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A STUDY OF SOCIAL WORK WITH FAMILIES WHICH HAVE A HANDICAPPED CHILD

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A STUDY OF SOCIAL WORK
WITH FAMILIES WHICH
HAVE A HANDICAPPED CHILD

Submitted by
GILLIAN M.L. LONSDALE

To:
The University of Exeter
as a thesis for the degree of
DOCTOR OF PHILOSOPHY
in the Faculty of
Social Studies and Law.
DECEMBER 1981.

I certify that all material in this thesis
which is not my own work has been identified
and that no material is included for which a
degree has previously been conferred upon me.

Gillian M.L. Lonsdale
This thesis represents an attempt to understand something of the many and varied needs of families which have a handicapped child and to explore possible ways in which those needs might be met, considering, in particular, the contribution of social work. Throughout, in making assessments and evaluations of professional performance, it draws extensively upon the parent or the consumer viewpoint.

The research project falls into three parts. The first stage is an exploration of the current situation. Details of all the families in Plymouth City which had a handicapped child were card indexed and then an approximate quarter sample was made. This constituted the Contrast Group. Sixty families were interviewed personally with a research questionnaire and wherever possible the interview was tape recorded. From these parents was learned much about the existing provision and the areas where improvements in the services were needed. The second stage was to implement some of the parents recommendations together with more recent conceptualisation concerning systems, crisis, loss and bereavement with another group of parents. This comprised all those families which, during one twelve month period in one paediatric department had either a handicapped baby or a child who at a later stage was subsequently diagnosed as being handicapped. These families formed the Experimental Group. The third stage of the project was an evaluation of the experience with these parents a year after their first contact with the hospital, again using the research questionnaire and tape recording the interview. The findings of the two surveys are presented comparatively and some deductions made about their implications for social work practice.

The whole project is concerned with exploring a social problem, developing some innovatory ways of practicing social work which might make it more effective, and collecting data to extend the professional
knowledge base and expertise in this area. It represents an attempt to put into practice some of the theoretical underpinning of an Integrated Approach dependent upon systems thinking, and to evaluate the possibilities and potential of this as a way of doing social work, particularly in connection with irreversible conditions.
ACKNOWLEDGEMENTS

I wish to express my appreciation to the Director of Plymouth Polytechnic and his Senior Staff for awarding me a Polytechnic fellowship for the academic year 1976-77, during which I was able to do the major part of this research project. I would like to acknowledge the stimulating supervision given to me by Dr. Jean Packman and to thank her, Dr. Barry Turner, and the other members of staff of the Sociology Department, for the help I received during the years I was a post graduate student at Exeter University.

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Finally, a special thank you to my husband and my children for bearing with this project and the inroads that it sometimes made upon our family life.
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CHAPTER 1

Introduction
"The hallmark of a good theory is its capacity to predict the outcome of any action."

Eileen Younghusband.

This is a project about a problem and a profession. The problem is having a handicapped child; the profession is social work. In the past there do not seem to have been strong links between the two, so this is an investigation into the nature of the problem and whether or not the rethinking currently going on in social work may be leading towards professional activity more geared to meeting the needs of chronic conditions. The main problems of contemporary social work are the uncertainty about method, about intellectual foundations and about social roles and function.

THE PROBLEM

A handicapped child could be born into any family. The odds of this happening are the same for the aristocracy as for the working class, for intellectual parents and for the less able, for white people or for coloured, and although the risk increases as a mother gets older, young couples also give birth to children who are impaired. It is a risk for the whole population that approximately 3 in every 100 children born will be impaired and this means that there is a likelihood that the family of every one of these children will be a handicapped family. No matter how easy the child is to manage or how much he is loved and accepted by the family, his arrival will completely alter their whole way of life and create problems which are ongoing and far reaching.

In such varied backgrounds it would seem unlikely that the arrival of a handicapped child would create similar problems in all families. It is known that some parents cope and some do not, but as yet we have
little explanation of the reasons for this. It might be to do with some people being able to manage and having adequate finances, or enjoying secure relationships within the family, or it might be something to do with the nature of the handicap itself, or even a combination of all three. The nature of the problems suggest that it is an area for social work involvement but of what kind and when it is likely to be most helpful has perhaps been insufficiently considered.

There is a wealth of literature in the medical world on the problems of handicap, the effect upon the families and the need for special skills at the crisis points, particularly the time of telling parents of their child's condition. (D'Arcy (1968), Farber (1959), Hewett (1970), Harrisson (1977), Anderson and Spain (1977), Tizard and Grad (1961), Kew (1975), McMichael (1971), Carr and Uppe (1971), Drillien and Wilkinson (1964).) Implicit in much of what is written is a recognition that more than clinical expertise is needed and that tentative steps are being taken into the field of caring for the whole family, traditionally the domain of the social work profession. As yet very little is written about social work practice with families of handicapped children. Papers such as those written by Ineichen (1973), McAndrew (1976) tend to be factual enquiries into family difficulties and are not primarily concerned with the practice of social work. As a profession, social work seems late entering a field in which it could be expected to be well able to contribute much in the way of skills and expertise.

The reasons for this need to be explored were contained in the report of the Working Party on Training for Social Work with Handicapped People published by the Central Council for Education and Training in Social Work in 1974 which drew attention to the low priority of social work with people who are handicapped and yet the evidence given to that
working party indicated that the numbers of handicapped people concerned
and the complexity of the problems, demanded workers with good assess-
ment skills and the ability to work in a multi-disciplinary team. This
need was further demonstrated in the Court Report (fit for the Future.
The Report of the committee on Child Health Services Cmnd. 6684, HMSO
1976), published two years later which recommended District Handicapped
Teams including a social worker who had had "special training in handi-
capping conditions, their prognosis and treatment and in particular
would be conversant with the implications for family management and
functioning and community involvement and support." The demand for
social workers specialised in working in the area of handicap was
becoming increasingly widespread; what did not appear was any clear
indication of the nature of the specialisation required, or of the
particular professional skills needing to be developed. There appeared
to be a vast area of need but how it could most effectively be met
seemed to be neglected by the social work researchers, a fact high-
lighted by this Central Council for the Education and Training of
Social work is concerned with the interactions between people and their social environments, more especially when these affect the ability of people to accomplish their life tasks. Professional social work practice provides a bridge that people may use to find a solution to, or alternatives to a disruptive condition, and as such is a means and not an end in itself.

Perhaps it was Dr. Richard Cabot who, having held the distinction of appointing the first social worker in the United States, first threw down the gauntlet to the profession to articulate its skills more clearly. He wrote in 1909:

"Even now I think that the value of the social worker and his proper recognition are considerably limited by the fact that he cannot recognise himself or tell you what the value of his profession is. He is an expert. But in what is he an expert? What is his special field of knowledge or skill?"

This project may be seen as an attempt to respond to Dr. Cabot's challenge in the light of new conceptual developments in the intervening years.

At the end of a century of professional development social work has tended to become compartmentalised into the triad of methods known as casework, social groupwork and community work, and particular approaches within each of these such as crisis intervention or task centred work are sometimes accepted as dominant or even exclusive ways of working. Over the years these divisions have been further compounded by the assumption of employing agencies, and the social workers themselves, that one method will be used, although in practice social workers have long engaged in a variety of activities beyond the boundaries of the method in which they were employed. Additional diversity to this was created by social work evolving and being described in
terms of its various fields of practice ranging from child care to mental health.

Theories of casework, groupwork and community work are abundantly in evidence but there is very little theory of social work. It may be that in the wide varieties of social work settings it is unrealistic even to consider such a thing as social work theory, yet if there is such a thing as generic social work it needs to have underpinning from an all-embracing theoretical framework.

It could be argued, then, that social work began as a collection of specialisations and was to be over-specialised long before it sought to become a profession. But alongside the divergent development in practice, and endemic to the profession throughout its history, there has been a strong call for more convergence in conceptualisation which ultimately will bear upon practice. Mary Richmond wrote in 1917:

"The division of social work into departments and specialities was both a convenience and a necessity; fundamental resemblance remained, however — — "

She also wrote later:

"I have spent 25 years of my life in an attempt to get social casework accepted as a valid process of social work. Now I shall spend the rest of my life trying to demonstrate to social caseworkers that there is more to social work than social casework."

Richmond (1922)

It was a thought which fifty years afterwards was to be reflected in this country in the Report of the Committee on Local Authority and Allied Personal Services, more commonly known as the Seebohm Report, of 1968:
"...the divisions between different methods are as artificial as the differences between various forms of casework...in his daily work the social worker needs all these methods to enable him to respond appropriately to social problems which involve individual, family, group and community aspects."

(Report of the Committee on Local Authority and Allied Personal Services H.M.S.O. 1968)

The clear implication of Seebohm was that social work practice needed to change. Services provided by social workers should be better integrated than they had been hitherto; social problems needed to be perceived in more holistic terms.

In no field could this be more true than in the case of handicapped children. It was an area of service divided awkwardly between education, health and social services in the statutory sector, and shared among a variety of voluntary services formed to generate concern for the needs associated with specific disabilities. (Sainsbury 1977).

In trying to understand the historical gap between the problem and the profession it is important to recognise that the problem had not been clearly identified with a department in which the social workers were principally employed. Although the Chronically Sick and Disabled Person Act of 1970 required a local authority to identify and compile a register of the disabled persons within its area it did not follow that those persons were offered a social work service. Likewise the reorganisation in local authorities resulting from the Local Authority Social Services Act of 1970 which drew together social work skills in child care, health and welfare might have been expected to create an improved service for the handicapped child, yet, if anything, the problem got buried in the post Seebohm landslide of increased responsibility by local authority social workers for all client groups.

The Seebohm Report came at a time when there was a tremendous upsurge of interest by the social work theorists in the inadequacies of social
work practice. In the early 1970s there were many publications, mostly in the United States of America urging the profession towards new ways of conceptualising practice that would provide a common core of principles which could be used by all social workers in dealing with all problems in all situations. (Goldstein (1973), Kahn (1973), Mullen, Oumpson (1972), Pincus and Minahan (1973), Middleman and Goldberg, (1974), Whittacker (1974).)

To this end social systems theory is increasingly being put forward as a possible model to understand the range of social work methods. At the moment it is little more than a conceptual framework within which the multi-dimensional qualities of social relations can be studied, but if it can help social workers to make sense out of interactions which previously have been ignored or have defied analysis, it is worth exploring despite the fact that it is recognised to be a theory at a high level of abstraction.

**GENERAL SYSTEMS THEORY**

General systems theory is the terminology used by von Bertalanffy (1971) to identify a way of analysing complex situations of interaction in which 'the whole is more than a sum of the parts'. It is conceived as a general science of 'wholeness'. Warren Weaver writing in *Science and Complexity* in 1948 said, "Classical science was concerned either with linear causal trains i.e. two variable problems, or else with unorganised complexity. In modern physics and biology, problems of organised complexity, i.e. interaction of a large but infinite number of variables are popping up everywhere and demand new conceptual tools." Bertalanffy mirrors this view in his book when he writes, "Many problems, particularly in biology and the behavioural and social sciences are essentially multivariable problems for which new conceptual tools are needed." His General Systems Theory emerged out of the need for new conceptual tools; it is an attempt to explain and conceptualise the
complexity of dynamically interacting variables that affect living organisms whatever the nature of their component parts and the relationship between them. He defines a system as being "an organised or complex whole, an assemblage or combination of things or parts forming a complex or unitary whole." It is important to recognise that these component parts have attributes and that their relationships tie the system together and thereby establish an environment which has a clearly recognisable boundary. It is not a unified body of knowledge but a way of looking at objects in inter-relation and as such may be attractive to those who work in social situations.

Of the several characteristics which are central to systems thinking there are perhaps five properties which have the most significance for a social work context:

1. **Social systems are open systems**

   Open systems maintain themselves by importing and exporting energy, by constantly exchanging material with their environment. A closed system has no environment, is isolated and is the domain of the traditional physical sciences at the other end of the continuum. "Open systems maintain themselves in a fantastically improbable state, preserve their order in spite of continuous irreversible processes and even proceed toward ever higher differentiations." (Bertalanffy 1971). They are dynamic and the property of every living organism.

   The significance of this for social work practice is in the inter-relations and transactions between the systems. Not only is there continuous interchange of energy with the environment but this is vital activity for the system's continued existence throughout life. An open system is utilising energy directed by the social worker and drawn from resources such as information, knowledge and skills.
elaborate a change in its structure to fit a more complex level. When a breakdown occurs and a problem is brought to the attention of the social worker it is viewed as a system disturbance rather than a loss of a single discrete function. Investigation of the configuration systems which impinge upon the client system may then indicate where the most effective intervention can be made to generate the necessary inputs to combat the disturbance.

(2) Social systems need energy to survive

"No social structure is self-sufficient or self-contained." (Katz and Kahn 1969). A system is dependent on a steady inflow of stimulation from its external environment which is called energy. This energy is transformed by the open system and absorbed, a process known as throughput, or by a process called output, energy of any kind may be generated from within the system as a result of the systems reaction to energy input. Some of the energy essential to the survival of a system may be carried from the external environment by the social worker. A systemic disturbance may cause some interference with the normal steady inflow of energy, or with the internal generating of energy and it is important to re-establish the energy flow lines. To some extent this is dependent upon the social worker understanding the various information links, input, throughput and output that operate within that particular system, and then being able to revitalise them by making links to additional energy sources.

