different context, Daniels and Sabin analyse in discussing the nature of priority-setting decisions and their legitimacy (Daniels and Sabin, 1997). The focus of Daniels and Sabin's work is decisions on the funding and provision of new technologies in managed care organisations in the USA. The question that they address is how can these largely private organisations make decisions on coverage which are seen to be legitimate and fair. This, in essence, is also the challenge faced by health authorities in the UK which is what makes the analysis of these authors both timely and pertinent. Notwithstanding fundamental differences in the funding and delivery of health care between the UK and the USA, the issues involved in decisions on the treatment of life-threatening illnesses when conventional routes have been exhausted are remarkably similar.

As Daniels and Sabin note, there is an inherent conflict between the rights of individuals and a collective approach to decision-making on priorities. This gives rise to a family of ethical dilemmas. In seeking to address them, they suggest that decisions on new technologies and associated rationales should be publicly accessible; the rationales for coverage decisions should give a reasonable construal of how the organisation concerned should provide value for money in meeting the health care needs of the population; there should be a mechanism for challenge and dispute resolution which includes the opportunity to revise decisions in the light of further evidence or arguments; and there should be either voluntary or public regulation of the process to ensure it conforms to standards of fair process. The point of emphasising these characteristics is to ensure that those affected by them understand they are legitimate and are not dictated by commercial or financial considerations.

Daniels and Sabin emphasise that 'reason giving' is especially important in decisions on new technologies, most obviously where patients have run out of standard treatment therapies. They note:

> 'Those patients (and clinicians) who are apparently most resistant to limits on new-technology use are those who face life-threatening conditions and who have run out of promising lines of treatment from standard therapies. In these cases ... the limits set by the organisation are widely perceived to be cost-driven or overly paternalistic. To the desperately ill patient, the organisation may appear to be denying a "last chance" just to save money... Alternatively, if it is insisting on its own view of acceptable risk-benefit ratios (medical appropriateness), it may appear as overly paternalistic ...
>
> Reason-giving assumes special importance in these highly charged situations ...' (p.344)

In making this comment, Daniels and Sabin are unconsciously echoing the argument of Mr Justice Laws in the High Court and the commentary on the case by some academic lawyers. Although English law may not require reason-giving by health authorities, the quality of decisions on priority-setting might be enhanced if this were to happen. At the least it would allay fears that these decisions are motivated by financial considerations alone. More positively, by placing an obligation on decision-makers to explain the rationale behind their choices it would promote consistency and rigour in priority-setting as well as enhancing public understanding of the issues involved. As such, reason-giving would help promote health literacy, to borrow a phrase used by Virginia Bottomley, and it would contribute to democratic deliberation.

This is particularly important given the confusion that arose in this case about the rationale for the health authority's decision. While the paediatricians argued that finance was not a factor, and that they were motivated only by clinical appropriateness and the best interests of the child, the health authority used both clinical appropriateness *and* financial arguments in explaining its decision.

If health authorities were to be required to set out their reasons at the point when decisions are made, and were also to set up an appeal mechanism for aggrieved patients, then such confusion might be reduced if not eliminated. Put another way, the process of decision-making, which in this case was already thorough, could be strengthened still further. This is in line with the views of the Institute of Public Policy Research which has called for a more explicit approach to rationing decisions, including procedural rights, to ensure fair dealing between patients and providers (Lenaghan, 1996).

As Daniels and Sabin argue, one of the effects of making public the reasons for funding decisions would be to establish a body of 'case law'. This:

> 'involves a form of institutional reflective equilibrium. The considered judgements reflected in past decisions constitute relatively fixed points that can be revised only with careful deliberation and good reasons. Overall, there is a commitment to coherence in the giving of reasons – decisions must fit with each other in a plausible reason- and principle-mediated way ...
>
> A commitment to the transparency that case-law requires improves the quality of decision-making. An organisation whose practice requires it to articulate explicit reasons for its decisions becomes focused in its decision-making'. (pp. 327–8)

The potential benefits would include increased trust and accountability between the organisations making decisions and those affected by them and consistency in the decision-making process.

