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In their major work on the development of social policy, Hall *et al.* have pointed out the scant attention given to the complexity of the process by which needs emerge and are accepted as priorities for government action at any given time, and a new policy formulated to tackle them.<sup>1</sup> Concepts such as 'social pity', 'national unity', 'public enlightenment', and so forth have often been the only explanation for policy developments adduced by the writers of early social administration textbooks.

The study of the origins of the Family Fund that follows in this chapter is, therefore, presented as not only an essential feature of any report on the work of the Fund, but also a contribution to the literature on policy development. We are concerned to try and answer the questions: why did the needs of families with handicapped children gain precedence over other needs in November 1972, and why and how was the Family Fund established to meet those needs?

To do this, it is necessary to reduce a myriad of variables into a simple and coherent whole which may in itself lead to gross distortion of the true process. It is also necessary to assess the role of those who frame policy; but here there is very little information available. In particular, no research workers in this field have ever been given access to information that may help them assess adequately the role of the civil service in social policy formation. Civil servants were only prepared to talk in the most general terms about the development of the Family Fund and it was not possible to obtain access to the departmental files which contain essential records of the meetings and the discussion papers that led up to the establishment of the Fund. The two principal civil servants from the social services and social security sections of DHSS involved in the origins of the Family Fund did, however, comment fully on a draft of this chapter, correcting a number of points of detail and confirming that the over-all interpretation of events is fair and accurate. Apart from the failure to get access to information held by the civil service, the other major blow to this analysis was Sir Keith Joseph's decision that he did not want to be interviewed about the origins of the Family Fund.<sup>2</sup>

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I have a relatively poor memory and do not keep records of what lay behind policies or decisions when in office.

As will be seen, Sir Keith, as Secretary of State for Social Services, may have played a key role, not only in originating the Family Fund but in developing it in the form that it took.

These imperfections in the data mean that from time to time in the analysis of the development of the Fund, one has to rely on more or less informed conjecture.

### **Developments up to September 1972**

Before the outburst of feeling about the attitude of the Distillers Company to Thalidomide children, the problems of the families of handicapped children were not a public issue, nor was there an articulated demand for a fresh policy initiative to help parents 'shouldering the various burdens which caring for these children entails'.<sup>3</sup> In public policy things were settling down after a spate of new social legislation which was just beginning to benefit these families. Just before the general election in 1970, Parliament had passed the Social Services Act which had implemented the main recommendation of the Seebohm Report - the establishment of integrated local authority social services departments. The new departments, preoccupied with establishing themselves and already preparing for local government reorganisation, were not pressing for new responsibilities, particularly as they were struggling to implement two other pieces of legislation - the Health Services and Public Health Act 1968, which had given wider powers to local authorities to help the disabled and elderly; and the Chronically Sick and Disabled Persons Act 1970, based on a private member's bill which had been rushed through Parliament before the dissolution in 1970, and which placed new duties on local authorities to identify all the disabled in their areas and provide aids and adaptations to those in need of them.

The other major new measure to benefit handicapped children and their families - the attendance allowance - had been introduced by the Labour government in 1970 as part of a bill, and was subsequently enacted by the new Conservative government in 1971. The allowance became payable to children in 1972 and was extended, at a lower rate, to the less severely disabled in October 1973. Both the attendance allowance and the Chronically Sick and Disabled Persons Act were the focus of public discussion during the period up to the summer of 1972. Sir Keith Joseph was pressed first to implement Sections 1 and

2 of the Chronically Sick and Disabled Persons Act and then to persuade local authorities to administer it more generously and more speedily. But this public interest was not focused on the additional needs of handicapped children, and was more concerned with the proper implementation of existing legislation than with the development of new initiatives.

A search of government and academic papers published in the years before 1972 does not indicate that child handicap was a developing issue of public concern. The only state paper published during the office of the previous two governments which paid any attention to the problems of families with handicapped children was the Seebohm Report.<sup>4</sup> The committee that drew up that Report devoted two chapters to the physically and mentally handicapped, and while it recommended the development, integration, and co-ordination of services for both groups within the new social services department, it did not single out the needs of children as a priority for extra resources.

In 1971 the in-coming Conservative government published a White Paper,<sup>5</sup> and although the needs of parents caring for handicapped children at home for counselling and practical assistance (see paras 14-20 and 139-45) were recognised, it made no mention of a new fund to assist them. In the same year the Government Social Survey Division published the first volume of Amelia Harris's large national sample survey.<sup>6</sup> This study, which had begun in 1967, presented an unprecedented amount of data about the number and condition of the impaired and was followed up in 1971 and 1972 by two further volumes on the housing and income of the disabled.<sup>7</sup> Although these studies reinforced concern and led to further public discussion of the needs of the handicapped, they did not deal with children and most of the attention which they generated was directed to adults.

During the 1960s and early 1970s, a number of independent research studies appeared.<sup>8</sup> While stressing the great physical and emotional burdens that many families had to cope with, they did not recommend any fresh tranche of money to alleviate their difficulties. This was also true of the other studies that were published in this period.

Perhaps the nearest thing to an official statement on the plight of handicapped children published during this period was the report of a National Children's Bureau working party on children with special needs.<sup>9</sup> Parents' letters received by the working party had stressed the need for financial help and described the extra cost of clothing, transport, and aids for incontinence. The report summed up the feeling of many parents with the following quotation from a mother with a

six-year-old mentally handicapped son:<sup>10</sup>

The easiest way as a first step towards helping to relieve the burden of increased costs a handicapped child causes would be to make an increase in his/her allowance on income tax or, in the case of parents of very limited means, a direct grant. But for dignity's sake don't make the parents be inundated with red tape, just a simple application, quick conferment and payment.