(3) Open systems may be goal directed

A goal-seeking system is one that can respond differently to one or more external or internal states. Its behaviour is responsive rather than reactive and so has a choice of behaviour. At its simplest the goal may be merely the maintenance of homeostasis,
a homeostatic system being one that retains its state in a changing environment by making internal adjustments. In more advanced systems the term homeostasis may be replaced by the concept of 'steady state', a term which Bertalanffy gave to the process whereby continuous decay and synthesis is so regulated that the organism is maintained and developed. It is different from a homeostatic state in that not only is the system maintained but work is allowed to be done and growth to take place. It is not a state of equilibrium but one in which some degree of tension is a permanent feature.

When systems are goal-directed the same goal may be achieved from different initial conditions and along different pathways, a characteristic known as equifinality. Since behaviour of the system is recognised as being responsive, then a social worker may become the key person in managing the planned social change necessary to achieve at least homeostasis. When one objective has been met another is immediately set so that the system not only maintains itself but elaborates and differentiates towards a steady state. A social systems model approach, by implication is problem centred; the problem is located in its related social environment and points of intervention most amenable to effective planned change can be identified. The various ways in which change can be achieved to solve one particular problem require the social worker to be conversant with a series of possible goal-directed activities.

(4) Open systems do not run down

In contrast to a system in isolation where all motion has come to a permanent state of standstill and no observable events occur, open systems receive energy from the environment and not only maintain themselves but progress to more advanced states. But
systems may become temporarily set apart from their sustaining environment by an incapacitating problem and move into a state of near standstill.

If a problem is brought to a social worker it generally indicates that the client's coping capacity is not reaching the goals set, either by himself, or by society, and that his system is lacking adequate energy supplies. The contact with the social worker creates a temporary system supporting and sustaining the client system and thereby affording a security within which to reorganise and then establish its functioning. Once this is achieved, the input from the temporary system may be safely removed and the client system continues to function as an open one.

(5) Systems communicate internally and with their environment

A system is dependent upon its relationship with its environment for its existence. Open systems are dynamic and constantly in communication, a principle central to the science of cybernetics. (The word cybernetics comes from the Greek word meaning 'steersman'.) Cybernetics examines patterns of signals by means of which information is transmitted within a system and from one system to another. A central concept of the theory of communication and control is that of feedback. The product which systems export into the environment furnishes the sources of energy for the repetition of cycles of activity. Any interference with the feedback loops of a client system is going to impair that systems functioning and an important role for the social worker is to alleviate this by exploring the communication patterns of the system that are both internal and external.
HISTORICAL ASPECTS

Right from the beginning of the history of social work there has been a polarisation between workers who were concerned with the individual and sought solutions for the social problems in his reform, rehabilitation or growth, and those who emphasised the social situation as a means to procure change in the interests of the individual. Sidney and Beatrice Webb, social reformers at the turn of the last century are reputed to have said that social workers spent too long trying to drag people out of the swamp rather than draining the swamp, a notion reflected in the writings of Mary Richmond:— "The good social worker does not go on helping people out of the ditch. Pretty soon she begins to find out what ought to be done to get rid of the ditch." (1917).

Gordon-Hamilton (1951) first wrote about the 'person-in-situation' but the potential of her theory was not recognised in the practice of her time which was still very much enmeshed in the medical cause and effect view. It was not until 1958 when Haern spent a year exploring systems theory and how this could be built into a profession such as social work that a theoretical underpinning to this earlier thinking was recognised. He published his findings in a book Theory Building in Social Work (1958) but another five years elapsed before there was any written evidence that colleagues in the Canadian and American social work schools were exploring further the general concepts of systems in which he had first stimulated interest. This culminated in an important conference on the subject in Minneapolis in 1958 to be followed in the next decade by a series of new text books (Janchill (1969), Pincus and Minahan(1973), Goldstein(1973), Siporin(1975)) and papers (Vickery(1974), Baker(1975), Evans(1976), Davies(1972), Forder(1976)) each reflecting clearly the influence of this approach. However, the use of systems thinking in connection with social work remains very much a theory of the academic
world and little tested out in practice. Sainsbury (1974) has argued that "the systems approach suffers at present from being newly fashionable, from the risks of gimmickry and from its attendant jargon," and Meyer (1972) has called it "a pretentious term at best." C. Wright Mills attacked social systems theory because it was so 'grand' as to be obscure and irrelevant. Forder (1976) has stressed that it is important for social workers to consider whether it is worth their while to master the theory and its jargon when it is at such a high level of generality. He points out the dangers of being eclectic and selecting out parts of a new model which seem to be compatible with an existing theory and by incorporating a few references to new terminology it is made to look more up to date. An example of such a culprit is Hollis who could be accused of trying to leap on the bandwagon in her latest publication (1970) when she claims that her psychosocial method is in fact a systems approach. An examination of her earlier writings and a thorough knowledge of systems theory would substantiate a view that they are two fairly independent approaches.

**IMPLICATIONS OF SYSTEMS THEORY FOR SOCIAL WORK PRACTICE**

Systems theory has very definite terminology - closed and open systems, cybernetics, homeostasis and steady states - and this has meaning to the natural sciences as well as the social sciences. One of the arguments that could be put forward in favour of the use of systems theory is that there is a terminology which is meaningful to colleagues in other disciplines. But there is a danger for social workers in lifting terms from other theories and then using them to mean slightly different things, understandable only within their own profession. They have done it in the past when for example, some psychoanalytical terminology (e.g. transference and counter transference) has been incorporated somewhat loosely into social work practice. They could try to take over the systemic
framework and reconceptualise current practice within it instead of converting some of the social systems theory into a set of principles relevant to the typical tasks of the social worker. The transition from linear to systemic thinking involves fundamental changes in practice, particularly in the perception of the unit of attention and in the utilisation of manpower. For example, the person presenting the problem is not necessarily the most appropriate target for the social worker's intervention nor to be regarded as the client. A systems perspective allows for viewing the unit of attention within the context of a society where people are highly interdependent with all social institutions. It means that the conceptual and actual boundaries within which the social work practitioner is employing his skills are expanded. Indeed, there is an argument that in conceiving social work holistically in systemic terms it becomes boundary work and the social worker's task is to locate where that boundary is and to help the human systems with which they work to regulate how much energy enters and leaves that system.

The multi-variable problems currently coming the social worker's way may be too complex for some of the old, well-tried, single track approaches to have much effect. It is debatable whether or not 'verbal ventilation' or 'talking out' does much to ease the presenting problem, although encouragement of this has long been a recognised social work tactic. However, in the long term this verbal ventilation approach is unlikely to have much to offer that is seen to be helpful in irreversible situations such as a family having a severely handicapped member. The implication of its use is that the social worker would be constrained to support the family as it was, rather than recognising that although the handicap itself cannot be changed, the environment of that handicap may well be open to considerable modification.
This involves a transition from predominantly linear to more lateral thinking in that there is a change in the perception of the case or the unit of attention. Linear thinking with its close analogy to cause and effect logic tends to see the problem located within the family which presents it rather than looking around that situation at the factors which may be contributing to the difficulties.

It is often as important to intervene in the social and material environments of individuals and groups of people as it is to intervene with the people themselves. Furthermore it is important to recognise that there are two parts of the environment in social work, that which surrounds the client and that within which the worker operates. Obviously the client's environment is more significant but that of the worker has until recently tended to be ignored with the effect of making a vacuum in which the worker exists. It follows from this that while at the same time making a higher demand for skills in communication to be developed, the greatest attribute of systemic thinking is to increase the range of possibilities for intervention. This thinking is basic to what is known as an integrated or Unitary approach to social work. If it can in any way fulfil that which theoretically it promises then it would warrant experimentation with some of its concepts in an area of work where hitherto the recognised patterns of social work intervention appear not to have been particularly successful.

AN INTEGRATED APPROACH

An integrated approach requires the practitioner to assess problem situations in a much wider context and to be prepared to intervene outside the client system. It calls for much more active liaising work between client groups and social organisations and greater skills in assessing the nature of the expertise needed, and where that may be located.
Theory is only useful to the social work practitioner if it helps him to organise his thinking and to keep abreast with new knowledge. There is nothing essentially new about the conceptualisations of an Integrated Approach, and the kind of practice it is fostering is familiar. Where it does differ from current practice has been stated to be in two important respects, that of choice and communication. (Specht and Vickery 1977). The way in which social workers make choices about what to do in professional practice will be changed by the increase in the range of possibilities which is made available to them by the higher degree of integration of knowledge and multidisciplinary work. It should also encourage social workers to communicate more with each other and with members of related disciplines which is particularly important when the care of the handicapped child divides between health and education as well as the social services.

A statement of the purposes of social work is provided by Pincus and Minahan: (1973).

(a) to enhance the problem solving and coping capacities of people.

(b) to link people with systems that provide them with resources, services and opportunities.

(c) to promote the effective and humane operation of these systems.

(d) to contribute to the development and improvement of social policy.

Again there is nothing new in these purposes and it would be easy to find examples of writing and practice in the last 100 years or so of social work history to illustrate all these points. What is new, perhaps, is the acknowledgement that one individual practitioner may now be doing all of these things and that many more possibilities are being included and called social work than has been the case in the past, so it is necessary for the worker to be aware of the increased
range. As such it links with Specht's (1977) ideas about choice and communication. Once the social worker has made the links with people willing and able to meet his client's needs he can relinquish his responsibility. The role of a catalyst within society would be much more part of the social worker's task than ever it was in the days of his psychosocial forbears where the thrust was much more towards intervention with the individual and very often in a long term supportive way because nothing was being changed. A social worker approaching the field of care of the handicapped child with such a perspective will be engaged in creating a network of smoothly operating services of which he may, or may not, choose to be a part.

Similarly the study, diagnosis and treatment terminology of the medical model of casework is being dropped to be replaced by a methodology based on problem solving. Perlman has written that rather than trying to fit knowledge and practice into traditional boundaries, what is to be known needs to be rooted in the kinds of problems that need to be solved.

"Maybe the way to go about identifying social work practice activities is not within the traditional boundaries of casework, groupwork and community work at all, but across lines, by asking ourselves what kinds of problems call for kinds of service and actions. It is possible that the ways we perceive a situation, define it and go about treating it are shaped by the particular methods in which we have allegiance or in which we have skill."

Some of this thinking is developed further by Jones (1975) in his ideas of bridging concepts. This is the grouping together of "what would traditionally be called methods and client groups under two heads in such a way that exclusive boundaries of methods or inappropriate categorising of clients are transcended without necessarily losing the specific skill areas". (P.46). As an example he takes
'disability' which etymologically refers to a lack of power and which he looks at within the context of the social functioning model of life. In this interpretation, 'disability' is the person's lack of power for satisfying living and as such has much wider connotations for social work practice than its more traditional physical aspects. It requires that the individual is seen in as much of his wholeness as possible, as a biopsychosocial being.

Inevitably there will be inconsistency in social work. "Inconsistency is simply a hidden awareness of the contradictions of the world" (Kolakowski (1964)) but if this is so how can the profession lend itself to theoretical underpinning? Cohen (1934) has written that "social work is still a long way from having a scientifically tested and validated practice theory. Social work practice theory was not developed via systematic research, but built up through trial and error." Yet conversely that could well be one of the strengths in social work for it is doubtful if there can be a scientific formulation for empathy and caring. Meyer (1972) asserts that social work is essentially a 'borrower' and that there are no boundaries to the knowledge necessary for social workers to accomplish their daily tasks. "Whereas other professional specialists become experts by narrowing their knowledge parameters, social workers expand beyond measure to broad horizons of knowledge." All that the recent theorists have asked of the professional practice is that there be some attempt to organise the random knowledge; the model being offered is a systems one which is claimed to be little more than a way of thinking which may lead to the development of some theory of social work practice.

An Integrated Approach is a useful conceptual framework for the assessment of problems and the planning of 'interventive' approaches. It is not itself a body of knowledge, but a way of thinking, an
analysis which accommodates knowledge from many sources and incorporates all known methods of social work intervention. Now it needs to be developed in practice as a problem solving approach in which areas for social work intervention are mapped and plotted, and a whole range of methods and skills employed. It provides opportunity for one-to-one work and for work with small and large groups, but the unit of attention is viewed within the context of a society where people are highly interdependent. Often caseworkers have found it harder to intervene effectively in the social system rather than the personality system, especially if the social system provides individuals with chronically impoverished environments. Meyer (1972) has written that "we cling to what we know because we know it, because it has served us well and because separation from the known leaves us stranded, and because we have no assurances that the future way will be better." This may partly explain a common social work professional attitude which is to kick hard against the Integrated Approach, saying either that there is nothing new in it and that they have been working like that anyway, or that it is too theoretical to work in practice. To end an apparent stalemate a monitored attempt to apply some of the integrated conceptualisation to the practice of social work is needed and then for this to be evaluated in light of the enthusiasm for it on the part of the theoreticians and the antipathy by the practitioners.

In the introduction to Social Work Treatment (Ed. Turner 1974), Younghusband has written that "the hallmark of a good theory is its capacity to predict the outcome of any given action." Yet the very nature of the social work task whether it be a committal to care, an allocation of financial aid or a planned short term treatment in a family having recently acquired a disabled member, is an uncertain
act in a complex environment and the outcome may not be predictable with any degree of certainty. The response of every family which suddenly gains a handicapped child is going to be different, dependent upon a whole range of interdependent biological, psychological, sociological and economic factors, and there can be no firm predictability of outcome when a social worker intervenes. An Integrated Approach does not promise to remove this uncertainty and as such would not meet this particular criterion of a good theory. What it may be able to do is to help a profession to understand some of the causes of the unpredictability of the outcomes and to tolerate its seeming failures in a way which the linear cause and effect concepts of the past have not. It may turn out not to be a good theory as such, but experimentation with the ideas can only contribute to the body of common knowledge which is the prerequisite for professional status.