It can be suggested that the approach taken by the Cambridge and Huntingdon Health Authority met some of the criteria set out by Daniels and Sabin but not others. In particular, the authority could have been more explicit about the basis of its decision not to fund treatment, not least by explaining in advance of the media attention why funding was not provided for further intensive treatment. This was done internally through the application of the authority's values to the case but more effort could have been made to communicate this to those not directly involved in the decision-making process. In addition, it could have set in place a mechanism for challenge and dispute resolution which might have avoided the need for legal action. Such a mechanism might have included arrangements whereby the Bowen family could have received counselling and support in exploring further treatment options and the risks associated with them in a situation in which medical advice did not point in a consistent direction. The relevance of Daniels and Sabin's analysis and the recommendations which follow from it is that it offers a framework for thinking about how difficult choices on priority-setting should be taken.

The role of the Department of Health

Throughout this case it was the Cambridge and Huntingdon Health Authority that was responsible for deciding whether to fund treatment and for explaining the basis of its decision. In telling the story of Child B we have noted the role of the NHS Executive within the Department of Health and of ministers and the confidence they expressed in the ability of the health authority to handle the issue. On one interpretation, the stance taken by the NHS Executive was entirely appropriate in a health service in which health authorities act as agents of the Secretary of State and have some discretion to interpret government policies and adapt them to local circumstances. It was this that Virginia Bottomley was referring to when she said that it would have been easy, but wrong, for her to have intervened and to have overruled the health authority because it would have been inconsistent with the government's line that health authorities were best placed to take these decisions as a result of their greater knowledge of individual cases. According to this argument, it is the role of ministers and the NHS Executive to set the policy framework for the NHS and to identify national priorities, while it is the responsibility of health authorities, as in this case, to take local decisions.

An alternative, more cynical interpretation is that it is politically convenient for ministers to devolve responsibility for controversial choices to health authorities because this takes attention away from those whose decisions on the money to be made available to the NHS necessitates such choices. As such, the role of the NHS Executive and health authorities in the Child B case conforms with Rudolf Klein's dictum that when things go well in the NHS those at the centre take the credit but when difficulties arise managers at the periphery pick up the blame (Klein, 1995). The criticism levelled at Dr Zimmern and particularly Stephen Thornton, and the abuse suffered by them and their families, is a vivid illustration of this. It could be said that while Thornton, Zimmern and their colleagues were in the media spotlight and had to account for their decisions, ministers and their officials were thus let off the hook. Putting the argument more bluntly still, by deflecting attention onto the health authority, the NHS Executive succeeded in masking its own role, thereby finding a scapegoat in a case where the press reports were always likely to be negative.

In reality, of course, both interpretations are too simplistic. To begin with, health authorities are charged with setting priorities for the populations they serve, but they do so within the framework of a national health service. If each health authority adopts its own approach without regard to that of others, then the idea of a national health service becomes meaningless. As the Cambridge and Huntingdon Health Authority pointed out in its *post mortem* on the handling of the case, although its own values helped it to reach a decision, there is a need for a common set of values for the NHS as a whole to promote greater consistency in decision-making. This is precisely what has been proposed by the Working Group on priority-setting established by the NHS Executive and other agencies in the wake of the Child B case (Academy of Medical Royal Colleges and others, 1997). The point to emphasise here is that local responsibility for priority-setting has to take place within a national framework and such a framework was lacking in this case.

The suggestion that politicians and their officials are using health authorities as scapegoats in the priority-setting debate also needs qualifying. While partly true, it fails to credit health authorities with the realisation that they may be being used for wider political purposes. Certainly in this case the Cambridge and Huntingdon Health Authority was under no illusions about what was happening and its staff used every opportunity to link the decision on Child B with the national debate on priority-setting. Not only did Dr Zimmern participate in the national Working Group on priority-setting, but he and Stephen Thornton also made frequent appearances on conference platforms to discuss the lessons of the case and they wrote up their experiences for wider consumption. They lost no opportunity to remind politicians and others that priority-setting was becoming a more significant challenge for the NHS. As Thornton wrote in the *British Medical Journal:*

> 'My experience leads me to believe that it is not sustainable for health authorities to be left to make such sweeping decisions as to fund or not fund whole categories of care – for example infertility treatment. Making decisions on issues of such profound importance to citizens is a matter for government ...' (1997, p. 1839)

What emerges here is a boomerang law of priority-setting as those who provide the initial impetus in the debate find themselves on the receiving end of the results.