This plea for a Family Fund was not taken up elsewhere in the report and in a short section on practical supportive services, the working party merely welcomed the attendance allowance.

Therefore, a search of official and unofficial publications suggests that there was no growth of special concern for the burdens which parents faced in caring for a handicapped child and certainly no call for fresh support for these families.<sup>11</sup> This view is confirmed if we examine some of the other principal participants in the policy-making process. None of the political parties mentioned child handicap in their manifestos for the 1970 general election, nor was there any interest in the subject shown by the policy-making bodies of the parties, such as the Fabian Society, the Labour Party Research Department, the Conservative Central Office, the Bow Group, or the Monday Club. The same was true of Parliament itself. In the late 1960s and early 1970s, an increasing amount of interest in the problems of the handicapped was shown by members but this concern did not extend to handicapped children. During this period, there were no Commons debates on this subject and in the Lords the only debate on handicapped children concentrated on educational facilities. Only six questions were tabled on families with severely handicapped children living at home. Activity in Parliament cannot, therefore, be described as sustained pressure for reform.

Nor is there any evidence that pressure groups were active in pressing for improvements in benefits. None of the large voluntary organisations representing handicapped children and their families has ever taken up a radical pressure-group role on their behalf. Indeed, it was because of the lack of such pressure from the older, established, traditional voluntary organisations that Megan du Boisson and Berit Thornberry founded the Disablement Income Group (DIG) in 1966 to 'secure the provision for all disabled people of a national disability income and an allowance for the extra expense of disablement'.<sup>12</sup> DIG was a pressure group with a more abrasive campaigning style than the other groups. It developed close links with the parliamentary group on disability, and

Peter Large, one of its officers, became the semi-official lobbyist for the disabled. DIG used the press, lobbied ministers, and pressed for reform with some vigour, but by 1972 they had campaigned only for a disability pension scheme for adults.<sup>13</sup>

There is no conclusive evidence, but it is clear from the course of events that *government ministers* were not proposing any new benefit for disabled children. The Conservative government came to power in 1970, committed to cuts in public expenditure and taxation. In its first two years in office, the sections of the DHSS that were subsequently to have some hand in the Family Fund, were preoccupied, on the social security side, with the legislation relating to, and later the provision of, the attendance allowance and invalidity benefit; and in the social services field, with implementing the Social Services Act and the Chronically Sick and Disabled Persons Act, and with the reorganisation of local government and the health service.

Busy as the Department was, though, further possibilities were not entirely ignored. When the House of Commons Paper on future social security provision for the disabled was published, it was based on some of the thinking that had gone on in the Department since 1970.<sup>14</sup> This Paper admitted (para. 6) that 'Where disabled children are concerned we lack adequate information about their numbers and about the precise character of their needs.'

It seems reasonable to conclude that the Family Fund was not a premeditated innovation in social policy. It was not part of a long-term strategy, consistent with other measures and carefully planned and organised.

### **The Thalidomide affair**

Earlier in this chapter it was suggested that writers who have ascribed the development of new social policies to 'public outrage', 'the national conscience', and so forth were taking too simplistic a view. But in the case of the furore over the Thalidomide affair, these ascriptions bear more closely on the truth.

In the 1950s a German drug company called Chemie Gruenthal manufactured a derivative of glutamic acid which they called 'Thalidomide'. It was sold as a totally safe, non-toxic sedative and sleeping pill, especially suitable for the tensions that occur in pregnancy. It was manufactured and marketed in the UK by Distillers Company (Biochemicals) Limited. In December 1961, after reports in Germany and Australia that women who had taken the drug between the fourth and

sixth week of pregnancy were producing abnormal children, it was withdrawn from the British market. Subsequent investigation pointed to the conclusion that about 400 women in the UK who had taken the drug in pregnancy produced children with terrible deformities.

During the next ten years there was little public discussion about the 'Thalidomide affair'; the *sub judice* rule restricted press coverage to reporting the successive attempts by parents to obtain compensation for their damaged children through the courts. In September 1972, the *Sunday Times*, which had been investigating the Thalidomide affair since 1967, decided to campaign more forcefully in a series of investigative and leading articles. On 24 September 1972, it published the first of a series of special articles 'Our Thalidomide Children. Cause for National Shame'. These articles led to a massive upsurge of public concern about Thalidomide children which involved the courts, Parliament, the government, shareholders, the rest of the press, trade unions, local authorities, the large city institutions, retailers, consumers, and many other organisations, institutions and individuals. The public furor over Thalidomide resulted in a number of developments in policy, including compensation for the children at least six times more than the sum originally offered by Distillers; a Royal Commission on Civil Liability and Compensation for Personal Injury;<sup>15</sup> changes in the legal interpretation of contempt in civil cases; a Law Commission report on civil liability in ante-natal injuries;<sup>16</sup> and an Act that changed the law on that subject.<sup>17</sup> It also led the government to establish the Family Fund.

It is worth reflecting briefly on why the Thalidomide campaign produced these results. The public conscience was awakened suddenly and without warning. The *sub judice* rule had stifled public comment and people generally had not become inured to the damage caused by Thalidomide. The numbers of children involved were small enough to identify with; their disablement was visible and was not associated with any kind of mental disability. They were, therefore, a group with which the public could easily sympathise. By contrast, Distillers was one of the largest, richest and most successful public companies in the UK and it was not at any risk if it paid the compensation. In these circumstances, as soon as the campaign became a public issue, it had a good chance of success. The decision of the *Sunday Times* to mount it was critical, and the matter would certainly not have developed without the newspaper articles. However, there were other important factors that influenced the outcome. The Attorney-General's intervention to suppress an article in the *Sunday Times* meant that the campaign became not

just the cause of one newspaper but an issue concerning the whole of Fleet Street. Parliament played an important part in keeping it alive during November and December, reflecting a developing public interest; and through the coverage given to debates and questions, MPs were also responsible for setting the tone of that interest. The actions of individual Distillers' shareholders were sparked off by the *Sunday Times* and eventually led to the intervention of the large City institutions, no doubt motivated partly by self-interest but also by the very strong wave of public concern. It was their intervention that finally decided Distillers to make a new and more generous settlement. One of the major participants in most social policies, the government, played a relatively dormant role. From time to time during the campaign, both press and Parliament attempted to involve the government: to get it to use its authority to persuade Distillers to settle or to provide a settlement itself, or to make special tax concessions to the company. Considering the extent of press, public, and parliamentary activity, it is remarkable how successful the government was in remaining aloof from the issue. One reason for this success was the Family Fund.