So I am not claiming that an Integrated Approach is the answer to the social work profession's century old quest for its own theoretical underpinning, nor that there is much in it that is new. I do not believe that we have reached the social work Mecca. I do recognise that social work has had something of a chequered history and that what may sometimes seem to be new is in fact re-discovery or re-emphasis of something already known. At times it is a corrective to narrow thinking and action at certain times and in certain settings. It is also true that some current practitioners are well into systems thinking, an example being the rapid development of family therapy which is using many aspects of this approach in its practice. In this study, I am going to explore such an approach with a group of people in a chronic situation.
THE PROJECT

This project is concerned with social work intervention with families which have a handicapped child. I took as my definition of handicap the one from the Younghusband Report on children with special needs:

"Handicap is a disability which for a substantial period or permanently, retards, distorts or otherwise adversely affects normal growth, development or adjustment to life."

Previous studies by members of other disciplines have tended either to be of the mentally or the physically handicapped and these might even be further categorised into different syndromes. I believe there is a risk of creating artificial boundaries by this continued segregation of handicapped children into variously labelled groups and communities, and furthermore, as in line with the national birth rate the numbers of handicapped children being born is falling, there may be a dilution of effect by the separation.

There are some who believe that the knowledge base of social work consists of hypotheses which can be empirically tested. But it is hazardous to try to set up clinical trial types of experiments because of the ethics of professional practice where it is believed to be wrong to knowingly and deliberately deprive people of a service to which they are entitled. Examples of social work attempts to approximate to the model of the clinical trial are few, perhaps the best known being Goldberg's Helping the Aged (1970), and two American studies, Girls at Vocational High (Mayer, Borgatta and James 1965) and Reid and Shyne's research conducted at the Community Service Society of New York and published in 1969. In these sort of studies there are five requirements crucial to their validity as research models:-
1) a reliable and valid measurement of conditions before and after 'the treatment'.
2) random assignment of different treatments and non-treatments to an experimental and a control group that are similar in all relevant respects.
3) measurement of the treatment dosage.
4) establishment of criteria for success.
5) some means of connecting outcome to the treatment given.

In social work each of these problems poses extreme difficulties not the least being a clear indication of what is 'the treatment'. One of the factors emerging very clearly from the three studies mentioned above is that it does very little good to state that treatment X is better than treatment Y if it is not made very clear of exactly what that treatment consisted.

The clinical trial, which so much reflects linear conceptualisation does not appear to readily lend itself to testing out an Integrated Approach.

It could be argued that we know very little of the meaning of social work and so it is perhaps premature to attempt to develop much sophistication in measurement. To help us become more sure of the meaning of social work before we start to measure it the client as a consumer of the service offers a perspective which could take a much more central place in our research strategy. Consumer research can help to refine what is currently known or believed to be known about treatment. So consumer evaluation has been the key factor in attempting measurement and assessment of service throughout this project.

All these dilemmas were considered in establishing the work plan for the project which had three main sections. The first part was
concerned with trying to meet the experimental/control group problem and yet at the same time maintain the professional integrity of not withholding help. To do this, I took an existing group of families which had already been through the experience of having, and rearing a handicapped child within the existing framework of services. As well as acting as some kind of control these families gave valuable indications of areas where help was really needed and of times when it should especially be available. The data was collected by structured interview with a questionnaire and was tape recorded.

The second part was to establish some kind of experimental group which would be offered an improved service that aimed to be multidisciplinary and included a social work component as an integral part of it. This was the action research programme. Finally, there would be an evaluation of this experience with the families in this experimental group a year later, again by interview and questionnaire and tape recorded, and the findings of these two groups would be studied comparatively with particular reference to the social work practice.

Timms (1971) has said that research and social work should go more closely together and that this requires some change in the research worker and the social worker as partners in the enterprise. He did not actually say that they should become one, but this is a logical outcome of the argument and one which is attempted in this research. There is a dearth of material about the actual practice of social work from the point of view of the social worker. An action research programme such as this one may help to remedy this deficiency.

The nature of the problems created for some families by having a handicapped member suggested that it was an area for social work involvement, yet apparently some of the more traditional supportive
methods of intervention had not been experienced by the consumers as being helpful. At a time when social work is being exposed to new concepts, and practitioners are being urged to reconsider the knowledge base and boundaries of the professional arena, it would seem appropriate to rethink the problem area and the modes for intervention. This project therefore, has been an investigation into the difficulties being experienced by families with a handicapped child, and an application of some of the conceptualisations of an Integrated Approach to the practice of social work within this area.

The project goes further in that it attempts to demonstrate the social work component by applying a Grounded Theory Approach (Glaser & Strauss 1967) to all the social worker's case records and producing an analysis of the common features of that particular worker's professional practice. The major concern of the project is to develop knowledge for professional practice.
CHAPTER 2

Resources in Plymouth
"Care of the handicapped demands ongoing support and specialised knowledge at a level immediately, easily and continually available to parents."

Court Report.

Plymouth, including Plympton and Plymstock has a population of slightly over 250,000 which given the proportion of families having a handicapped child makes this a feasible study area for a lone researcher. It is a relatively isolated urban centre, its nearest large town being Exeter some 42 miles away. The city is built on the east bank of the River Tamar and this forms a natural geographical region which is recognised by the Department of Health but not by the Department of Education which works within county boundaries. The Plymouth hospitals serve the populations of east Cornwall and west Devon and handicapped children receive all their medical treatment in Plymouth.

All children living within Cornwall have to be educated in Cornwall's special schools which are towards the western end of the county and for many children this necessitates weekly boarding. The first survey to establish the control group was confined to children living within the city, but the referrals from the hospital in the second part of the project included children living outside the city, and these helped to expose further problems.

Although it was originally planned to confine the study to children who were eleven years old and younger, it was early realised that chronological age is of no great significance when dealing with handicapped children, a fact recognised frequently in the flexibility of class ages within the schools. For this reason a 13 year old boy more severely handicapped than his younger handicapped sister is included in the control group and the experimental group includes one older boy. Plotting the distribution of handicapped children on a street map of Plymouth established that there was a widespread and fairly even scatter with no
interestingly abnormal pockets of density.

HISTORICAL ASPECTS

The beginning of state involvement in the problems of handicap was with the appointment of a Royal Commission in 1885 which four years later was to include amongst its recommendations the following:

(1) School authorities to be responsible for the education of the deaf and blind.

(2) Mentally handicapped children should be given special educational treatment.

(3) Education of the handicapped should be continued until the age of 21.

(4) Selection of children for special education should be made by doctors and not teachers.

Only the first recommendation was incorporated into the Act of 1893. The report was given legal effect in the Act of 1899 but the Local Authority provision was permissive and not mandatory. A new Royal Commission on the care and control of the feeble minded established in 1904 was to advocate an institutional system with admissions at an earlier age than before and that the control of the Special schools should be the responsibility of the local Mental Deficiency Committees. Under the 1913 Mental Deficiency Act the Education authorities assumed responsibility for assessing children between the ages of 7 and 16 and making decisions about allocation into special schools. This Act also divided the mentally handicapped into 'idiots', 'imbeciles' and 'feeble minded', terms which were to remain until the 1959 Act when they were replaced by 'subnormal' and 'severely subnormal'.

The 1944 Education Act enabled the Local Authority to provide Special Education for children from the age of two and established
The only handicap which requires education away from Plymouth is blindness and partial sightedness, and these children go to Exeter.

In April 1971 the Education Act of the previous year was implemented and the responsibility for the education of the mentally handicapped was transferred from the Department of Health to the Department of Education, a move which represents the final official acceptance of the problems being essentially social and educational rather than medical. From that time onwards 'no child is ineducable'.

Inevitably such a piecemeal development of provision has left a hybrid service for the handicapped which makes for confused functioning at times. It will later be argued that one of the most helpful parts that the social work profession can play is to help expose some of the anomalies and put pressure to bear on the bodies which prevent the operation of a truly functional and efficient system.

EDUCATION

In a project which is concerned with the issues of an integrated approach it was important for the researcher to visit all the schools and educational institutions in the area. Not only did this enable
information to be exchanged but laid the foundations for developing some of the boundary work in the later stages of the experimental section. If there were to be hold ups in school admissions it was important to know which schools might be over subscribed and which might be below established numbers. If parents had a choice available to them then it was important for the social worker to be fully equipped with information about the educational facilities so that they could be helped to make informed decisions. It was important for the schools to meet a social worker from the hospital, to know about the research, and that it might be involving some of their parents. All of the schools were visited in the early days of the project and it was clear that none was overcrowded with children, all were well staffed, most were in modern purpose built accommodation and there was a balance of provision from the state and the voluntary sector.

The schools in the area were the following:

Mill Ford School E.S.N. (Severe)

Mill Ford School was planned to accommodate 130 children, but the Head thinks that the maximum should be 120 and when I visited there were 109 children in the school. There are never more than 10 children in a class which reflects the high teacher/pupil ratio. Formerly this school was at the Highbury Training Centre and known by that name, the whole being the responsibility of the Health Department as a centre for the mentally handicapped.

Children are taken from the age of 2½ years until they are 16. The nursery is not full and there seem to be historical reasons for this. In the past, before this nursery was opened, parents were advised of local playgroups which could cope with one or two handicapped children, or the children were channelled towards Dr. Barnardo's St. Nicholas nursery. The Head thought that at that stage Barnardo's
nursery was giving a better service, mostly because social work is provided from the onset and continues with the family right the way through. At Mill Ford it is only the Educational Welfare Officer, the School nurse and occasionally the teachers who make any contact with the family and only when it is thought to be absolutely necessary.

**Downham School E.S.N. (Severe)**

The original catchment area of Downham was established under the old Devon County Council and included Dartmouth, South Brent, Tavistock, Kingsbridge, Princetown, Plympton and Plymstock. Today the transport is shared with Mill Ford but the schools are run independently and try to retain their catchment areas. Children may start here when they are 3 and there is a weekly boarding hostel for 18 children between the ages of 5-16 years. The school has always had qualified staff and is very much a formal school with the emphasis on education for future living. It began 20 years ago with 5 children in a church hall, then it moved to Harewood House and 14 years ago into its present purpose-built premises to which extensions have been added in the intervening years. There are 10 children in the special care unit who are severely handicapped and they are looked after by 3 staff with a speech therapist and a physiotherapist coming in to do sessions during the week.

**Courtlands School E.S.N. (Mild)**

Built on a pleasant 10 acre site this school was opened in 1969. It serves the city to the west of the River Plym and a rural area to the north stretching from Ivybridge to Tavistock. Most of the children travel to school on the special bus or in a taxi but a few can manage to come on public transport. The school is staffed by 15 teachers in addition to the headmaster and his deputy, referred to as 'my second mistress'. At the time of visiting there were 220 children in the
school although there is room for 240. Of these some 60 boys and girls are in the infants section which caters for 5–8 year olds, and there are about 100 children in the juniors. At 11 the senior boys transfer to what is called Hillside school, but the girls remain here until they are 16.

Longcause School E.S.N. (Mild)

This school was built in 1967 for about 100 children who are divided into seven classes. The boys outnumber the girls by about 2:1 and in the past the boys have had to wait much longer for vacancies. As with the other schools this one had recently moved to a new situation of having a few vacancies. Theoretically the school serves a catchment area on the east side of the area from the River Plym; in reality the children come from all over the city. As the pressure on places is easing off it is now becoming more possible to allocate places on a geographical basis which means that the children have to spend less time in the bus travelling each day. Staff roles are not rigidly defined and all the domestic staff attend and contribute to staff meetings.

Woodlands School (Physically handicapped)

Plymouth had the first open-air school in the country when in 1918 a centre was opened to meet some of the needs of children with tubercular bones and rickets which abounded in the slums of the post war years. However the display of initiative and a forward looking approach were not always to be features of planning in the south west. Sixteen years after the 1944 Education Act Devon and Cornwall were asked by the Ministry to produce immediate plans for making provision for the physically handicapped as stipulated in the Act. Neither county seemed able to co-operate in this venture so in the end a further directive from the Ministry ensured that the proposals should proceed on a neutral site in Plymouth City and in 1964 a school recently built as
a primary school, was developed, instead, as a much needed unit for handicapped children. Over the next five years extensions were made for full physiotherapy provision and for hostel accommodation. Currently there are about 130 children aged between 2½ and 17 years. Of these, 25 are weekly boarders, but none of the boarders is under 5 years and the preference is for older boarders who live a long way from the school.

The nursery caters for 20 children. Until recently there were usually twice as many boys in the school as girls, but the pendulum is swinging in the other direction now. The range of handicap also seems to be changing; spina bifidas are declining in number but heart conditions and muscular dystrophies are on the increase.

Trengweath (School run by the Spastics Society)

Some 25 years ago a Mr. Wyatt put an advertisement in the local Plymouth paper asking if anyone else had a child with the same symptoms as his son and these he carefully described. Over 300 parents responded and after sifting thoroughly through these he established that there were about 30 other spastic children. He made contact with these parents and together they raised £500 which was a down payment on Trengweath. This was to be a centre for the spastic children where they could receive education and intensive physiotherapy. As well as Trengweath this very active association established a work centre and Clivedon which is a residential hostel.

In 1966 the local association approached the Spastics Society in London and Trengweath became nationally controlled. Two years before that a new wing with additional classrooms and physiotherapy treatment rooms had been added and this was further extended by the Spastics Society to include a 14 bedded unit for short stay children.