What would be the consequences of a national approach and would it be an advance over current arrangements? While there would be greater consistency if the government provided leadership and clarity on those services that should be funded, there is also a risk that health authorities might disagree with the outcome and would prefer to retain responsibility for decision-making even if this means taking the blame for unpopular decisions. This much was indicated in 1996 when government guidelines on the use of beta interferon for patients with multiple sclerosis were criticised by some health authorities for requiring them to fund a treatment they felt did not meet the NHS Executive's own precepts on evidence-based medicine. The likelihood that those at the centre will make decisions of this kind therefore has to be balanced against the benefits that might accrue from a national approach as the arguments for political leadership in the rationing debate gather momentum.

Ethics and priority-setting

We are left to consider the ethical dilemmas raised by the Child B case and its relevance to the debate on priority-setting generated by recent research and commentary. Our starting point is the acceptance that making choices in health care raises dilemmas in both theory and practice.

One well-established approach involves the identification of four principles and their application in cases of this kind to illuminate the nature of the choices involved (Gillon, 1985 and 1994). The principles are *autonomy*, *non-maleficence*, *beneficence*, and *justice*.

Respect for *autonomy* entails recognition that individuals can make their own decisions and impels consultation with them and obtaining their agreement to treatment. *Non-maleficence* and *beneficence* are closely linked, requiring that doctors should produce more benefit than harm. *Justice* is open to alternative interpretations, ranging from a concern to achieve a fair distribution of resources to respect for people's rights. It also encompasses the notion of desert, in the sense referred to by Professor Goldman when he said that Jaymee deserved further treatment on the basis of her courage and fighting spirit. It is important to bear in mind Gillon's observation that, 2,500 years after Aristotle first discussed these issues, we are still struggling to understand the competing moral concerns of justice (Gillon, 1994). It is therefore necessary to beware of simple solutions to these dilemmas wherever they may come from.

In the case of Child B, the principle of autonomy arose when considering Jaymee's best interests and the question of who should assess those interests, including the dilemma of consent to treatment discussed earlier. Non-maleficence and beneficence were of particular concern to the clinicians in the case. Differences between clinicians in their assessment of the probabilities of harm and benefit arising from further treatment account in large part for the lack of medical consensus on Jaymee's treatment. Justice was of particular concern to the health authority, not least in weighing the consequences of funding Child B's treatment in relation to other priorities. This came out clearly in Dr Zimmern's affidavit which referred to his responsibility:

> 'to weigh up the needs of the individual with the requirements of the population within the Cambridge and Huntingdon Health Commission'

and to:

> 'a responsibility to ensure that sufficient funds are available ... for the treatment of other patients which is likely to be effective'.

In this case, the concern for justice emerged as more important than respect for autonomy when the health authority, on the basis of clinical advice received, judged that further intensive treatment would do more harm than good.

This illustrates the point that invoking ethical principles may illuminate the issues involved in priority-setting but does not remove responsibility for decision-making from health authorities or others charged with allocating fixed budgets between competing demands. This is also the conclusion of Draper and Tunna (1996) in their review of how the four principles may assist health authorities in making decisions. As they note:

> 'The process of commissioning is the process of adjudicating between the competing demands and needs of the local population. This process requires that each person is respected as an individual in his or her own right, that none is harmed by the services provided and that benefit for all is maximised. The conflict between the principles arises because there are insufficient funds to meet all needs as individuals would prefer them to be met'. (p. 42)

Draper and Tunna argue that for health authorities the principle of justice is of over-riding importance, rather than being one principle among many. For them justice does not conflict with the other principles but a consideration of each principle is required by justice. Draper and Tunna also note that policies which work at a population level may seem unfair when applied to individual cases. For this reason they suggest that health authorities need:

> 'some method of resolving appeals made by, or on behalf of, individuals who appear, on the surface at least, to be special cases'. (p. 44)

Such cases may well arise when the needs of the community conflict with the interests of individuals. Here, respect for autonomy and a concern for justice may indeed point in different directions. In Jaymee's case, the health authority's decision not to fund further intensive treatment relied partly on a set of values which did not explicitly include autonomy and which gave greater emphasis to the requirements of the population at large.