### **The announcement and establishment of the Family Fund**

A government fund was not one of the original objectives of the *Sunday Times* campaign. The only action it demanded from the government was the reform of the law relating to compensation and the establishment of a state insurance scheme. However, on 29 October 1972 the *Sunday Times* reported that the Shadow Cabinet was to press for an early debate on Thalidomide with two aims:<sup>18</sup>

Firstly, to press the government to make immediate *ex gratia* payments under an urgent *ad hoc* scheme to help all known and outstanding cases, and secondly, to have the law of compensation amended.

The motion already tabled by the all-party Committee for the Disabled still said nothing about a fund, but during the following week it was announced that the German government and Chemie Gruenthal had established a joint fund for the German victims. Jack Ashley followed this up by writing to the Prime Minister to suggest that the government should take a similar initiative. Then, in the adjournment debate on 16 November, Mr Ashley urged the government 'to establish a fund for the children immediately without prejudice to present negotiations' and Mr Astor supported him, saying:<sup>19</sup>

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that the government should consider setting up a national fund for these children and their families . . . In the meantime [they should] consider the possibility of . . . giving financial support to one of the charities, such as the Lady Hoare Trust.

Mr Dean answering for the government said:<sup>20</sup>

As for the special fund I am sure that the Hon. gentleman appreciates that I cannot on such an occasion as this add to what the Prime Minister said to the House on Tuesday.

The Prime Minister had said that he would agree to consider carefully the setting up of a special fund or the support of existing funds. On 19 November, a leader in the *Sunday Times* took up the idea of a fund, saying:<sup>21</sup>

The case for the government establishing a foundation is twofold: first common humanity, secondly the responsibility the state has for their part in distributing a damaging drug.

On 25 November, the Sunday before the debate and the announcement of the creation of the Family Fund, the *Sunday Times* reported that<sup>22</sup>

when the Commons debates the plight of the Thalidomide children this week the government will say that a national foundation cannot be set up until pending legal negotiations are complete.

By the time the matter came to be debated on 29 November, the Opposition motion clearly called for<sup>23</sup>

immediate legislation to deal with the problems of such Thalidomide children including the establishment of a trust fund to provide for the Thalidomide children.

In his speech Sir Keith Joseph gave two reasons why he considered the recommendation for legislation was unsuitable:<sup>24</sup>

First it might prejudice negotiations . . . a company that wishes to avoid responsibility might welcome the responsibility being taken by the taxpayer. Secondly, desperate though the plight of the Thalidomide children is, there are many other children equally disabled.

The announcement about the Fund came towards the end of his speech and it is worth quoting in full:<sup>25</sup>

No, I will not give way. I have something to say which the House will want to hear before I sit down. I must say again, so that I do not lose the thread of the argument, that compensation is for the company and that the new offer indicates active negotiation.

The government must recognise that there are others born with desperate congenital disabilities which gravely burden their families and which are as severe as the loss of limbs due to Thalidomide. Such families are inevitably involved in all manner of special needs. Many of these needs are the responsibility of statutory authorities but there are other forms of help outside these responsibilities which could improve the life of a child and reduce the burden on its family. The government accept that more needs to be done for children with very severe congenital disability whether or not caused by the taking of Thalidomide.

In many cases the parents need more help in shouldering the various burdens which caring for these children entails. I have already paid tribute to the remarkable achievements of many of the parents concerned. The government have therefore decided to make the sum of £3 million available for this purpose, virtually at once. It is not intended that this money should be by way of compensation for being disabled, but rather that it should serve to complement the services already being provided by statutory and voluntary bodies to help the families concerned.

With this in mind the government will begin at once to consider, in consultation with the statutory and voluntary bodies likely to be concerned, what arrangements they can set up so that the money can best be used for the benefit of the children and their parents. The House can be assured that this will be carried out as quickly as possible. Further, in the light of experience with this operation and as soon as the cases are no longer *sub judice* the government will consider whether to provide a similar further amount of money in trust.

He concluded this speech with the following:<sup>26</sup>

I come now to the motion and the amendment. Because we do not believe, as the Opposition motion presses, that we should legislate at once, or that we should weaken the pressure on the parties to reach a satisfactory settlement, I ask the House not to approve the motion. The motion as amended, in the light of what I have been able to announce today, does meet the three tests

which I believe all Hon. Members should set. The amended motion does not prejudice the settlement; it does not wholly and in the light of what I have announced leave out the other very severely congenitally disabled. It provides help now for Thalidomide families, those who need help complementary to that provided by the local authorities in their noble effort to bring up these children. I hope that the House will not accept the motion. I hope that if it is pressed my Hon. Friends will vote against it and support the amendment.