From the beginning this was not very successful so in 1970 it was changed to weekly boarding accommodation thereby enabling distant
children from Devon and Cornwall to come for treatment. There are 13 boarding places and one for emergencies. Currently there is no waiting list.

Babies can be referred for physiotherapy as early as six weeks old but children do not start attending the nursery until they are between 2 and 3 years old, and even then most of the week is spent in having physiotherapy. There were 55 children in Trengweath when I visited with a staff/child ratio of 1:4. The Family Help Centre is heavily staffed and open continuously. Children with average ability remain at Trengweath until they are 11 and then they transfer to one of the other special schools, usually Woodlands or Courtlands. Those who are mentally handicapped remain there until they are 16 and then may go to Rockfield which is a pure care group for spastics over 16 who are unable to work. About a third of the children at Trengweath are in this category.

The National Spastics Society will be drawing out of the running of Trengweath in the very near future and the administrative responsibility will be assumed by Devon. This should eliminate many of the anomalies which exist in the overall service for the handicapped when it is shared between a Voluntary Society and a Local Authority, and one is fee paying and one is not.

In addition there is a Special Unit at Trelawney School for maladjusted seniors which takes up to 12 children at a time with two teachers, and the newly opened school for the deaf and partially hearing children at Hartley House. Again the headmaster of this school likes to have the children from a very early age so that they are having training at the critical period for language development which comes well before the normal school starting age. Finally, there is the St. Nicholas nursery which was begun in 1973 by Dr. Barnardo's and is now housed in the Trelawney Youth Centre and taking up to 16
children each day. The children are now allowed to start before they are 2 years old and must transfer to one of the special schools when they are 5. One of the big advantages of this unit is that it remains open during the school holidays. Staffing ratio is 1:3 and the funding of the project is shared between Barnardo's and the Local Authority. A full time social worker is attached to the Nursery and may continue to work with the families after the child has moved on to a special school.

**Educational Psychological Services**

The Educational Psychological service became very actively involved in the assessment of handicapped children when responsibility for their education was transferred from the Department of Health to the Department of Education in April 1971. The new procedure for special school admission is initiated by the completion of an SE1 form which is completed by the head teacher of the school where the child is attending. This is followed by an SE2 form filled in by the Community Health Physician when he has medically examined the child. Both forms are then sent to the Educational Psychologist who tests the child and makes an assessment of his educational potential, and then he, or a senior colleague completes the SE4 form which is a summary and action sheet. All the forms are sent to the Education Office for a decision about school allocation. Casepapers are sent to the Head of the Special School suggested and he decides on priorities and waiting list places. Previously the waiting lists were much longer, but now theoretically it is possible for a child to be found a place fairly quickly once the SE procedure has been finalised.

Speech therapists and physiotherapists are actively involved in the services to the schools although there is widespread acknowledgement that they are very understaffed and not able to provide as good a service as a fully manned department would.
The expansion in educational provision for the handicapped children in Plymouth occurred in the 1960s, but it was a decade or so later before there was any comparable development in the Health and Social Services. At the time of doing this research there was a lot of interest around and new ideas were being put into practice. It meant a much wider range of resources was to be made available to the parents of the more recently diagnosed handicapped child, this in turn making for greater comparability between the original sample group and the experimental group set up during the year at the hospital.

It was only in early 1976 that an additional paediatric consultant was appointed bringing the total to three. All are based at the hospital but also attend out-patient clinics at various bases in Devon and Cornwall. One of them acts as Director of the Child Development Centre at the Scott Hospital, where most of the children are referred at the end of their first year when the problems are established as being developmental rather than medical. Attached to the Centre is a Community Health Physician who specialises in testing and assessing developmental progress. Auditory testing and speech therapy sessions may be conducted here and there is a small remedial teaching group. All physiotherapy for any handicapped child is organised by the large physiotherapy department at Trangweath and the Head Physiotherapist works very closely with the consultants. Although some treatment is done in the other schools on a sessional basis the vast majority is done in the department at Trangweath where the equipment is more sophisticated.

In 1968 one of the community Health Visitors was asked if she would like to specialise in working with families where there was a handicapped child. In the eight years that she was in this post she developed considerable skill in this area and gave tremendous support
to very many struggling families. It was only when she left to get married that it was perhaps fully realised how much support ought to be made available to these families. Although another health visitor was appointed in her place there was a marked increase in the involvement in this area of working by the hospital based social workers.

**SOCIAL WORK**

Dr. Barnardos in Plymouth was largely responsible for pioneering the specialist social worker with families which have a handicapped child when they made such an appointment at the time of opening their St. Nicholas nursery. The Spastic Society also employ a full time social worker but as she has to cover Devon and Cornwall a large part of her working week is spent in driving a car and she is only in Trengweath for a few hours each week. There is one part-time social worker at the Development Centre and two full time paediatric social workers at the hospital, although only a relatively small part of their time can be allocated to the needs of families with a handicapped child. At the time of doing this research the Principal Social Worker at the hospital was actively involved in developing facilities for the handicapped, one of which was the Beckley Unit at the Scott Hospital. From the beginning of 1976 there was to be no more nursing of acutely sick children at this hospital; instead there was to be the establishment of short term hostel care for handicapped children. In the future, it is envisaged that this will be extended to provide long term care for the very severely handicapped who cannot be cared for in their own homes and currently have to be sent to hospitals in east Devon. At the moment, parents are encouraged to leave their children at the Beckley Unit while the rest of the family has a short holiday, or perhaps to put the child in there for a day or two so that the family can go to something special like a wedding, or do something ordinary like going shopping, both of
which can become impossible if a handicapped child has to be taken as
well.

The social workers have largely been responsible for the mush-
rooming of parent support groups. One is run at monthly intervals in
the afternoons at St. Nicholas and another at monthly intervals in the
evenings at the Beckley Unit. Both seem to attract the attendance of
the same group of parents. Likewise the schools have parent staff
groups but these tend to be primarily fund raising organisations rather
than encouraging support group activities as envisaged by the social
workers.

The Social Services Departments are required to keep a register of
handicapped persons, but as far as the children are concerned being listed
on the register seems to carry with it very little advantage. The numbers
included on the register varied quite considerably between Area offices
which may have reflected a varying degree of enthusiasm for maintaining
the register rather than any particularly great variation in the numbers
of handicapped persons involved. In 1977 an attempt was made to create a
centralised register of all children confirmed as being handicapped.
This was to be maintained by the specialist health visitor for the
handicapped with the onus being upon the hospital staff to feed in in-
formation.

FINANCIAL AID

National provision includes the Attendance Allowance which is avail-
able from the age of two to persons who need constant caring attention.
There is a full time allowance for those who need care by night and
day, and a reduced rate if the care is for only one of these times. At
the age of five a person who cannot walk may qualify for the Mobility
Allowance provided that he is able to appreciate going out. There are
also discretionary grants from the Joseph Rowntree Trust in York which
is a government sponsored fund administered by the Rowntree Trust, established to give financial aid to families experiencing additional expense through having a severely handicapped child. Occasionally some of these children may qualify for grants from the Sir Malcolm Sargent Cancer Fund for Children and locally there is the J. Beckley Fund for Sick Children and the financially more limited Patients' Voluntary Welfare Fund.

SUMMARY

Plymouth appears to be reasonably well endowed with facilities for handicapped children. There is a range of special schools and although several of the children have quite long journeys each day, this is a feature of the national situation so long as policy is to provide separate schools rather than classes attached to local schools. Financial aid provided by the State is supplemented by local trusts which make generous donations to families in need. Statutory provision of services is augmented by voluntary agencies, as for example, the recent opening by Dr. Barnardos of the nursery for handicapped children which with a social worker attached has filled a gap in the services in this city.

However, there were some indications from my visiting that there was not widespread acceptance of the notion that an increase in the amount of services necessarily made for improvements. One headmaster complained about delays being created by the educational psychologists being required to carry out testing, whereas in the past he had been able to make speedy decisions in consultation with the Health Visitor about accepting a child. There was quite considerable evidence to suggest that the services were not inter-relating as well as they might.

For a research project wishing to implement some of the concepts of an Integrated approach the situation concerning resources was almost ideal. There was in existence a range of comparatively new and
well equipped services. As yet they did not appear to be working closely together nor inter-relating to provide a continuum of care for handicapped children and their families.
CHAPTER 3

Establishing the Contrast Group
All happy families are alike but an unhappy family is unhappy after its own fashion.

Tolstoy: Anna Karenina

In the introduction to her book Hewett (1970) points out that there is plenty of comment about the problems which can beset the handicapped child and his family but very little about "the families who meet the crisis of handicap as they meet other crises, with resilience and common sense". This is a study of families who cope as well as those who do not, a study of families who have had every existing service and those who have availed themselves of very little. It is an attempt to look at a sample of the whole rather than a section of it and to learn from the families who do cope what may be relevant to professional working with families who encounter difficulties.

METHODOLOGY

The number of handicapped children is only known approximately although every department concerned was certain that its figures were accurate. To try to establish a more true account of the overall situation information about handicapped children in the age category 0-12 years was collected from the records of the Health Visitor for handicapped children who at the time of the survey had been in the post for eight years, from the questionnaires of the West Devon Mental Handicapped survey which for the younger age groups was based principally on the special schools registers, Dr. Barnardo's lists of children who had attended their nursery since its inception and the Handicap Registers of Plymouth Social Services. Although the resulting list cannot be complete it is probably the most comprehensive in existence and resulted in a total of 269 children. It was originally envisaged that I would take approximately a quarter of the total as a sample which would form my Contrast Group and that I would interview them with a
The data was card indexed. At this stage it became important to verify the application of the term handicap to the children on this list. My definitions of the terminology I used are based on the publications of Younghusband (1970), Harris (1971) and Court (1976).

**Defect** is some imperfection, impairment or disorder of the body, intellect or personality.

**Impairment** is an anatomical, pathological or psychological disorder which may be described in diagnostic or symptomatic terms. It may cause or be associated with disability so that while every disabled person has an impairment, not all people with impairments are necessarily disabled.

**Disability** is a defect which results in a limitation of performance in one or more of the activities which are generally accepted as essential basic components of daily living. This does not necessarily affect the individual’s normal life.

**Handicap** is a disability which for a substantial period, or permanently, retards, distorts or otherwise adversely affects normal growth, development or adjustment to life.

Further checking established that 49 of the cases could not now be included. Of these 3 had died, 12 were living outside Plymouth, 2 had left the area, 2 previously thought handicapped were now deemed to be all right, and a further 30, although still having a minor impairment, were attending and managing well in normal school. The sources from which the data was collected indicated that there were four fairly clearly defined categories into which the remaining families could be placed:

(1) Families which had availed themselves either currently or recently of both supportive services in having visits from the Dr.
Barnardo's social worker and the Health Visitor for the handicapped children. These tended to be the families of the younger handicapped child.

(2) Families which currently or previously were being called upon by the special Health Visitor, but had had no other key professional person much involved.

(3) Families which had never received any social work help nor visits from the specialist Health Visitor and would have liked to have had them. Obviously a general health visitor would have called upon the under fives but she would be lacking in expert knowledge of the handicap.

(4) Families which had never had social work or specialist health visiting and would not have wished to have had it.

Categories (3) and (4) were established by reference to the West Devon Mental Handicapped Survey questionnaire forms and although mental and multiple handicap far outweigh those of pure physical handicap, these categories must be regarded as slightly inaccurate because they would not be including the very small numbers of purely physically handicapped. It was important that the sample was not overweighted by families predominantly from one group. From the 220 children remaining a controlled random sample was taken so that of the final 60 families 15 should come from each of these groups.

I did a pilot run of the questionnaire (Appendix A) with a group of parents from the St. Nicholas nursery, and after making a few minor alterations, I proceeded with the main survey. Initially I wrote to 74 of the families enclosing a reply slip and a stamped addressed envelope. Of those contacted, 46 replied that they would be willing to participate and 3 said they would prefer not to be involved. I then further contacted those from whom I had not heard
and discovered that 2 had left the area, four did not wish to do the questionnaire but the rest were willing to take part. From these I took another 14 to make the total up to 60.

The interviews were carried out between December 1976 and March 1977. Most were in the evenings and each took at least an hour and some were very much longer. Although both parents were invited to participate this was not always possible mostly due to there being a high proportion of naval fathers who were away at sea. At the time of the survey 11 were at sea. In fact only 40 sets of parents were seen together, and 18 mothers and 2 fathers were seen alone. For this reason some of the answers for the fathers have had to remain blank. Unless the competing noise of television or general family life was too great each family was asked if they would agree to the interview being tape recorded. Only one mother said that she would feel less inhibited if the tape recorder was not switched on. I did explain to parents that I would be the only person who would listen to the tape and that it was a second check on the accuracy of the information I had written down. The tape recorder was a small portable one which was left unobtrusively on the floor and in no way did it appear to restrain people in what they wanted to say. One couple had a violent argument during the interview and obviously, at least momentarily, were oblivious of the fact that what they were saying was being recorded. As soon as possible after that interview I played back the tape recording, made detailed notes on what had been said and wrote down particularly relevant quotations, then scrubbed the interview from the tape as I had promised to all the parents that I would do. Apart from the fact that tape recording enabled me to obtain rich data it also meant that I kept monitoring my own interviewing techniques. Quantitative data was transferred to work sheets which facilitated a speedier and more accurate handling of facts.
DISTRIBUTION BY AGE OF HANDICAPPED CHILDREN 0-13 YEARS ON 1-1-77.
IN PLYMOUTH.