It is here that the 'rule of rescue' is relevant. This suggests that when individuals are faced with the prospect of death, there is an obligation to intervene even though this may run counter to the concerns of the community as a whole (Hadorn, 1991). This rule applies regardless of the level of expenditure involved. An example from outside the health sector concerns the yachtsman, Tony Bullimore, rescued in 1996 from his upturned boat in the South Atlantic by the Australian Navy. On utilitarian grounds, it could be said that the effort and expense involved in the rescue were not an effective use of scarce resources. But applying the rule of rescue, the action was justified because death otherwise would have been the outcome. By extension, medical intervention to save the lives of patients who would otherwise die is appropriate, even though the resources involved might bring more health benefit if used in other ways.

In essence, this was the argument advanced by Mr Justice Laws in the High Court when he invoked the right to life contained in the European Convention on Human Rights to request the health authority to reconsider its decision not to fund treatment. And as Draper and Tunna note:

> 'In adjudicating a special claim on resources, by an identifiable individual, who is likely to die quite quickly if resources are not forthcoming, commissioners may feel compelled to assist, even if they would not consider the small possibility of benefit worth the cost under other circumstances, perhaps where death is not imminent'. (p. 44)

In the case of Child B, the question that arose was whether the rule of rescue applied when the potential harm involved in the act of rescue might exceed the potential benefit? Expressed in the terms of the four principles, the clinicians involved and the health authority had to determine whether the concern with non-maleficence and beneficence could resolve the conflict between respect for the autonomy of individuals and a desire to achieve justice at the population level. On this issue there was no consensus. Lack of agreement meant that the health authority had to reach its best judgement on the basis of the information that was available and the competing interpretations of this information. It also had to explain the basis of its judgement and the reason why some of the advice it received was seen as more important than other advice.

Jaymee's story illustrates then the conflict that may occur when a concern for cost-effectiveness at the population level coincides with a request for heroic and expensive intervention on behalf of an individual who is likely to die and which has a limited chance of success. As Hadorn notes in comments on the Oregon experience of priority-setting:

> '... there is a fact about the human psyche that will inevitably trump the utilitarian rationality that is implicit in cost-effectiveness analysis: people cannot stand idly by when an identified person's life is visibly threatened if effective rescue measures are available'. (1991, p. 2219)

In the event, Oregon used a modified form of cost-effectiveness analysis which represented a compromise between a utilitarian approach and the need to accommodate the rule of rescue. And as Hadorn points out, there is in any case no obligation to observe the rule of rescue when rescue becomes futile and pointless because no reasonably effective treatment exists. From this perspective, what matters is to adopt an approach to priority-setting which is informed by evidence on cost-effectiveness but which is also socially acceptable and intuitively sensible. Such an approach may appear flawed to those who argue that cost-effectiveness is of overriding importance but, as Calabresi and Bobbit (1978) have stated, the challenge is to reduce imperfections in the making of tragic choices, not to search for the single best way. For this reason it is essential that the process of decision-making be consistent and fair. That is why we have emphasised the need to strengthen the way in which choices on treatment are made.

This applies as much to clinicians as to health authorities. One way of strengthening clinical decision-making would be for hospitals to make greater use of clinical ethics committees. The potential role of such committees has been discussed by a range of authors who have illustrated the contribution they may be able to make to resolving ethical dilemmas in medicine (Thornton and Lilford, 1995), which includes cases involving children (Larcher, Lask and McCarthy, 1997). It has been argued that clinical ethics committees with advisory, practice development and educational roles could contribute significantly to clinical practice in the UK, as has happened in other countries.

Chapter 3

Conclusions

Our purpose in this research and book has been to draw on the experience of the Child B case to identify the lessons that emerge for the NHS. Analysis of the roles of different actors and of the ethical issues involved has begun to indicate the nature of these lessons. In this chapter we bring the strands of the argument together to suggest a way forward for the NHS. As well as the specific proposals outlined below, we would suggest that those involved in making tragic choices in health care may learn how to cope with these choices simply by reading this story and reflecting on its significance for their work. If nothing else, we hope that this book will serve to stimulate such reflection, thereby increasing understanding and making more explicit the basis on which choices are made.

We have endeavoured to tell the story of Child B from different perspectives because no single account is likely to do justice to the complexity of the issues involved. The lessons that arise affect all of those who played a part in the story. We begin with the implications for patients and then move on to consider the lessons for health authorities and others. It should be emphasised that the proposals in this section are our own: the people we interviewed do not necessarily concur with them. There is inevitably some degree of repetition in the proposals in so far as they impact on those involved in treatment decisions in different ways.