The announcement of the Fund was generally welcomed in the debate, though one or two Labour speakers said that it was too little and others argued that if the government was to establish a proper trust fund, it could do so without prejudicing present negotiations and that Thalidomide children could be selected for special treatment, because their condition was man-made. Alfred Morris, summing up for the Opposition, asked a number of questions about how the Fund would be administered and in his reply Sir Keith Joseph gave the following information:<sup>27</sup>

The House has generally welcomed the government's decision to make available virtually at once, as soon as we can make the necessary arrangements, a fund of £3 million. I emphasise again that this is not compensation. Its purpose is to ease the burden of living on those households containing very severely congenitally disabled children.

These children and these households look, above all, to the local authorities and the statutory services for the help they need. We intend to help from this fund to complement the statutory services available.

We have it in mind - this answers a question asked by my Hon. Friend the Member for Clapham (Mr William Shelton) - to try to find a set of trustees of an existing trust with responsibilities sufficiently wide to cover beyond Thalidomide the other very severely congenitally disabled cases. We hope that we shall be able to put this into action very soon. We believe that the trustees should have power to spend income and, where they judge fit, capital.

I do not wish to overstate this case, but I suggest that those households which are under particular strain and about which we are, above all, worried during the period of waiting for a satisfactory settlement will be able to be helped to some extent by the trustees of this new sum.

Hon. Members asked me about the second £3 million to which I referred. I emphasise again that this also is not for compensation. It is intended to benefit, via the same channel, if our experience of handling the first £3 million is satisfactory, the same limited but rather wider than Thalidomide group, by the same means; namely, the use of income plus capital as the trustees judge fit.

My Hon. Friend the Member for Clapham pressed me hard to give a time by which this second tranche of money would be paid. I only wish that I could satisfy my Hon. Friend, but I must stand on the words of the amendment. This second tranche will be paid when the cases are no longer *sub judice*.

Outside Parliament the announcement of the Family Fund was received with a confused welcome. On 1 December both *The Times* and the *Daily Telegraph* reported any clarification of the details of the Fund which they had been able to obtain from the DHSS officials and from the reactions of voluntary bodies representing disabled children. *The Times* also carried a leader welcoming the announcement 'even if that approval must be tempered by the uncertainty surrounding the proposals and the limited assistance that can be provided with such a sum'. The leader went on to speculate about how the Fund should be administered and whether an independent trust should or could be given discretion.<sup>28</sup>

The administrative arrangements therefore need to be capable of carrying a heavier responsibility later on . . . the government should act on the assumption that they are establishing a framework for a more ambitious system of help for disabled children in the future. What is really no more than a small step now could then become of more lasting benefit.

The following day the *Guardian* also carried a leader questioning the adequacy of £3 million but congratulating Sir Keith Joseph for establishing the Fund. The leader concluded:<sup>29</sup>

It is already devastatingly plain that it has needed the campaign to relieve the suffering from Thalidomide to bring forward action to help both kinds of victims. Even that must be regarded as only a small beginning to what must be a national reappraisal of responsibility to such people.

The *Sunday Times*, on 3 December, under the headline '£3 Million Question: Where Will Mercy Money Go?' posed four questions.<sup>30</sup>

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What did Sir Keith Joseph mean by 'very severely congenitally disabled'?

How many children need the money?

Who will qualify?

Who will administer the Fund?

On 30 November, the day after the debate, a professional social work official in the DHSS telephoned Robin Huws Jones, the associate director of the Joseph Rowntree Memorial Trust, and asked him which of the larger trusts (including the Joseph Rowntree Memorial Trust) might be likely to consider running a Fund of this kind. With the agreement of the trustees, Lewis Waddilove, director of the Trust, and Robin Huws Jones met officials at the DHSS on 6 December to assess the possibility of the Joseph Rowntree Memorial Trust's assuming responsibility for administering the Fund. At that meeting, the under-secretary of the DHSS said that he was anxious to entrust the task of administering the Fund to an organisation that was reliable, efficient, and discreet; and which was not one of the voluntary bodies concerned with specific aspects of disability. The Department would lay down broad guide-lines relating to the use of the money but the duties of the Trust would be to decide which parents of very severely handicapped children needed help, what kind of help they needed, and to make available that help by way of payments to parents. The Trust representatives said that if they were formally asked to administer the Fund, agreement by their trustees would be dependent on the proposed guide-lines being acceptable to them and then, subject to these guide-lines, disbursement would be at the complete discretion of the Trust. The resulting discussions were minuted and the points made became the basis of the subsequent guide-lines. In the light of this meeting, Lewis Waddilove prepared a document explaining the background of the DHSS proposal and the matters that had been settled at the meeting on 6 December. This document was the first to state that the purpose of the Fund was to relieve stress.

At its meeting on 11 December, the Trust agreed to take on the Fund but, as one trustee pointed out, never before can six people have taken so long to accept £3 million. The chairman, Lord Seebom, was initially against the Trust's taking on the job. He expressed concern about the impact that such an administrative task would make on the rest of the Trust's work. He feared that some of the acrimony surrounding Thalidomide would transfer itself to the Trust and to himself as its chairman, and as a vice-chairman of a very large international

bank, he had natural reservations about associating himself with an issue that was already involving other City institutions. He also wondered whether this was the best way to help families. Were they merely bailing out the government who had gone out on a limb? The trustees were, however, persuaded by the arguments of Charles Carter, vice-chancellor of the University of Lancaster. He pointed out that if the Trust was capable of taking it on, they must find very good reasons for not doing so. It would benefit children and there were few other trusts to which the government could turn. It was something they ought to do; it would benefit the Trust, it was an honour to be asked; and it would enable the Trust to expand its interests. Above all, the Fund represented an opportunity for the Trust to be involved in a unique social policy experiment.