Fig. 1.
NUMBER OF CHILDREN IN THE FAMILIES IN THE SAMPLE INCLUDING THE HANDICAPPED CHILD, BY SIZE OF FAMILY.

<table>
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<td>15</td>
<td>15</td>
<td>60</td>
<td>181</td>
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</table>

Fig. 2.
The distribution by age of the handicapped children (Fig. 1) illustrates the fall in the number of handicapped children which may reflect the falling national birth rate.

There are many more handicapped children aged 8, 9 and 10 and this coincides with the years of active surgical treatment of children born with spina bifida. Today the apparent trend within the medical profession is towards not treating bad spina bifidas because the quality of life for them is so poor. The sample did pick up several families which are large by modern day standards (Fig. 2) and this has resulted in the average size of the family in the sample being 3 which is slightly higher than the national average for all families. Group 1 (see page 22 for definition) has an average age of handicapped child of 4 years and family size of 2.5; in Group 2 the average age is 5 and the family size is 3. Group 3 has an average age of 9.8 and family size of 2.9 and in Group 4 the average age is 8.9 and family size is 3.6. (Fig. 3).

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<tr>
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<td>5.0</td>
<td>9.8</td>
<td>8.9</td>
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Fig. 3
SIZE OF FAMILY AND AVERAGE AGE OF HANDICAPPED CHILD IN EACH GROUP.
The very different average age of the children in the four categories may well reflect the changing patterns of availability of services. These figures (Fig. 3) suggest that those families who had no help have the older children; those who have had or have it are with the younger children. Such a trend might indicate that the services are relatively new and expanding.

In 11 families the handicapped child was the only one and in another 37 situations he/she was the youngest child. Eighteen families had a further pregnancy after having a handicapped child. The parents in 55 families were living together, 3 mothers had remarried and 2 mothers were bringing up their children on their own. All 60 mothers were still actively caring for their handicapped child, although in some situations the handicap was so severe that the child had to be away from home for some of the time. In 11 families the parents were over forty but the rest were younger and most were in their twenties.

Rearing a handicapped child requires a great deal of time and makes tremendous demands emotionally and physically the burden of which inevitably falls mostly upon the mother. Five of the fathers were said by their wives to have found the stress of having a handicapped child all too much and had left the family at an earlier date. Another two were on the point of going. Although the nature of their employment meant that several fathers had to work long hours or be away at sea for lengthy periods, for some this was a means of escape from a situation which they found to be somewhat distressing. Others developed an active social life for the evenings. One father said:

"I go to the pub most evenings because it gets me down. The wife is very patient but she does take it out on me a bit."
TELLING PARENTS THAT THEIR CHILD IS HANDICAPPED

Caplan (1961) and Lomas (1967) both regard pregnancy as a period of susceptibility to crisis. When normal pregnancy results in the birth of a child who is impaired, crisis almost inevitably ensues. Parents suddenly have to make enormous practical and psychological adjustments on a variety of different levels. The time lag between the event and the emotional acceptance of the event may be marked by two distinct reactions—shock and denial. Parents experience grief, fright, anxiety, horror, guilt and shame, all of which are negative emotions in response to the negative aspects of handicap. Although these are likely to prevail initially and often for a very long time they are not unmixed with some joy of childbirth. It is likely that there will be an arousal of two incompatible sets of desires. On the one hand they want to nurse and protect the child because it is their own, and on the other they want to reject it because it is deformed. For the child to have a reasonably healthy upbringing a balance needs to be found between the two conflicting desires and help may be needed here as otherwise the outcome frequently is extreme. Either every effort is made to get the child into an institution which may be a symptom of total rejection or the parents become so utterly devoted to the child and his care that he, and the rest of the family, suffer a condition which is sometimes referred to as ‘hyperpaediatrafilia’.

Obviously the actual conveying of the information about having a handicapped child and the help given at this stage may have long term consequences for the overall acceptance of the situation. As perhaps is to be expected the parents remembered very clearly who it was who told them about their child. Possibly with the passage of time and the displaced anger of the crisis, parents remember less clearly what was said, but their recollections tend to be predominantly negative.
and seemingly some situations were handled rather insensitively.

Of the total, 68% of the mothers and 37% of the fathers were told by the doctor at the hospital. A further 5% of the mothers and a much higher percentage of the fathers - 42% - were told by their spouses. Only 28% of the mothers and 33% of the fathers were told with their spouse whereas 56% of the mothers and 40% of the fathers were told on their own. Overall 10% of the parents felt that they had never been told, and the remaining few learned of their child's condition from a midwife, educational psychologist or the physiotherapist. When asked if they had been told at the right time 53% of the mothers and 45% of the fathers thought they had, but 36% of the mothers and 28% of the fathers thought not. All who were critical said one or both of two things; they should have been told earlier (nobody said that they had been told too soon) and they should have been with their spouse. Some acknowledged that this was not always feasible, for example, in situations when a husband was away at sea, but there was resentment when a wife had been told on her own in the ward during the day when it was known that the husband would be coming to visit in the evening. Nearly half of the mothers (43%) and 30% of the fathers believed that they had been told only once.

Some conditions are obvious from birth or very soon afterwards. Down's syndrome, spina bifida, external congenital deformities and heart conditions may all be recognised early. Other conditions only gradually become apparent when a child is slow in reaching his 'milestones' (medical terminology for the landmarks in the developmental stages) and this is investigated. Some babies have problems in the neonatal period and there is a question mark over them until evidence occurs to confirm the situation either way. The following extracts from parents' comments about being told reflect what they remembered.
and felt about their experiences which range from seeming to have been
done with care to being quite insensitive. In these cases the handi-
cap was apparent at birth.

Parents of a five year old son who was very severely handicapped from birth:

"Doctor said, 'I am going to paint a black picture. I don't believe in telling people it is going to be all right when in my heart of hearts I know that it is not. He will be handicapped.' But it was 7 months before anyone knew that he had a malignant brain tumour."

Parents of a ten year old son with Down's syndrome:

"Doctor said that he was a mongol with a heart condition. We've known from the very beginning. He's always been very straight with me and told me everything. I think we have accepted it better through knowing at the beginning."

Mother of a two year old boy:

"I'm sorry we've got to send Stephen to the Special Care Baby Unit; he's lost so much weight. As you know he's got one eye smaller than the other, we think he is blind, he's got a hare lip, a cleft palate, a bad heart. The tears were just running out of my eyes. I asked the doctor if Stephen would ever be normal and he said do you mean physically or mentally and I said both. He said no he is not going to be normal either way."

Parents of a three year old daughter who had been born in London:

"They continued to take head measurements and when I asked why, they said, 'Oh we're just checking.' When we came down here they were surprised that we did not know. All we were told was that she was premature and would be slow catching up. Nobody told us in black and white that she was mentally handicapped."

Mother of a ten year old very severely handicapped son. As a child she herself had been in care and so was lacking in family support. Her husband was in the Navy.
"He was two months premature and very jaundiced. He was transfused twice and then sent to C—where a shunt was fitted. The doctor said that he might be a bit slow but otherwise all right and we thought that William was going to be O.K. He went for a check up at C—when he was a year. The doctor there said, 'when their computer (that's what he called the brain) is as badly damaged as is his let's face it he'll never be any good to anyone! Nobody told us that it was as bad as this, nobody sat down and told us what was going on. I came out and put William in his little push chair and walked the five miles home and I cried all the way.'

More than one mother remembered being put into a room on her own, the reason for which is hard to understand but it might have been that by putting the problem out of sight the staff coped with their own feelings and with their wish not to have other patients upset.

"I was in a room on my own. I was crying. I'd looked at him and I knew that something was wrong. The nurse came in and went for the doctor. He said, yes I did have a mongol. They gave me six tranquillisers and sent me home the next day.'

Another mother of an eight year old son who was her sixth child and born with spina bifida:

"I knew something was wrong because when the others were born I had natural births, no gas or whatever and when he was born there was no cry. Sister grabbed him and took him away and moved me into a private room. I wondered why. I was put in a room on my own instead of with the other mothers.'

for those parents where the child's handicap became apparent later the telling was usually even more traumatic and the scars of it still very apparent. These parents had bonded to a normal child believing this to be what they had got. Then they learned that their child was handicapped and for them it was much harder to accept and they felt much bitterness and anger which they often directed towards the medical profession and others.

Mother of a severely handicapped seven year old son:
"They told me that I had a perfectly normal boy but they never let me see him for three days. He was nine months old and not doing a thing so our G.P. sent us to Dr. – . He did some tests and said that there were abnormalities of the spine and a cleft palate. Then he said, 'you know he was brain damaged,' We didn't because he hadn't told us."

Mother of another seven year old son:

"We were always going to the hospital for check ups because of the bad birth. It was all very vague. I felt that something was wrong and I worried about it. I didn't like to confide in my husband or parents because I thought it was just my imagination and really you bottle things up inside instead of talking to people which can help a lot. Doctors tend to treat you as children and we're not children and can't behave as children. It's kinder to tell you all the possibilities."

Mother of an eighteen month old son with an hereditary handicap:

"I used to go to the welfare clinic every fortnight and say something is wrong with Kevin – he wobbles his head. And they said, no he's just lazy in his back and kept on until he was seven months and then I thought, 'darn it' and went to see my own doctor and he sent me to a specialist. The clinic said I was being daft."

Mother of a nine year old daughter:

"That's one grouse I've got – they let me find out for myself. Nobody told me in so many words. I did ask the doctor at the clinic one day why they didn't tell me and he said so many mothers won't accept the fact that their child is mentally handicapped and get in a temper when they are told that he would rather that they found out for themselves. I would much rather have been told that Sheila was mentally handicapped rather than be given fairy tales that she is probably all right."

Sometimes it has not been apparent to the parents and is not formally acknowledged until school time. In the first example, the little girl was a fairly high-grade Down's syndrome, the tenth child in the family and born when the parents were well into middle age.
"We thought that she was only backward; we never dreamed anything like this. We had a letter from the school doctor saying that she was not well enough to go to ordinary school and had to go to the mentally handicapped school. We had never thought of her being mentally handicapped."

Parents of a handicapped boy who had been born to them in their late teens:

"The first that we realised he was mentally handicapped was when it was time for him to go to school. The doctor wrote and said that he was to go to special school."

Occasionally parents had to resort to more clandestine ways of finding out about their child:

"We didn't suspect that anything was wrong; nobody told us. In the end we steamed open a letter from the Educational psychologist - that was how we knew that he was severely mentally handicapped."

"We read 'gargoylism' on the Path. Lab. form she gave us. It frightened the life out of us. I went to the library and read it up."

These comments from the parents, which in some instances were made several years after the actual telling had taken place, show a considerable amount of criticism of the evasions, the crudeness and the delay in giving the information which they still resented strongly. Certainly many parents felt the insensitive way they were told about their child's condition hurt them much more than did the fact that they had a child who was handicapped. They recognised that the handicap was something that could not be changed, and had to be accepted, but they also knew that the way the shattering information is given can always be improved upon. From the comments of these parents the implication is that the telling needs to be done kindly, directly and as soon as possible, and I believe it is right for parents to be critical of those who do not achieve this. I would go further and suggest that professional people should be vigilant so that in what
they do and say they do not injure further people who have received one of life’s hardest knocks.

Although neither I nor these parents would argue that their comments are entirely accurate nor indeed at times justifiable, they are based on strongly felt emotions and as such are worthy of consideration. Interestingly these parents generally seem to be more accepting of the failures of Nature and less tolerant of the shortcomings of their fellow men particularly so when this can be focussed on an individual one. When the latter hurt them it appears to take much longer for the wound to heal and the bitterness keeps erupting and perhaps prevents the scars fading.

**PARENTAL REACTION TO HAVING A HANDICAPPED CHILD**

Some parents talked about non-acceptance of their situation:

"He found Mary very difficult to accept to start with. For many years he didn't tell any of the man about her. Well now they all know and its much nicer. I always tell people but its only recently that he has been able to do that."

"My first husband could not accept Keith and could not accept the responsibility. Within a matter of months we had found out about Keith and that was it. He was afraid of him and could not help."

"My wife has never been able to accept it; she took to drink."

"I feel bitter sometimes. I don't accept it and I don't think we ever will. I'd rather keep it inside me; I don't like talking about it."

At face value other parents seem to take it philosophically in their stride: although there are indications of rationalisation seeking for explanation and understanding in their comments:

"He was born on Friday 13th so what can you expect."

"It's one of those things; you've got to accept it."

"We don't think about it; we've accepted the fact that its not going to improve and we've got to look after them."
"I look at it this way I've got four healthy girls and I'm grateful for it. When I had a handicapped boy it was as if my number had come up and I accepted it."

"Everybody has got a cross to bear; some people are a bit heavier than others. You can always look round and see people worse off."

"It's made us less selfish. We've accepted the fact that we've got to live with a problem."

"I think Nature is a wonderful thing. It's got to go wrong somewhere and it just went wrong on us. I've got two perfectly normal children. I appreciate normality and good health much more."

"I believe in a scientific approach to life and accept that it has happened and we can't do anything about it. This is our life and we don't dwell on it."