For *patients* there is a need to:

- clarify the way in which consent is sought from children and siblings. This includes giving consideration to the adoption of a code of practice setting out the rights of children, as proposed by Alderson and Montgomery, involving a presumption of competence to consent to treatment and clarifying the autonomy of children in treatment decisions and the roles of parents and professionals

- ensure that patients are advised by GPs about treatment options (in consultation with specialists) and that GPs, patients and their families share in the decision-making process

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- make available independent advice and counselling to patients and their families, either in place of GPs where a long-term relationship with a family doctor does not exist, or as a supplement where patients request it
- assess how many opinions it is reasonable for patients to seek within the NHS in a climate in which patients and their families are increasingly inclined to shop around for advice and act as active consumers of health care
- establish explicit procedures for making decisions on treatment to ensure consistency and fairness and to earn legitimacy for these decisions
- have direct access to health authority staff when appropriate and the opportunity to appeal against decisions not to fund treatment

For *health authorities* there is a need to:

- discuss and agree a set of values to guide decision-making, building on the values laid down by ministers, and involving other agencies such as NHS trusts. This includes debating what these values mean and testing them in both hypothetical and real cases
- clarify the process for making decisions on priorities, including arrangements for delegating responsibility from board level and for taking ECR decisions
- review arrangements for dealing with complex ECR decisions and for identifying and handling exceptions to agreed policies, including tertiary ECRs for which formal prior approval is no longer a standard requirement
- demonstrate that each case is examined on its merits taking into account all relevant facts
- ensure that the decision-making process is robust and enables relevant options to be examined rigorously
- obtain access to independent professional advice and draw up guidelines on how many professional views should be sought and the range of views that are relevant, especially when doctors disagree
- ensure that there is effective internal communication between the staff involved in decision-making

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- provide patients with direct access to a designated decision-maker within the health authority in order to communicate the results of decisions effectively and to display appropriate sensitivity when difficult cases arise
- give reasons for decisions to fund or not fund treatment, explaining the basis of these decisions in order to demonstrate the legitimacy of the process, consistency and fairness
- establish an appeal mechanism to enable patients and their families to question and challenge decisions
- examine policies on communications and PR to ensure that effective arrangements are in place, should the need arise, for explaining the authority's position to the media and the public, including the roles to be played by different staff

For *clinicians* there is a need to:

- assess the way in which doctors are trained to break bad news and communicate with patients in difficult cases of this kind
- debate the definition of experimental treatment and how such treatment should be provided e.g. at designated centres or in some other way
- clarify the guidelines that govern experimental treatment, particularly in relation to children, in order to ensure that these guidelines are neither so rigid that they constrain innovation, nor so loose that they put patients at risk
- determine whether these guidelines apply in all parts of the NHS and the private sector
- consider what further safeguards are required to protect the best interests of patients, whether through clinical ethics committees or, to return to an earlier point, through more effective arrangements for obtaining the consent of patients to treatment
- ensure that in controversial cases of this kind, the views of clinicians are communicated to the media and the public, and that the clinical reasons for either treating or not treating are well understood
- explore ways in which disagreements between clinicians can be debated and resolved

For the *NHS Executive* there is a need to:

- decide what action to take on the report of the Working Group on priority-setting and its recommendations
- consider whether national guidance is needed on the processes that health authorities should follow in making decisions on priorities
- offer support to the NHS in working through at a local level the ethical issues involved in priority-setting
- work with the health service professions and health authorities on some of the specific issues identified above e.g. consent to treatment, the definition of experimental treatment and how this should be funded
- review with health authorities, perhaps through the NHS Confederation, the balance between national and local responsibility for priority-setting
- determine which decisions should be taken nationally and which can be left to local discretion.
- further strengthen the provision of advice on clinical effectiveness, through the proposed National Institute of Clinical Excellence and other means

Finally, we return to the ethical issues raised by this case. Citing Calabresi, Gillon (1994) likens health service decision-making to:

> 'the juggler trying to keep too many balls in the air; like the juggler we must do our best to improve our juggling skills to keep more balls in the air for more of the time and to avoid letting any ball stay on the ground for too long. We must accept, however, that in the context of competing and mutually incompatible claims there will always be some balls on the ground. Moreover, we should not be surprised that there will always be some people dissatisfied after justice has been done because by definition not everyone's claims can be met'. (p. 187)

The implication here is that we cannot hope for more than marginal improvement over existing decision-making approaches and constant adjustment in these approaches over time.