So the Trust agreed to take on the administration of the Fund, subject to a number of conditions, the more important of which were that they should do so for three years in the first instance and that the introduction of the scheme should be phased. These points, and the general terms of the Fund, were agreed at a meeting between Sir Keith Joseph, Lewis Waddilove, and Lord Seebom at the House of Commons on the evening of 12 December. The announcement that the Trust had agreed to administer the Fund was made through the medium of an agreed answer to a parliamentary question on Friday, 15 December. After further discussions the Department wrote to the Trust's directors on 21 December, setting out the agreed principles which were to apply in the administration of the Fund.

### **Reasons for the Fund**

It has been shown that the demands for a fund for any sort of families with handicapped children had not been articulated before the Thalidomide campaign, and the concept of a trust distributing public money directly to families is unprecedented in British social policy. The following section attempts to explain the reasons for both these developments.

Part of the explanation must be in the political background. There was general outrage at the plight of the Thalidomide children. The government was being pressed by MPs and by the press to take various initiatives to provide immediate assistance. The German government had established a fund, the Opposition motion called for one. Although there had been no public threat, the government must have taken account of the fact that some of their own supporters might fail to vote

for their amendment. In *Thalidomide: My Fight*, David Mason claims there was considerable background political activity. After Dr Tom Stuttaford had dropped a hint at a dinner party at 10 Downing Street that the government would be defeated over Thalidomide by its own back-bench MPs, Mr Heath sent his parliamentary private secretary, Timothy Kitson, to a meeting of the parliamentary party to ask what would persuade them to support the government. 'We won't take a penny less than £6 million', Stuttaford replied.<sup>31</sup>

The decision to establish the Fund was taken only the day before the debate in Parliament in which it was announced. It is likely that Sir Keith Joseph, having decided that it was necessary to provide some sort of assistance to Thalidomide-damaged children, turned to his officials to work out speedily, without prejudicing the court case and without discriminating against other families with equally handicapped children, the form that help should take. He may himself have hit upon the idea of using an independent trust. Such a scheme accords with Conservative philosophy, which inclines to voluntary rather than government action. The Conservative government was also interested in controlling the growth of the civil service. There was, and is, also a tendency in British public policy to separate purely executive operations from ministerial departments. However, although a Labour minister might not have instinctively turned to an independent trust for assistance, it is unlikely, in view of the need for speed and flexibility, that the decision made at such short notice, was based upon administrative or philosophical considerations. Very probably, the civil servants would have advised him to turn to an independent trust. In their discussions on the evening before the announcement they may have considered and rejected a number of public executive bodies who might do the work. The Supplementary Benefits Commission, for example, was already hard pressed and in any case it had limited legal powers to help families where the head of the household was in full-time work. Although the Commission's staff had experience in making discretionary payments to families, their traditions and procedures were wedded to providing for the essential needs of poor people rather than the generous and imaginative support envisaged as the role of the Fund. The Attendance Allowance Board was similarly pressed, coping with applications for the higher, and newly introduced lower, rate allowance and its staff had no experience of distributing *ad hoc* payments. Officials knew from their experience of supplementary benefits and the attendance allowance how difficult it was for government agencies to exercise discretion flexibly and to justify decisions in

marginal cases. The DHSS had had recent experience in the Jimmy Martin case of the public outcry that can result from being forced to make invidious distinctions between different categories of severely handicapped children.

The civil servants may also have considered distributing the money through local authorities, but in one sense it was the inadequacy of existing services that created the need for a Fund. Experience in implementing the Chronically Sick and Disabled Persons Act 1970 had shown how difficult it was to get local authorities to maintain equivalent standards and it would have been impossible to ensure, through the rate support grant, that the money would reach families with handicapped children. To use local authorities to disburse the money would have required special legislation and, even then, the project could have foundered on the rock of the rate support grant and the administrative division between health, housing, and social services. The Fund clearly had to complement existing services, but the decision to establish an independent fund was probably made because speed was imperative - and not to outflank agencies already operating in the field.

The officials might have considered establishing a new trust but it would have taken time to establish and organise, and the Department's first consideration was to provide help quickly. The press and Parliament were demanding help immediately; a solution requiring legislation would have involved unacceptable delay, as well as prolonged and bitter arguments, and the civil servants must have decided that it would take too long to establish an organisation of their own.

So it was natural to turn to an existing trust for help. No doubt, the existing voluntary organisations working for handicapped children, particularly the Lady Hoare Trust, were considered, but their terms of reference were too narrow to enable them to take on the job. Furthermore, to select one of these agencies could possibly introduce jealousy among the organisations. They therefore had to choose a large and respected trust, the terms of which were broad enough to embrace the role envisaged for the Fund.

One reason why a government may choose to operate through an unorthodox agency is that the policy area is experimental; thus, voluntary organisations may be used to 'blaze a trail'. The DHSS was certainly operating in the dark when it established the Family Fund. It has been argued that there was no planning or thinking about this type of operation before the Thalidomide affair and there was little information available to officials at short notice about either the numbers or the needs of handicapped children. The experimental nature of the

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Fund was taken up by the press after the announcement and it was perhaps the most important factor influencing the Trust to take on responsibility for its administration. However, it is not likely to have been the reason for turning to the Trust for help. The view in the Department at the time concerning the announcement was that they were making an *ad hoc* response to political circumstances. It was only after the announcement that they became aware of the Family Fund's potential as an experiment in the administration of a social service.

It was not clear from Sir Keith Joseph's statement in the House why the government had settled on £3 million and a further £3 million 'in trust as soon as the cases are no longer *sub judice*'. Clearly, the decision to give the £3 million was made in Cabinet and may have been influenced by the fact that it approximately matched the amount that Distillers were offering then. There appears to have been some confusion at the time of the announcement about the numbers of children that might come within the ambit of the Fund. Speaking about the second £3 million, Sir Keith said:<sup>32</sup>

It is intended to benefit via the same channel if our experience of handling the first £3 million is satisfactory the same limited but rather wider than Thalidomide group.