The parents who made these sort of comments tended to be the ones who were not unduly critical of the way they had been told of their child's handicap, whereas the parents who recalled very negatively the initial information giving, more frequently made comments revealing their despair and some rejection of the handicapping situation. It would be impossible to link the reactions directly with the way parents were told, for this survey was relying entirely upon the parents' interpretations of the events at that time. A close check of the 60 questionnaires revealed a discernible pattern linking experiences felt to have been bad with continuing negative attitudes to the handicapped child but it may be that it is more directly a result of the parents' personalities and overall approach to life. For some parents no matter how carelessly they had been told and no matter how severely their child was handicapped, they saw this as part of life's pattern for them and rose to meet the challenge with an attitude of acceptance and caring. Inevitably their recollections of the past were mellowed with time but they tended to be only rarely critical of how they were told. On the other hand for some parents the problems created by
having a handicapped child were enormous and they showed very little resilience in coping with them. One suspects that they might have felt overwhelmed by other problems in their lives. These were the parents who gave the most negative accounts of how they were told and tended to be as negative about everything that had happened since.

It is of interest, and not without significance, that the parents in Group 2, the group which had the on-going support of a rather exceptional health visitor, and Group 4 the group which did not feel that they needed a social worker, were the ones who were less critical of what had happened to them. The most negative attitudes and accounts of experiences were found in Group 3, the group of parents who had never had social work help and would have liked to have had it. In fact these parents had had very little professional help from anywhere and this was very evident in some of the comments they made which reflected still the agony of it all:

"What did I do to deserve this? Either I accept the child as he is or become a martyr for the rest of my life."

"I never gave a thought to handicapped children before. If you saw a child you thought poor thing. But now you understand and know what a grind it is and the heartache involved. I was given Jason because I was a selfish person."

"God pays his debts and he pays them without money and he paid one on him (pointing at her husband). He never makes a cruel joke about spastics any more."

"I used to go to church but now it makes me wonder. I felt bitter; what had I done to deserve it. I must have been a wicked woman to have had two. But I push it to the back of my mind and give them what I can. It makes me sad (tears in her eyes) talking about it; it's a lifetime's job not 20 years like the others. You've got to push it back otherwise you couldn't live with it."
In several of these statements there lurks the law of talon, an eye for an eye, a tooth for a tooth, wickedness and suffering are linked together and in their search for meaning this is all the parents can find to help them with their understanding. Religious beliefs were often challenged:

"How can there be a God? The vicar said that he was sent for a reason."

"You can't believe in a God when you've got a handicapped child like mine. He says suffer little children to come unto me. Them that comes to the door, they've got no answer to it."

"It shouldn't have happened to me. Why did it happen to me? Crikey, if there was a God there wouldn't be any disabled children. All children are supposed to be perfect."

"She was christened in hospital and the priest was speaking the word of God and I was thinking is there a God to let this happen to a child like that."

"Oh I've had Jehovah's witnesses come to the door and I've asked them in to look at Patrick. How can there be a God to have children like that?"

Generally having a handicapped child killed off any vestigial religious beliefs within the families, but in one church going family the parents said:

"We're more aware of things and think more. There are many with heavier crosses to bear. Our initial reaction was why did it happen to us but we've grown up with it. We've always been church goers and take the words which are said more seriously."

Another mother who had personally suffered much as a consequence of having a handicapped child said:

"These are the angels - they are going to be meek and pure. Only so many are picked and these are they."

Even a long time after the event there was often a lot of anger around which was frequently aimed at the medical profession.
"I blame the midwife for the way she is. I had all my babies at home and I told her that I had quick deliveries. She came at 8 o'clock and told me that I had a long way to go. Then she took her car in for servicing and caught the bus back and at five past eleven arrived here. I knew that I could have had the baby before then. She delivered Mary with her hat and coat on. Mary was purple; she had to pump fluid out of her ... ."

"The midwife did not get here in time. We rang her at 2 a.m. and she went back to sleep. He arrived at 3.20 a.m. with the cord round his back and nearly blue. The G.P. didn't come until 7 a.m. by which time he was twitching."

"She had a booster for whooping cough so I think it was that; there was nothing wrong with her brain at 5 months."

One mother blamed herself:

"I often wonder if I've done this to Lucy because when I was pregnant I was a goddumb thing. I didn't want to wash or dress; I didn't want another you know."

Other parents spoke about feeling guilty when they were out enjoying a rare evening with friends and then they thought that they should not feel happy when their son could not be at home all the time with them, and had to be in residential care because they could not manage him. Another mother spoke of always feeling guilty when she left her son at the hostel. One mother broke down and wept at the time she told me:

"She's mine and I love her and I wish I could be better and then she would not have to go away all the time. It's awful."

FAMILY STRESS

Parents

Of the total, 28% of the parents felt that their marriage had not been affected by having a handicapped child and 17% recorded an improvement in their relationship. The remaining 55% felt that their relationship had been strained by having a child who was handicapped,
and for 8% of these this was extreme leading to desertion. For 22% it was marked and for 25% it was slight but of significance. Over half of these marriages were reported to be stressed and if the marital relationship is to be regarded as the barometer of family functioning then there is a lot of stress around which may be focussing there, and which is inevitably being felt elsewhere. Some parents were faced with having a handicapped child early in their marriage:

"We'd only been married six months and then I fell for Philip so we didn't have much of a start. Father and son didn't get on. I'd sooner have had Philip on my own. I wish Stan could have been more helpful. If it hadn't been for Philip I would not have stayed, but if Philip hadn't been the way he is it may not have been as bad as it is."

"It was our first, only married a year and the wife was only 17, we have never had a time without Roger."

"We were only married ten months when he was born. It was all new to us; we've always worked together."

Of the smaller proportion who felt that they had been drawn together there were remarks like these:

"It's drawn us together because we have always shared the problem."

"I don't know what I would have done without Cecil. I was so depressed and I've never ever suffered with depression before. It's the first time and I was really down but he helped me through it."

"In some respects it has drawn us closer together, in some respects it has been a source of trouble - emotional strain and physically we are very tired. We'd like another child but making the decision has caused more trouble in the marriage than anything else."

But for many other parents there was considerable stress and strain:

"It has been terrible sometimes, that's why Lucy (the handicapped child) started going away really to let him (the father) spend more time with us. To my knowledge he's not understanding of her enough. He flares up and leaves us for a while; he bashed me up last summer."
"My husband went through a stage when he wouldn't talk about it. We've had many, many rows over William and having any more children. I did have a miscarriage but with the likelihood of other handicapped children there will be no more. If anything happened to William it would split us apart. He has been off with other women."

"Being on my own was more difficult but the father never was any use; he never did anything for the kids."

"At first it was terrible. I used to fly off the handle at the slightest little thing. Fred had to have the patience of Job to put up with me. I got so depressed with all of them and took it out on Fred, the one I shouldn't have took it out on."

"We see each other all day and every day and get fed up with each other; we're getting on each other's nerves. You're satisfied to sit there and watch television and I'm not. I go nowhere; I'm in a rut, same four walls. If he wants anything it's Mum, never Dad. If I'm at the shops he waits till I get back. He knows that he can depend on me. I can't afford to be bad: what will happen if I am, I don't know."

The figures suggest that the marital stress which results from having a handicapped child is high and this is suggested by evidence from the research of Farber. Bernard Farber did some research using a marital integration score for married couples. He compared groups of parents who had a severely retarded child with groups who were similar in all other respects except that they had only able-bodied children. His results showed that parents in the former group had a significantly lower marital integration score than had parents in the second group suggesting that the parents of handicapped children had on average a poorer marital relationship than other couples. The status of Farber's research may be suspect but whatever the reliability of the marital integration score and the problems of getting control groups equal in all respects the indications are that having a handicapped child puts additional stress on a marriage.

Parents readily admitted that there were times when it all got on
"It makes me more patient and I try to grin and bear it. When things get really bad I go and soak in the bath for an hour. My husband was told that I was on the verge of a nervous breakdown but I've never had it yet."

"I smoke more than I should do."

"We often have blinding rows because I have to let off steam."

"I've trained myself to cope. If I get down I take the car out and go for a drive."

"At times I let rip; it's a safety valve."

"Sometimes you explode, you feel you can't go on; you've got to get out and get away."

"I often have screaming sessions in here, I don't know what the neighbours think. If I don't shout I would burst."

"I've got depressed and fed up and I'll ring somebody up and talk."

"It would be so bad that I'd just sit down and cry and then somehow they realised that they would have to be good."

Several parents feel that if they had known what they were in for they could never have faced it. A mother of a ten year old boy whose spina bifida had been operated upon in the era of maximum surgical activity said:

"If I was told now your baby is a spina bifida I'd say 'take him away' I could not see another child going through what he has done. It's the waiting..."

"If I'd known Mark was going to be like this, I'd never have had him."

Many parents dare not look into the future and for those who do that future often seems bleak:

"I take each day as it comes. I dare not think ahead and the more you think about it the worse you get. I thought it could never happen to me."

"As you and they get older it gets harder."

"He'll have to go to hospital in the end. He's getting too much for the wife. It's not that we don't love him but there comes a time when you can't go on."
Two parents in separate families spoke of being very involved and perhaps there are some signs here of hyperpaediafilia; although obviously this is always a subjective interpretation:

"That little maid; she could not live without me because I have done so much for her. She is all dad."

"If I thought that I had something wrong and I knew that I was going to die I'd kill her first. Nobody would be able to replace me."

Many families could not enjoy normal family outings to the beach, picnics on the moors, or going to the swimming pool or the cinema:

"We're keen walkers, outdoor people and we do miss it now that we are restricted by him."

The parents of a ten year old boy with Down's syndrome ruefully explained why they could never again pursue their passion for visiting stately homes. One young son had attempted to wreck priceless antiques and they were shown the exit very quickly. Several parents felt isolated since having a handicapped child:

"Daniel has been a bit of a barrier particularly in my relationship with my brother and his wife. My brother is scared, never even picking him up and then he suddenly stopped coming to see us."

"Our relations can't accept Roy and I can't accept them. Everyone is afraid of Roy. He's getting worse; he's so strong."

"I find it difficult to take him into town because I feel embarrassed by him."

"Having a handicapped child doesn't make it easy to make friends. People are kind; they stop and say hello and how are you, but that's it."

Relatives and friends fear of a handicapped child came out several times and this perhaps supports Margaret Burnett (1973) when she writes of "being able to cope with our own disability in situations when we do not know the rules." We, as members of society, can cope with normality because here the rules are known, but with abnormality we
are in a situation of the unknown.

For many families the problems were aggravated by the unending disturbed nights and loss of sleep which the mother inevitably seemed to have to bear. Comments about this included:

"I never get a night's sleep."

"Night times is our big problem. Norman doesn't sleep. My husband needs his sleep so we make the best we can of it."

"I'm up every night at some stage of the night. He sleeps maybe 2½ hours at a stretch and he kicks his legs all the time then. Doctor says if it gets too much to dose him up with phenergen but that doesn't seem to touch him."

"Paul cries during the night every night. The neighbour has stopped talking to us. We take him in bed with us but he still cries. The sleeping tablets - he's on Mogaden - don't work; he still wakes up."

Parents were asked about any illness of theirs which seemed directly linked with having a handicapped child, and illnesses other than these were not included. Of the mothers, 33% had suffered with illness which they claim resulted from having to look after a handicapped child. Without exception these illnesses were either psychiatric or a chronic back condition. One mother who at the time of the interview was obviously quite ill said that she did not suffer any ill health. A short time afterwards she was admitted to the local psychiatric hospital with a fairly severe breakdown. An example like this may suggest that the figure for illness may be higher than that quoted. Likewise 10% of the fathers had back troubles caused through lifting a heavy child, or they suffered bouts of depression. Many parents were on tranquilizers and anti-depressant drugs. As research evidence it is impossible to infer that there is any correlation between the incidence of illness and having a handicapped child. It is included because that was how it felt to the parents and may be a further
symptom of stress. Also it is a comparison for the evaluation of the experimental group.

**Siblings**

The earlier research of Tizard and Grad (1961), McMichael (1971) and Kew (1975) has produced evidence to suggest that siblings of the handicapped child are very much a group at risk. Children certainly are rivals with each other in bids to secure the time and affection of parents, and aggression to the rival sibling tends to increase in direct proportion to the parental preoccupation with the other child. Inevitably a handicapped child is going to need a lot of parental time and there is little chance for another sibling if he feels resentful of this situation to act out the hostility that this may create.

McMichael's work of 1971 quoted a figure of 21% of the siblings in moderate to severe degree of failure to adjust to the situation of handicap and Kew's figures of 1975 reflect a similar, if slightly higher pattern. However, in these surveys the research was done on families who were in contact with a professional caring agency and were in receipt of help for their ongoing problems. This might be taken to be indicative of either particularly severe problems or the families generally having a lower coping threshold. In this survey only 40% of the families had ever had any contact, and only 22% were currently in contact with a social work agency, a fact not entirely due to neglect by the professionals but an acknowledgement that some families do cope in spite of it all.

Of the total 181 children covered by this survey 65 were handicapped. (Fig. 4). Four families had two young handicapped children and in another there was a 31 year old elder brother, who beyond being acknowledged as being a sibling for the purposes of this section, was elsewhere disregarded because he was an adult. Another mother found
<table>
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<tr>
<th>Size of Family</th>
<th>Number of 'not handicapped'</th>
<th>Number of handicapped</th>
<th>Total</th>
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<tr>
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<tr>
<td>10</td>
<td>9</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>Totals</td>
<td>116</td>
<td>65</td>
<td>181</td>
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Fig. 4.

NUMBER OF HANDICAPPED AND NON-HANDICAPPED CHILDREN IN THE SAMPLE BY SIZE OF FAMILY.
that her diabetic daughter was almost as much trouble as her retarded daughter but the problems do not meet the criteria of this study, since with insulin this daughter's life was to all intents and purposes normal. Eleven handicapped children were only ones but all the rest had siblings and in a few cases one of these was handicapped too. Of this total there was information taken from the parents only of:-

(1) behaviour disorders in 9% of the siblings

(2) disturbed relationships with the peer group in 13% of the siblings

(3) disturbed relationships with the handicapped child in 13% of the siblings.