While many of our recommendations have been framed in precisely this spirit, there is one area in which we wish to take issue with those who believe that 'muddling through elegantly' by implicit decision-making (Hunter, 1995 and Mechanic, 1997) is the best that can be achieved. This is the need for greater openness and debate about health care decisions.

In the literature on rationing, a number of writers have argued that choices should be explicit and open to scrutiny. Fleck (1992) in particular has outlined this position at some length. In so doing, he rejects the contention that rationing decisions should remain implicit and solely the responsibility of doctors or managers.

Fleck's thesis is that the allocation of health care resources is essentially a moral and political problem – 'a matter of social justice' (p. 1601) – and that decisions on resource allocation need to be explicit to be seen to be legitimate and morally defensible. In his view, this calls for an informed democratic consensus model in which through broad mechanisms of public deliberation there is debate about how limited health care resources can be distributed in a way which is both fair and cost-effective.

We would endorse the need for greater explicitness. Indeed, many of the proposals set out above are designed to ensure that health authorities strengthen the process of decision-making in order to secure legitimacy for their decisions. While our proposals are particularly concerned to enhance the quality of decisions in relation to individual cases, like that of Jaymee Bowen, there is also a need to secure greater legitimacy for priority-setting decisions that affect communities and societies. This again requires much wider debate of priority-setting than has typically occurred so far. In view of the partial reporting of the Child B case by the media, a properly informed debate will only occur if attention is given to the structuring of that debate. That includes involving clinicians more fully in discussion of priority-setting to incorporate considerations of appropriateness and effectiveness as well as costs. It also means examining innovations in democratic practice, such as citizens' juries (McIver, 1998), as a way of promoting effective public deliberation on priority-setting.

What relevance does the case have to the wider debate on priority-setting in health care? Much has already been written on this subject and this is not the place to repeat the arguments in full. We would emphasise that Child B was an event waiting to happen. The circumstances that arose in the NHS at that time meant that if Jaymee Bowen had not come to epitomise the challenge of priority-setting in health care then some other case would have done. The particular importance of Child B was in providing a tangible example of the general challenge of health care priority-setting, an example made poignant by the personalities involved and the manner in which they captured the interest of press and public. In this sense, Jaymee Bowen was the distant cousin of Coby Howard, the seven-year-old boy whose death from leukaemia in the USA while waiting for treatment under Medicaid was instrumental in forcing the Oregon legislature to initiate the programme which resulted in the Oregon plan, and the global interest in priority-setting which has followed.

Jaymee's lasting contribution to the UK debate is the programme of work on priority-setting sponsored by the NHS Executive, the Academy of Medical Royal Colleges, the British Medical Association, and the National Association of Health Authorities and Trusts. This led to a report being published at the beginning of 1997 (Academy of Medical Royal Colleges and others, 1997). The report reviewed the issues involved in priority-setting in the UK, it analysed experience in other countries, and it made a series of recommendations on future action. These recommendations included the need to recognise that priority-setting is inevitable, proposals for a wide debate on the core values of the NHS, and work to ensure that values are translated into action more consistently within the NHS. Our own view is that it is only a matter of time before the UK government emulates the example of countries such as the Netherlands, New Zealand and Sweden and initiates a national debate on priority-setting. If nothing else, Jaymee Bowen's tragic life and death has brought that day nearer.

References

Ablett, S. (1994) *Good Clinical (Research) Practice*, UKCCSG.

Academy of Medical Royal Colleges and others (1997) *Priority-setting in the NHS: A Discussion Document.*

Alderson, P. and Montgomery, J. (1996) *Health Care Choices*, Institute of Public Policy Research, London.

Barclay, S. (1996) *Jaymee: The Story of Child B*, Viking, London.

Browett, P. and Palmer, S. (1996) 'Legal barriers might have catastrophic effects' *BMJ*, 312: 242–3.

Calabresi, G. and Bobbit P. (1978) *Tragic Choices*, Norton, New York.

Calvert, J. and Connett, D. (1997) 'Dying British Children "exploited by US cancer doctors"' *The Observer*, 24 August, 1.

Cambridge and Huntingdon Health Commission (1995) *Learning from the Child 'B' Case*, Paper for the NHS Executive Board.