This statement seems to suggest that he intended to restrict the Fund to disabilities broadly comparable with those of Thalidomide children.

What we have in mind are children suffering from the most severe condition analogous to lack of limbs such as those suffering from the extremely damaging forms of for instance spina bifida. We have some difficulty because we must make a distinction. Because we have in mind the sort of children mentioned by the Hon. Member, I have had to exclude from this undertaking those who are born blind or those who are very shortly after birth discovered to be totally deaf. There has to be some limitation.<sup>33</sup>

Judging from these statements it is very probable that at the time of the announcement the Fund was intended to benefit a limited (but unknown) number of *physically* handicapped children. It was only after the announcement and the speculation about eligibility by the voluntary organisations representing different categories of handicapped children that it became clear that a wider range of handicaps, including the mentally handicapped and the blind and deaf, could not be excluded.

The lack of information in the Department about the numbers and nature of handicapped children was probably responsible for the

decision to make the money available only to congenitally impaired children. We have since become aware that the non-congenitally handicapped children in the UK are likely to number less than 10,000. If it had been realised how the Fund would develop, it could have included from the beginning all severely handicapped children. There was no justification for excluding them.

The word 'stress' was not mentioned at the time of the announcement. Sir Keith used the words 'burden', 'strain', and 'special needs', but 'stress', which eventually became a key word in the Fund's operation, was not mentioned. Neither did the word 'stress' appear in the minutes of the first meeting between DHSS officials and the Trust's officers. The word first appears, almost in passing, in the document which Lewis Waddilove prepared for the Trust meeting on 11 December. In it he wrote:

The fund is to be used to relieve family stress directly; there is no question of grant-aiding organisations or institutions.

The point of this sentence was to explain that the help was to be provided directly (rather than indirectly) but the word 'stress' was repeated in subsequent documents and the relief of it was finally incorporated as the purpose of the Family Fund. In such ways are the goals of social policy set.

## **The participants in the policy-making process**

### *The minister*

It is not clear what initiative, if any, was taken by Sir Keith Joseph in establishing the Fund and the form which it took. The issue was raised not from within the Department but through pressure from outside, and though he *may* merely have followed official advice, he is unlikely to have done so. He had the reputation within his ministry of being a highly independent figure; he was known as 'The Baron' because of his style of direction, and because during his office he demonstrated his intellectual independence from his advisers by his controversial views on the cycle of deprivation. Not content to rely only on departmental advice, he was an energetic meeter of people and a visitor to agencies and institutions. It is, therefore, difficult to believe that he would have played a passive role during the Thalidomide debate. Yet his department's policy until quite soon before the debate was to reiterate what services were already being provided and to avoid intervening in the

dispute between Distillers and the parents. Even after the debate and despite repeated calls in the press for him to play a part in the settlement, he remained aloof. It is probable that he and his Cabinet colleagues were determined not to embroil the government in the issue, but that they were eventually driven by the crescendo of public outrage and the threatened revolt of their back-benchers to provide some short-term assistance for the families.

### *The civil servants*

We have shown that the Family Fund was not a policy initiative that had taken years to evolve; nor did it fit easily into the existing pattern of benefits and services or the existing administrative structures within the DHSS. It is, therefore, very unlikely to have resulted from a demand emanating from within the Department. The Thalidomide affair acted as a powerful catalyst in bringing together the various interests within the Department – cash benefits, social services, health, and law. The role of officials in developing the Fund was critical; they were responsible for devising how £6 million could be raised and how it was to be distributed and, after the announcement, for recruiting the Trust and setting out the terms under which it was to operate. (It will probably never be possible to find out who exactly was responsible for extending the Fund outside the various categories of Thalidomide children, but the decision most likely emerged in the course of the urgent discussions between officials and ministers that preceded the debate.) However, the Fund did not spring from the action of officials; their role, like the minister's, was probably reactive.

In view of the limited time between the decision to provide £6 million and the announcement in the Commons, and the fact that the idea of a Fund for handicapped children was completely novel, there could have been no contingency plans and only limited information available to officials. Yet the civil service responded with extraordinary speed and imagination. They were operating in a most favourable context – urgent and general public demands for action, the threat that their minister faced a defeat in the House, and a Cabinet decision that £6 million should be made available. It was because of this climate of opinion and the need for speed that they were able to obtain the resources from the Treasury, cut across their own departmental divisions, override any doubts they themselves might have had about the implication of establishing such a Fund, and waive the consultations that would normally take place with the local authorities' associations and voluntary bodies.

### *The private citizen*

Among the individuals who played a decisive part in the establishment of the Family Fund perhaps the outstanding one was David Mason.<sup>34</sup> It is certain that without his determination to stand out against the proposed settlement with Distillers, the issue would certainly not have been raised by the *Daily Mail* and the *Sunday Times*.

The Thalidomide affair was also an unusual example of the 'pressure of public opinion'. The general public was involved as consumers of Distillers' products, as shareholders, as electors of MPs, as correspondents to newspapers, and even in some cases as demonstrators. This public opinion was naturally articulated and shaped by Parliament, the media, and through *ad hoc* pressure groups, but the concern of individual citizens was without doubt an important factor in setting up the Fund.

### *The pressure groups*

There was no existing group with the resources, experience, and enthusiasm to harness the issue and press the case. The Lady Hoare Trust, which had been established to provide support for families with Thalidomide-damaged children, was a service-giving agency, and Sir Keith Joseph himself said that his department had never received representations from them on behalf of the families.<sup>35</sup> Lady Hoare herself was ill when the affair broke and though the Trust did provide the Department with information about the children (and show Sir Keith Joseph a film in the House of Commons before the debate), it never actively called for changes in policy. The parents of the Thalidomide children were divided between those who had settled, those who wanted to settle, and those who refused to settle; and the extent to which they were able to participate was also influenced by their legal advisers, Messrs Kimber Bull, who throughout the affair maintained that the best interests of the parents would be served by pursuing their case through the legal channels.