These categories are overlapping and include the same children and again it should be stressed that it was on parental hearsay and not on empirical evidence none was reported to be severe enough to warrant referral to a Child Guidance clinic. Comparisons must be tentative because the methods of assessment are not similar, but if these figures are looked at alongside those of Kellmer Pringle's National Child Development Study (1966) where 8% of 7 year olds showed signs of emotional disturbance then the indications of the Plymouth survey are much nearer to normality than to the other recorded figures for siblings of handicapped children. Certainly there was evidence of rivalry situations but some appeared to be within the context of what could be regarded as normal healthy sibling relationships. Some of the quotations from the parents may illustrate this.

The father of a 5 year old sister who was a bit jealous of a 3 year old handicapped girl said:

"I walked in and found her smacking her, really smacking her and Penny was crying and when I tackled her about it she said, 'I never hit her she called me a bugger and I'm not having that in this house.' Penny can't even speak!"
Another 12 year old, one of four girls and a younger brother who was handicapped had said:

"The trouble with you Mum is you've got no time for me; it's all Ian."

Brian aged 6½ years had said somewhat ruefully one wet morning:

"I wish I was spastic and then I could go to school in a taxi instead of having to walk."

Occasionally there were descriptions of rather more bizarre happenings within the family which suggest some unusual aspects of sibling relationships. A mother of a 17 year old boy with a mentally handicapped sister of 9 said:

"He often refers to her as the animal and that hurts me a lot; he's very cruel with the things he says, gets very annoyed with the smell of her bowel movement. There was a spell when he did not bring anyone home because he was so embarrassed with her taking all her clothes off and walking around naked half the time."

A mother of two older brothers of a handicapped 8 year old daughter:

"They tie her to a chair while they do something boisterous. She sits there giggling and wetting herself with excitement."

One mother spoke of the situation for her daughter who was three years older than her handicapped brother. Four years later another baby was on the way:

"Pauline put up with a lot of teasing at school; she was called spastic and felt it very deeply. When we were expecting Margaret, Pauline used to pray every night that it was a little girl because you know what is going to be the matter with boys."

THE PROBLEM AND THE RESOURCES

Rearing a handicapped child requires a great deal of time and makes tremendous demands emotionally and physically, and inevitably the burden falls principally upon the mother. Parents need a break
and school at the statutory age and optional playgroup earlier are seen as very important in meeting this need. However parents of the older children frequently spoke of the battle to get a place for the child in school. Several of them said that all the energy they had was needed to bring up their child and did not leave anything surplus to engage in external encounters with the Education Department. The worst situations were concerned with children who had moved into the area and for whom the machinery of allocation to special schools seems to grind exceedingly slowly.

A mother of an 8 year old boy with Down's syndrome:

"We came down from Scotland in September and I had to battle until the following Easter to get him a place at school, although I had let them know that he would be coming. In the end, I wrote to the papers but he had to stay at home until they made a place for him. There should always be school places for these children."

One mother who had lived in the city all her married life said:

"She didn't go to school until she was 6. I wrote to the M.P. I made myself unpopular; I kicked up because I wanted Hazel to go at 5."

Once the children had their places the parents were almost without exception most appreciative of the educational facilities provided. The survey revealed only one instance of a child not attending special school due to parental conflict with the Education Department.

Another father was very cynical overall about education for his step-son saying:

"School is somewhere to throw them, get rid of them for a day. They don't teach them anything."

His wife retorted:

"You couldn't teach Kevin anything because he couldn't learn anything ... ."

to which her husband replied:
"It's because he can't speak. The speech therapist ought to be teaching him to speak and then he could learn."

The need for speech therapy often came up and this reflects parents' frustrations in not having verbal communication with their child. If only the child could tell them what was wrong, they were sure, would be that much easier. Likewise the missing two-way response which sustains relationships creates frustration:

"You're doing so much for Pam and not getting anything in return."

On the positive side one father said:

"I think we are very, very lucky. It's all right as long as she has got her sentences."

Playgroups are seen as being of great importance by many of the parents, especially the specialised ones of Dr. Barnardos and Mill Ford School. In response to a question concerning the need for playgroups the following proportions of parents expressed the view that playgroups were:

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<th>Not necessary</th>
<th>Important</th>
<th>Essential</th>
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<tr>
<td>14%</td>
<td>31%</td>
<td>55%</td>
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If 86% of the parents rate the need for playgroups so high then allocation of resources to this end should continue to be made. Any tentative plans which Dr. Barnardos had at that stage for withdrawing the playgroup service need to be reviewed again in the light of the parents' views on this provision.

Some of the older children had had experience in ordinary playgroups in the days before the specialist ones came into existence. Comments by the parents included the following ones:

"He was expelled from his first school at the age of two!"

"They couldn't control him in the playgroup so he left after two days."
"Most of the mothers knew that she was handicapped and I knew she was troublesome. One day she bit another child and one of the mothers said a child like that should never be here with normal children. I shall never forget that woman saying that. I never took her there again."

One young child's parents were worried about her having to mix with backward children. She was just about holding her own in an ordinary playgroup and they did not want her to go to a special one because:

"she would be with other backward children and would pick up bad habits like running around with her tongue hanging out; silly habits from silly children."

Although the felt need for playgroups came out so strongly there was an interesting contrast occurring in the following proportions of parents expressing a view on short term hostel care:

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<th>Important</th>
<th>Essential</th>
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<tbody>
<tr>
<td>Short term hostel care</td>
<td>45%</td>
<td>27%</td>
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The parents who saw this as being essential tended to be those with difficult to manage handicapped children who thought their lives would become well nigh intolerable without it. For 27% of the parents it was important to have such a provision and in emergencies they would be glad to use it. A much larger proportion (45%) considered hostel provision to be unnecessary and would never leave a child of theirs in such a place. When pressed to consider the unexpected emergency the response was that they could not think of any situation that could not be met within the family circle. There is still a very real antipathy to "putting a child away" and associated with this whole area is considerable stigma, even when it is temporary and local. Parents were asked about their use of parent support groups and of counselling and information giving:
Many of the parents who said that they thought the groups were not necessary attributed this to the fact that they found it depressing to be with other parents who were in the same situation as themselves. One of the mothers who was bringing up her three children single-handed said:

"I don't go to any parent associations. I couldn't face people saying this is what I went through with my child and then I'd know I'd got it to go through. I'll worry in six years time but just now I'll take each day as it comes."

Most of the parents said that if they did go out it was to be with normal people so that they could forget handicap rather than have to share it. Of those parents who did go to the groups many said they did so in case they heard of anything good that was going rather than for gaining emotional support from parents who were similarly placed. Certainly the need for information - giving ranks high compared with some of the other possible categories of need with 66% believing this to be important and 30% as essential. But again there is an element of 'getting to know what's going' as an important feature in this. As one mother said:

"Things don't hurt like they used to but it's become a question of getting all you can and fighting for what you can have."

Parents were asked how they rated their practical and financial situation. Of the total 72% felt that their financial circumstances were just about adequate, but one father said:
"We're only just able to cope with the expense of having Roy at home. He went through eighteen light bulbs in four days and we had broken crockery and broken glass. After he set fire to the place the insurance company won't take anymore on. Without him we'd be in a higher bracket and have a better standard of living."

For 17% of the parents they claimed it to be a hard struggle financially and they felt as if they were barely keeping their noses above water. Shortage of material resources was proving to be a very large additional stress. Some of the 72% who recorded their situation as just adequate did add that unless they had had the weekly Attendance Allowance and grants from the Joseph Rowntree Trust they would not be in this category. This immediately indicates that the costs of rearing a handicapped child are likely to be more than involved with normal children.

At a time of spiralling inflation financial help may be regarded as being more essential than it would have been had the cost of living remained fairly steady but no one would deny that in rearing a handicapped child there is extra expense that would not occur with a normal child. The parents rated their needs as follows:

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<th>Not necessary</th>
<th>Important</th>
<th>Essential</th>
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<tr>
<td>Financial help</td>
<td>6%</td>
<td>30%</td>
<td>64%</td>
</tr>
<tr>
<td>Help with aids and appliances</td>
<td>10%</td>
<td>46%</td>
<td>44%</td>
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Likewise with aids and appliances. In the south west where the annual rainfall is well above the national average, the mountain of nappies and bedding which continues to pile up from an incontinent child makes a washing machine and a tumble drier desirable. The tumble drier was the most frequently mentioned piece of equipment to make life bearable, followed next by the telephone.

Although various resources are available to help parents with a handicapped child some families feel that they have had to battle for
<table>
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<tr>
<th>Resource</th>
<th>Not Necessary</th>
<th>Important</th>
<th>Essential</th>
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<tr>
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<td>55</td>
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<tr>
<td>Hostel care for short stay relief</td>
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</tr>
<tr>
<td>Parent Support Groups</td>
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<td>2</td>
</tr>
<tr>
<td>Counselling and information giving</td>
<td>5</td>
<td>65</td>
<td>30</td>
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</table>

**FIGURE 5.**

Opinion of Parents in the Contrast Group of the major resources available to families with a handicapped child.
these. At the time of doing the interviews the first children to be
allocated the Attendance Allowance (Statutory payment to families with
a handicapped member needing constant care. Two rates are payable, the
lower for only day care, and the higher for day and night care.) were
coming up for review and several had had their full rate reduced to
the lower one. Parents were angry. If anything the handicapped child
was more difficult to handle and many regarded the Attendance Allowance
as the sugar on the bitter pill of handicap which the family had had to
take. At an earlier date some parents had had to enlist the help of
their M.P. to get this Allowance and having had previous experience of
how to do battle they set forth to fight again, but were maddened by
the necessity of having to do this. Many parents had missed out com-
pletely on resources that were theirs by right.

"Nobody tells you where to get anything until
it's too late."

"I found out about the Attendance Allowance
from the man who came to repair my meter.
Mary was 7 and I knew nothing about it."

"The lady in the Post Office told me when I
went in to get stamps. I didn't want to apply
but she said don't be silly... ."

"My husband was off sick so I went to the
Social Security and they told me about Rowntree.
I got a tumble drier and a washing machine
but I can't use them because I've nowhere to
plumb them in and so I'm hoping for a council
house. The lady on the school bus told me about
the Attendance Allowance."

Of the mothers who were not working 51% felt they were prevented
from doing so by having a handicapped child. Of those who were working
(and in most cases it had to be part-time) 27% thought that their
work performance was affected through having a handicapped child.
Factors like lack of concentration, needing to take a lot of time
off work, having to take less well paid jobs because the hours would
fit in with their having to meet the school bus were all mentioned. 85% of the fathers were working at the time of the survey and another 10%, although at that time without a job had worked fairly recently. Overall 20% thought that their work performance was affected by having a handicapped child. There were a few positive features in this. One General Practitioner whose child had Down's syndrome said:

"It has helped me to be more tolerant of people with a handicap and less tolerant of those with nothing very much wrong."

Generally the inevitable loss of time at work had made for difficulties with some employers and a few naval fathers had had to leave the service life which they said they loved to be shore-based so that they could help their wives to cope. One father had been a salesman but he was so worried about things at home that he found he could not sell anything to anyone anymore. As the sales dropped off so did the money and he had to take on a labouring job which did not require much concentration. Another father who had been at sea said:

"I was a merchant seaman. I used to nearly crack up thinking about them when I was at sea. There's many a night I've laid on my bed and cried about Penny. It put me right off ships; I wrapped it up and came home."

A slightly higher proportion of the mothers (50%) compared with 42% of the fathers felt that their social life was affected. This may reflect a situation of wives being housebound more than their working husbands. Obviously social needs vary greatly and many parents said that they had never been ones for leaving their own firesides, but for many there was not even the chance to think about the possibility. The group as a whole tended to be a fairly static population and only two of the families had lived in Plymouth for less than two years. Of the total 48 families had lived in the area for more than five years and of these 26 had been there for more than ten years. This could
suggest that having a handicapped child limits mobility. Life does have to become very geared to the needs of the child, as one father put it:

"It's been one long concentrated round of hospitals, doctors, appliance fittings and physiotherapy."

It would be a gigantic upheaval to re-establish this process in another environment. Certainly most of the families who had moved to Plymouth since having a handicapped child spoke well of the services compared to some of those that they had experienced elsewhere.

A variety of resources are required to help these families and not all are valued equally by everyone. The dislike shown by some parents of support groups and short stay hostels was in contrast to the widespread high regard for the play group and nursery provision, and shows that uniformity of approach and blanket provision may not suit everyone so a range of services is needed. However, in times of stringent economy when a wide range of necessary services is not made available the parents views are important in determining priorities.

SOCIAL WORK

This was a project concerned with social work intervention therefore a major section of the questionnaire was designed to find out the extent of social work involvement with these families. There were replies from 118 parents although in 20 cases it was one parent speaking for a spouse who was not present at the interview and saying in effect, that to the best of their knowledge this was the situation.

Of these parents:

70 had never had any contact with a social worker.

48 had had some contact.
Table to show the number of mothers and fathers in the sub groups of the Contrast Group who recalled some contact with a social worker.