Daniels, N. and Sabin, J. (1997) 'Limits to Health Care: Fair Procedures, Democratic Deliberation and the Legitimacy Problem for Insurers' *Philosophy and Public Affairs*, 26: 303–50.

Draper, H. and Tunna, K. (1996) *Ethics and Values for Commissioners*, Nuffield Institute for Health, Leeds.

Delany, L. (1996) 'Protecting children from forced altruism: the legal approach' *BMJ*, 312: 240.

Eden, O.B. (1996b) 'Treatment for Children with Brain Tumours' *BMJ*, 312: 575.

Entwistle, V.A. and Watt, I.S. (1996) 'Postscript: media coverage of the death of Child B' in Marinker, M. (ed.) *Sense and Sensibility in Health Care*, BMJ Publishing Group, London.

Entwistle, V.A. and colleagues (1996a) 'Media Coverage of the Child B Case' *BMJ*, 312: 1587-91.

Entwistle, V.A. and colleagues (1996b) 'The media and the message' in Marinker, M. (ed.) *Sense and Sensibility in Health Care*, BMJ Publishing Group, London.

Feldman, D. (1993) *Civil Liberties and Human Rights in England and Wales*, Clarendon Press, Oxford.

Fleck, L.M. (1992) 'Just Health Care Rationing : A Democratic Decision-making Approach' *University of Pennsylvania Law Review*, 140(5): 1597-1636.

Gillis, J. (1997) 'When lifesaving treatment in children is not the answer' *BMJ*, 315: 1246-7.

Gillon, R. (1985) 'Justice and allocation of medical resources' *BMJ*, 291: 266–8.

Gillon, R. (1994) 'Medical ethics: four principles plus attention to scope' *BMJ*, 309: 184–8.

Graham, P. (1994) 'Children: Problems in Paediatrics' in Gillon, R. (ed) *Principles of Health Care Ethics*, John Wiley and Sons, Chichester.

Hadhorn, D. (1991) 'Setting Health Care Priorities in Oregon. Cost Effectiveness Meets the Rule of Rescue' *JAMA*, 265:2218–25.

Hunter, D.J. (1995) 'Rationing: the Case for Muddling through Elegantly' *BMJ*, 311: 811.

James, R. and Longley, D. (1995) 'Judicial review and tragic choices: Ex Parte B' *Public Law* 367–73.

Klein, R. (1995) *The New Politics of the NHS*, Longman, London.

Larcher, V.F. Lask, B. and McCarthy, J.M. (1997) 'Paediatrics at the cutting edge: do we need clinical ethics committees?' *Journal of Medical Ethics*, 23: 245–9.

Lenaghan, J. (1996) *Rationing and Rights in Health Care*, Institute for Public Policy Research, London.

Longley, D. (1993) *Public Law and Health Service Accountability*, Open University Press, Buckingham.

McHale, J. and others (1997) *Health Care Law: Text, Cases and Materials*, Sweet and Maxwell, London.

McIver, S. (1998) *An Evaluation of the King's Fund Citizens' Juries Programme*, King's Fund, London.

Mechanic, D. (1997) 'Muddling Through Elegantly: Finding the Proper Balance in Rationing' *Health Affairs*, 16(5): 83–92.

Month, S. (1996) 'Preventing children from donating may not be in their best interests' *BMJ*, 312: 240–1.

Nedwick, C. (1995) *Who Should We Treat?*, Clarendon Press, Oxford.

Parkin, A. (1995) 'Allocating Health Care Resources in an Imperfect World' *The Modern Law Review*, 58: 867-78.

Price, D. (1996) 'Lessons for health care rationing from the case of Child B' *BMJ*, 312: 167–9.

Royal College of Paediatrics and Child Health (1992) *Guidelines for the Ethical Conduct of Medical Research Involving Children*, London.

Royal College of Paediatrics and Child Health (1997) *Withholding or Withdrawing Life Saving Treatment in Children*, London.

Savulescu, J. (1996) 'Substantial harm but substantial benefits' *BMJ*, 312: 242–3.

Schmitz, N., Gratwohl, A. and Goldman, J.M. (1996) 'Allogenic and autologous transplantation for haematological diseases, solid tumours and immune disorders. Current practice in Europe in 1996 and proposals for an operational classification' *Bone Marrow Transplantation*, 17: 471–7.

Sikora, K. (1995) 'Second opinions for patients with cancer' *BMJ*, 311: 1179–80.