During the campaign, *ad hoc* pressure groups did spring up - notably the shareholders - and the final settlement was a result of the pressure of large City institutions; but the Family Fund did not originate in the information, advice, ideas, or influence of promotional or interest groups.

*The mass media*

A question often asked in discussing the role of the media in policy formation is: Do they reflect public opinion or do they formulate it? The Thalidomide affair is a clear example of the media initiating and carrying through a campaign with the explicit purpose of achieving policy changes. Bruce Page, Phillip Knightley, and Elaine Potter of the *Sunday Times* Insight team had engaged in inquiries into Thalidomide for a number of years. Harold Evans, the editor, finally made the decision to launch the campaign despite the risk of prosecution. He may have been confident that public opinion would be moved by his coverage but in no real sense was the newspaper *reflecting* public opinion; indeed, the public were largely unaware of it. Of course, once the issue had been raised, the *Sunday Times* and the rest of the media reflected public opinion in the sense that they provided a forum for actors in the policy process. But the *Sunday Times* continued to lead opinion and open new fields of action. For example, Tony Lynes was given the names and addresses of other Distillers' shareholders to help him form an action group; a group of those concerned met regularly throughout the campaign in the paper's offices; and Evans kept in close touch with Jack Ashley and certain other MPs. Through the paper's determination to contest the injunctions as far as the House of Lords, it kept the issue alive and involved the rest of Fleet Street; and by publishing lists of the Distillers' shareholders, it ensured the involvement of the institutions. This policy issue is an unusual example of the press formulating public opinion and the action of the *Sunday Times* demonstrates that a newspaper can be the principal cause of policy change.

*Political parties*

The Thalidomide affair was not a party political issue. It is true that Parliament debated an Opposition motion, that the parties followed their whips through the lobbies, and that Barbara Castle, at the Labour Party Conference, committed the parliamentary Labour Party to fighting for a just settlement, but this was no more than the formalism of political debate and the natural stance of an Opposition. The issue arose too suddenly, and with too general a consensus, to develop into a party political issue. The Conservative Party, with its business links, might have been in danger of being associated with Distillers, particularly after the intervention of the Attorney-General to stop the publication of the second *Sunday Times* article. Sir Keith Joseph himself

admitted an interest during the Thalidomide debate; he was 'a name at Lloyds', and in so far as insurance money was involved in meeting the settlement for the children, he would, albeit at a great distance, have borne part of the cost. Clearly, this would not have influenced his views one way or the other and is only mentioned here to illustrate the links that existed.<sup>36</sup> But it soon became clear that the business world was as disturbed as anyone by Distillers' actions, and with the Chancellor refusing to 'let Distillers off the hook' with tax concessions and Conservative ministers refusing to be drawn into a defence of Distillers, and with the Labour Party, for the most part, leaving the running to the all-party disablement group in the Commons, the parties managed to avoid an ideological dispute.

### *Parliament*

Modern political scientists consider that government, not parliament, is decisive in the making of policy. Parliament has a measure of formal control over policy and may influence the details of it but, in general, priorities for action are determined by government and not Parliament.

This view is qualified by the events leading to the establishment of the Family Fund. Individual MPs, the all-party group on disablement, and the Opposition all evidently played key roles in determining the outcome and, behind the scenes, it is probable that pressure by back-bench Conservative MPs was influential in obtaining government action.

Parliamentary activity during the Thalidomide affair was particularly important because comment in the press was to some extent stifled by the *sub judice* rules. Through parliamentary questions, the tabling of motions and speeches in the adjournment, supply and Queen's Speech debates and, finally, in the full debate, MPs were able to maintain pressure on the government and Distillers. The lead in this was initially taken by the all-party committee on disablement chaired by the deaf MP, Jack Ashley, but as the issue gathered momentum the demands within Parliament became more general. This activity, the specific demand for the establishment of a fund in the Opposition motion, and the fear that they might be defeated in the debate, must have decided the government to announce the establishment of the Family Fund. A defeat in the House would not have brought them down but it would have been a serious embarrassment for them.

It seems clear that in this instance, the policy-making role of ministers and civil servants was negligible. It was action by parties outside government that was decisive in framing the policy adopted.

### Conclusion

This description and analysis of the origins of the Family Fund leaves much to be desired. Any attempt to do justice to the complexity and diversity of the influences, events, and personalities that go to make up the policy-making process is bound to oversimplify, to be selective, and to be in danger of over-emphasising in one place or under-emphasising in another. Even with unfettered access to the necessary information this would be the case; but students of social policy development do not have open access to vital data, particularly the part played by civil servants and government ministers in the policy-making process. As a result any case study must in part be speculative and incomplete.

With this limitation in mind, let us now, however, try to set the Family Fund against Hall *et al.*'s three criteria - legitimacy, feasibility, and support - by which they claim the priority accorded any issue may be assessed.<sup>37</sup>

### Legitimacy

There was certainly some doubt about whether the provision of new help for these children was a legitimate concern for the government. It felt that the Thalidomide-damaged children were no more a state responsibility than any other group of children. The state was not at fault and therefore it had no special responsibility to compensate the parents; this was a private matter between the parents and Distillers. Uncertainty about the proper role of the government went further than this and was evidenced by the establishment of the Royal Commission on Civil Liability and Compensation for Personal Injury. Compensation for injury, except for war and industrial injuries, had not become a legitimate activity of the state. Yet here were new demands for a state fund for Thalidomide children. The government decided that the proper response was to legitimise help for Thalidomide children by including all handicapped children, by denying that it was compensation and presenting it merely as a complement to existing services and, meanwhile, through a Royal Commission addressing itself to the whole question of compensation. While a compensatory payment to one group of handicapped children who had been damaged by a privately manufactured drug was not a legitimate field for government, the extension and improvement of existing services raised no such problems.