Thornton, J.G. and Lilford, R.J. (1995) 'Clinical Ethics Committees' *BMJ*, 311: 667–9.

Thornton, S. (1997) 'The Child B Case – reflections of a chief executive' *BMJ*, 314: 1838–9.

Watt, I.S. and Entwistle, V.A. (1996) 'What are the implications of the Child B case for the debate on health care policies' in Marinker, M. (ed.) *Sense and Sensibility in Health Care*, BMJ Publishing Group, London.

Zimmern, R. (1995) *Challenging Choices*, 2nd Annual Report of the Director of Health Policy and Public Health for Cambridge and Huntingdon Health Commission.

The extracts from the Court Transcripts are drawn from the files of the Cambridge and Huntingdon Health Authority (a) in the High Court of Justice, Queen's Bench Division, Crown Office List, Case No: CO/1677/95, The Queen *v* Cambridge District Health Authority *Ex parte* 'B' (b) in the Supreme Court of Judicature in the Court of Appeal (Civil Division) on Appeal from the Queen's Bench Division, Crown Office List, Regina *v* Cambridge Health Authority *Ex parte* 'B' (minor). The latter has been published in *All England Law Report* (1995) 2: 129–38.

Appendix

Methodology

The fieldwork for this study consisted of in-depth interviews with the key individuals involved in this case, including David Bowen, health authority managers, Department of Health (DoH) officials, clinicians, lawyers and journalists. Although interviews were predominantly carried out face-to-face, where this was not possible they were supplemented by telephone discussions. Quotations drawn from the interviews have been checked for accuracy with interviewees who have also commented on earlier drafts. Information gained in this way has been supplemented by analysis of documentary material including health authority papers, newspaper articles and television features and transcripts of the court judgements, together with articles and books.

Below we set out the key individuals involved in the case. Those whose names are asterisked were interviewed for this study, in some cases on more than one occasion. The fieldwork was undertaken between September 1996 and October 1997.

The family

*David Bowen, father; Jaymee Bowen and her sister, Charlotte.

The health authority

*Stephen Thornton, Chief Executive; *Dr Ron Zimmern, Director of Public Health; *Robert Jefford, Head of Administration; *Maggie Scott, Chair.

The clinicians

*Dr Valerie Broadbent, Addenbrooke's NHS Trust, Cambridge; *Professor Ross Pinkerton and *Dr Simon Meller, The Royal Marsden NHS Trust, Surrey; *Professor John Goldman, The Royal Postgraduate Medical School, Hammersmith Hospital; *Dr Peter Gravett, the London Clinic;

*Dr Jackie Cornish, Bristol Royal Hospital for Sick Children and Chair paediatric BMT group, a working party of UK Children's Cancer Study Group (UKCCSG).

The lawyers

*Howard Weston, solicitor at Mills and Reeve, Cambridge, acting on behalf of the health authority; *Rose Sunter, solicitor at Sharpe Pritchard, on behalf of the Bowen family; Justice Laws, High Court judge; Sir Thomas Bingham, The Master of the Rolls; The Right Honourable Stephen Brown, the President and Lord Justice Simon Brown, Court of Appeal.

The Department of Health

* Virginia Bottomley, Secretary of State for Health, 1992–95; * Alaistair Liddell, Director of Planning; *Dr Graham Winyard, Medical Director.

Journalists

*Sarah Barclay, BBC; *Fergus Walsh, BBC; *Jock Gillespie, *Cambridge Evening News*; *Andrew Tomlinson, BBC.

The case of Child B, Jaymee Bowen, has come to epitomise the dilemmas involved in making tragic choices in health care.

After being treated for cancer twice, Jaymee was, on the recommendation of the paediatricians responsible, refused funding for further intensive treatment by the Cambridge and Huntingdon Health Authority, when she was diagnosed for a third time. After an appeal by her father, the health authority's decision was backed by the courts. Despite an anonymous donor paying for Jaymee's treatment, she died over a year later.

For many involved in this case, the decision not to treat Jaymee was not just about funding, but what care was appropriate for a child with her medical history. There were also ethical dilemmas to consider and questions about the rights of children and their ability to give consent to treatment.

Tragic Choices in Health Care draws out the implications of such difficult decisions for patients, doctors, managers and others and makes recommendations for how cases of this kind should be handled in the future.

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