### Feasibility

Whether a policy development is feasible not only determines its chances of gaining attention but also helps to explain why one course of action is introduced rather than another. The most important questions regarding feasibility are whether the resources of money, manpower, parliamentary time, or equipment are available. The Family Fund was possible because it was a relatively cheap initiative in money and man-power and called for no parliamentary time. In fact, if there had been time for reflection the government might have decided on other grounds that it was not feasible. There was no existing government machinery for distributing the money; the Fund would create anomalous and overlapping functions between existing administrative units; the size of the population to be served was large; and it would inevitably prove difficult to find an alternative to the provision made by the Fund. If these objections had been formulated, they would have been overridden by the demand to take action of some sort.

### Support

The Family Fund was a measure that attracted extensive approval and certainly improved the government's stock of general support. Indeed, so successful was the initiative that it enabled them to continue to maintain an independent attitude to the Thalidomide settlement.

Hall *et al.* mention other factors affecting the over-all 'image' of an issue which may influence its fortunes. Some of these are:

### Crises

Writing of the welfare state, Myrdal has claimed that:<sup>38</sup>

all the time new measures were introduced *ad hoc* to serve limited and temporary purposes, to safeguard special interests, and often to meet an emergency of one sort or another . . . new intervention was usually not only motivated by special circumstances - a particular need, an emergency or a pending crisis - but also designed accordingly, as limited and often temporary measures.

Sir Keith Joseph himself, speaking at a National Association for Mental Health Conference, said, 'I must tell you that one day somebody will write a book . . . about the part that scandal has to play in procuring reform,' and added, 'The sudden revelation of conditions well known

to the experts, of which the public is unaware, gives ministers a chance to galvanize their colleagues and get the resources to improve things.<sup>39</sup>

Sir Keith Joseph faced a mild political crisis over Thalidomide. He was being pressed to give help quickly to the damaged children so that they would not be forced to settle on unfavourable terms with Distillers. The crisis was engineered, but it was real enough at the time and was certainly a vital factor in setting up the Family Fund.

### *Origin*

Hall *et al.* suggest that:<sup>40</sup>

Where an issue constitutes a challenge to a government's competence and is advanced from outside, its recognition is likely to be resisted or ignored. In these circumstances other factors (irrefutable evidence or crises) would have to be particularly favourable if the issue is to make progress.

The demand for a Fund arose from outside government and was expressed first in an all-party motion and then in an Opposition motion. Without the danger that the motion might be supported from the Conservative back-benches, it might have had little chance of success. The government annexed the Opposition demand, extended it to include all children, and presented it as a fresh new idea.

### *Information*

It is suggested that the extent to which the existence of a problem can be supported with facts has an impact on progress. This was not true of the Family Fund. At the time when the scheme was devised, the government had little information about the number and nature of the needs of handicapped children and was unclear about what groups of handicapped children should be included in the scheme. We have shown how little research evidence was available before 1973, and though civil servants had access to their professional advisers and Sir Keith Joseph had received information from the Lady Hoare Trust, they had little time in which to clarify what burdens they were seeking to support and why these were not being carried by existing services.

The other participants in the process were convinced of 'the facts' by the case studies presented by the *Sunday Times*.

### Ideology

There was no conflict between the ideology of the government and the essence of the Family Fund. The Fund was a selective response, calling for no significant increase in public expenditure or civil service manpower and it was to be administered by a private organisation. To the extent to which these factors were considered they must have made it easier for the government to accept the idea of a Fund.

### Some general considerations

In analysing the nature of the Fund, there is a danger of confusing *post hoc* with *propter hoc* considerations. The form that it took is not necessarily a valid guide to the motives underlying its establishment. Indeed we have suggested that it was set up as an unpremeditated response to external demands, announced without clear definition of its purpose or of those whom it was intended to benefit, and unclear as to its mode of operation and its long-term implications. It was subsequently hailed in the press and elsewhere as a new experiment in social policy; but this was a *post hoc* rationalisation designed to raise the status of an institution that had a more expedient purpose.

This, perhaps, explains the disappointment that has been felt at the subsequent response of government to the Family Fund. The DHSS has, for the most part, left the Fund, once established, to its own devices. This has certainly been partly because of the independent status of the Trust and partly because of the Department's confidence that the Trust has managed the Fund successfully, but it is also because there has never been in the government - either among politicians or civil servants - a commitment to broaden the scope of the Fund. There is a natural tendency in social policy for government to concentrate more on the initiation of new policies than to monitor existing ones, and there is also a tendency for the civil service to take a reactive rather than an initiating role. But particularly in the case of the Family Fund, it seems as if the civil service, knowing that the Fund at its inception was an expedient, has continued to view it in that light. Thus, there is as yet no clear picture of what the future of the Fund will be.

This is not to say that the Fund has been viewed with any disdain by ministers and civil servants; indeed, it has become a small weapon in the armoury of successive ministers. Demands for help for vaccine-damaged children, for compensation for children damaged *in utero*, for the attendance allowance to be paid for foster children, and general demands for improvements in policies for the handicapped, have been met with

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assurances that in addition to its other responsibilities, the Family Fund exists to provide help in such cases. The Fund has, in fact, continued to play the role for which it was devised - to take the heat out of new demands. But as it was never devised as part of a coherent plan to help the families of handicapped children, it has not yet become part of such a plan.