<table>
<thead>
<tr>
<th>Group</th>
<th>Mothers</th>
<th>Fathers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>1</td>
<td>15</td>
<td>-</td>
</tr>
<tr>
<td>2</td>
<td>3</td>
<td>12</td>
</tr>
<tr>
<td>3</td>
<td>8</td>
<td>7</td>
</tr>
<tr>
<td>4</td>
<td>4</td>
<td>11</td>
</tr>
<tr>
<td>Total</td>
<td>30</td>
<td>30</td>
</tr>
</tbody>
</table>

**FIGURE 6.**
This reveals that exactly half of the mothers recall having had some contact with a social worker and half did not. Obviously all the parents in the first group which covered a sample of families with a child attending the Dr. Barnardos nursery had had contact because it was the policy of the Barnardo project that the attached social worker made routine visits. Of the total sample 18 fathers had contact with a social worker and 14 of these were in Group 1. Of the remaining 45 fathers only 4 recalled having ever been in touch with a social worker and none of these was in Group 4.

These figures might suggest that fathers needs are not always recognised or conversely since there appears to be still a stigma attached to some areas of social work fathers may be less receptive to social work intervention. There could be quite a practical interpretation if the social worker visited during conventional working hours when the father would not be at home. This is a factor which might have implications in the subsequent work for greater deliberate effort to involve fathers. Although mothers appeared to bear the brunt of the burden created by the handicap there was evidence that many fathers were very involved in sharing the task of the child's upbringing and it is possible that they could have felt unsupported in this.

Although subgroups 3 and 4 were established by reference to the West Devon Mental Handicap survey and were based upon the replies about not having had contact with a social worker and whether or not they would have wished to, in fact, 12 of the mothers and 4 of the fathers in my survey recorded that they had had contact. Some of the confusion seems to have stemmed from the interviewers in the West Devon survey themselves not being clear about the differences between a health visitor and a social worker, and for some parents a single visit from a social worker was not regarded as a contact. This must
to some extent make these figures suspect but of the total of 48 parents who recorded having had contact:

12 had had a single meeting.
36 had had more than one meeting.

Of the 36, ten had now ceased to have involvement but 26 were currently in contact and of these 19 were seeing the Dr. Barnardos social worker.

In Group 1 eight of the families who had had the Dr. Barnardo's social worker were not very impressed, whereas five thought the help had been good. In the three years since St. Nicholas nursery had been opened there had been four social workers successively attached to the unit and this had not helped in establishing an on-going supportive service. This contrasted with the eight years which the specialist health visitor had been in post and all who mentioned her work held it in high esteem. Although they were not specifically asked, five families in this group spoke spontaneously of how much they had appreciated this health visitor. Only three families thought they had had contact with a Local Authority social worker and of these two were not impressed and one thought that the service was reasonable.

The second group had been supported almost entirely by the specialist health visitor and only one family said anything that could have been regarded as mildly critical, and that was to state that although she was a pleasant person they did not need her to call. For the rest it was genuine enthusiasm for the help she had given them saying that 'she was worth her weight in gold', was 'a super person' and 'we just could not have got through without her'. The majority of these parents did not know what social workers did and certainly would have had difficulty in differentiating what they had received from this health visitor from what it was that social workers are
said to do. Some had ideas about social workers 'listening' or 'advising' or 'helping' but there was a general scepticism that they had enough specialist knowledge about handicapping conditions which was probably valid. Three of these families had had visits from Local Authority social workers, but for two they had been once only and the third family had had two visits by a 'nice person' but nothing more was recalled.

Group 3 included two families who gave good reports of the brief contact they had had with the Local Authority social worker but another six mothers and a father said they had only seen a social worker once and there was no ongoing care. They felt that these 'occasional social workers' did not know the resources nor understand the problems. Another repeated comment was on the youthfulness of the social workers which was seen as a grave disadvantage. Again three families in this group recalled somewhat nostalgically their appreciation of the health visitor.

Finally, in Group 4 where only four mothers had seen a social worker once or twice and none of the fathers remembered ever having done so, general ignorance of the social work task prevailed. Most parents said they did not know what social workers did so it is understandable that they did not feel a need to see one.

I asked all the parents what was their impression of what a social worker did; their replies are shown in Figure 7. The question was open ended (See Questionnaire A, question 15 in the appendix) with no prepared categories and yet the answers did lead to some marked groupings. Although contemporary social work practice does not claim to be primarily concerned with providing material aid it was a very important aspect of the profession's early development, and in the case of the early hospital almoners, the price they had to pay for access to the
Analysis of the replies by parents in the Contrast Group to question on social worker's activities.

<table>
<thead>
<tr>
<th>Type of reply</th>
<th>No. of replies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don't know</td>
<td>25</td>
</tr>
<tr>
<td>Resources</td>
<td>13</td>
</tr>
<tr>
<td>Do nothing</td>
<td>8</td>
</tr>
<tr>
<td>Help</td>
<td>6</td>
</tr>
<tr>
<td>Deal with problems</td>
<td>5</td>
</tr>
<tr>
<td>Liaise</td>
<td>5</td>
</tr>
<tr>
<td>Visit people</td>
<td>4</td>
</tr>
<tr>
<td>Listen</td>
<td>3</td>
</tr>
<tr>
<td>Do a good job but don't know what</td>
<td>3</td>
</tr>
<tr>
<td>Advise</td>
<td>2</td>
</tr>
<tr>
<td>Support</td>
<td>1</td>
</tr>
<tr>
<td>Change jobs a lot</td>
<td>1</td>
</tr>
</tbody>
</table>

FIGURE 7.
patients. It is interesting that resources ranks high in the list and that only one family mentioned support which perhaps would be rated as a key task by the social workers themselves.

There was quite a wide ranging view of the social work task but in by far the largest proportion of the parents' comments negative aspects seem to predominate.

"They tell you what you can get; somebody to sit down and talk to about your problems."

"Comes and chats and when she goes away I feel better. They know the services to contact if you require anything and give support."

"Person who listens - do what they can if they can: go back to high ups for decisions."

"Somebody to talk to but one step out of line and it goes on paper. Feel they have always got an eye on you ..."

"Not sure what they do other than waste the taxpayers money."

"Sometimes I get the impression that she does not know what she is there for. She seems to try to talk about everything and anything. There is a need to talk but with an older, more experienced one."

"Basically they try to do a good job, but they have lots of faults. Young people with not much experience of life, unmarried, no children, how can they know what it is like? I will never forget one, a first class bitch and now she is head of a children's section in London. What did she ever know about having kids?"

"I'm afraid I haven't got much time for social workers. Most of them who come are young, unmarried bits of stuff who know nothing at all about kids. They read it all from books and are not practical."

The preference for an older social worker came out many times in this survey. To several of the parents age appeared to be correlated with wisdom, caring and understanding, but obviously these should be attributes of any professionally qualified social worker regardless of age. It might be that there was something less
tangible that the parents felt but could not verbalise. In any relationship the quality of it is very much dependent upon the two way interaction between the persons concerned. Many of the handi capped children are incapable of showing any emotional response to their parents and it becomes a one way process of the parent giving and receiving virtually nothing in return. It could be argued that to sustain this one way relationship parents need to be given warmth and caring in other significant relationships. It might even be that they have a need to be 'parented' themselves to keep functioning in this abnormal situation of almost complete one sided giving. An older social worker may be seen to be fulfilling this particular need and because it entails an excessively long period of professional depend­ency it might need a worker with long experience to carry this role.

Some parents spoke from personal experience, others from having no experience, but some of their comments were strongly worded and spoken with considerable feeling:

"Nobody's ever come and said, 'Hello, I'm the social worker' but then I'd really rather they didn't thank you. We don't really need social workers and it would get up my nose if they came and tried to work on me."

"When you've first had a baby the social worker comes along to sum up the home situation, is it adequate, is it clean, is the mother capable..."

"A social worker deals with inadequate people who cannot cope with day to day average life: a normal person doesn't need a social worker."

"... float around and do nothing. We haven't had personal experience and we don't really know but our impression is that they are a bit rigid and arrogant."

"Nothing, absolutely bloody nothing."
"Somebody came from the hospital - a young girl about 19 - came every week from April to July and had a cup of tea. I had no confidence in her at all and couldn't have gone to her with any problem I had. But she seemed to enjoy her visits ... I was glad when she went back to college though."

It was a fairly dismal testimony to the social work profession and perhaps some of the dissatisfaction with the social workers themselves was that they were sharing the field with a specialised and seemingly extremely competent health visitor who had skills far beyond her own professional training. For example, she told me that only rarely did the mothers of handicapped children ask her for advice on feeding problems which were the regular queries to her colleagues. The problems with which she had to try to help were to do with stresses created by the handicap and very frequently these were marital difficulties. The mothers group at St. Nicholas nursery with whom I did the pilot survey told me that they preferred to take their anxieties to the health visitor in preference to anyone else. Intuitively and repeatedly this health visitor met the needs of these families by working well beyond the traditional boundaries of her role, often because there was nobody else offering help. She was a warm, concerned person in her late thirties. Just as I was finishing the survey she completed eight years in the post and left to be married. Until then she had been fairly free of family ties and made herself readily available. In times of crisis she would go and spend a whole day with a family supporting them through the worst of it; she would spend long hours on the telephone when distressed parents rang her late at night. She would go to the funeral when a handicapped child died. Her method of working to a model of maximum availability at times of greatest need might have implications for the subsequent professional involvement in working with the experimental group.
The survey revealed quite considerable needs particularly at the time when parents were first told about their child's handicap, and then subsequently when family stress would build up as a result of having that handicapped member. It would seem to be a very appropriate area for social work practice and yet clearly it was not being very successful.

Several comments might be made about this. It is said that social work training hitherto has not generally included the high degree of specialisation that working with the families of handicapped children requires, hence the need for the C.C.E.T.S.W. Report of a Working Party in Training for Social Work with Handicapped People (1974). Not only did this Report review a dearth of professional expertise in this area of work, it also implied that unless a student in training had at least one case where a person was handicapped he would leave his course without any knowledge in this field.

But this suggestion in itself is trying to perpetuate an approach in social work which is somewhat unrealistic. It is saying that to be effective the worker needs to have the detailed knowledge of handicap, their effects, what services are available, and appropriate. Such a degree of specialisation would inevitably put the worker out on a limb and reduce the effectiveness of intervention in other areas. The individual social worker only needs to know where to go for that information. That, of course, assumes that the information is readily available and in the early stages the social work profession may have to contribute to the information stockpiling in the relevant quarters.

The comments from these parents suggested that the theoretical underpinning to the practice might well have been lacking but that is something which goes beyond information availability. A social worker
needs to be equipped with models for intervention in situations which are stressful, whether they are created by handicap, by old age or even by deviancy. Forearmed with this sort of expertise a worker can intervene with confidence in the wide range of problems which inevitably come to the social work departments. This is an argument, not for an increased specialisation in knowledge of a client group, but for specialisation in a range of versatile models of social work intervention.

It is also frequently argued that one factor which could adversely affect the acquisition of particular skills in one specialised area of social work practice is the somewhat peculiar career structure of the profession. Once a basic grade social worker is promoted to senior level he loses direct contact with the client. This contrasts with the medical consultant who, at the top of his profession, is still seeing the most complex problems within his speciality. It also contributes to what the client perceives as a rapid turnover in social work staff (for example, one of the comments from the survey was to do with social workers changing jobs a lot) whereas their relationship with the consultant, and possibly also the health visitor, is over a much longer period of time.

All this may be true, but it denies the very opportunity that an Integrated Approach offers with regard to the use of middle management. This is a resource in itself. If the social worker is recognised as being a liaising person, a go-between, and a link between resource and need then the expertise of a senior is readily available to a client.

To work effectively in this field a social worker needs also to be able to straddle the educational, medical and social components more widely than the social work profession normally requires, even of
those working within a hospital setting. The comments from the parents in the survey suggest that the social workers were ill equipped to tackle the problem being created by the handicap. For example, there were references to the worker not seeming to know why she was there. There might have been some evidence to suggest that because the limited social work contact which many of the parents experienced was so piecemeal it could not be felt as being effective. If this was so, it may well link with Wolkon's research findings (1972) on crisis theory which demonstrated that the earlier the intervention the more effective it is felt to be. The social workers seemed to have been going in after the crisis created either by having been told of the condition or by subsequent family stress, and therefore missing the moments when parents may have been more amenable to assistance. In contrast to health visiting where all babies are potential cases until they are 5 years old, social work cases are only established if need is known and offered help accepted. Many potential cases inevitably slip the net and examples of these are in subgroup 3 where parents stated that they would have liked to have been offered social work help. This suggested for the second part of the research study that a more effective referral system needed to be established. It was also beholden upon that social worker in addition to the expected professional intervention skills to be thoroughly knowledgeable about all aspects of the handicapping condition and the system of services pertaining to that handicapped person, because the information as yet, did not appear to be clearly located.

DISCUSSION

The main aim of this survey was to learn from a sample of parents about their assessment of the services which they had or had not received as families with a handicapped child. Because the sample was
designed to include families which had managed without very much support, as well as those which had actively sought it, it is hoped that a balanced perception of the situation is presented. However it is important to stress that this is a subjective evaluation of the situation entirely by the consumer of the service and no investigation of the professional's viewpoint was carried out. It might be argued that little confidence can be placed in the validity of some of the parents' comments because their strong feelings would distort their accuracy. But equally, it can be argued that feelings are facts, and if these are strongly held then they are symptomatic of equally strong causative factors. The design of the questionnaire was to give a certain amount of structure to the areas to be covered, but the questions were fairly open-ended so that the parents could determine how much information they wished to give. It may be that the most verbose were the ones with a grievance so the overall result of the survey findings is skewed more negatively. Perhaps parents find it easier to be critical of rather than to praise what had happened, and this certainly seemed to be the case with regard to the social work intervention.

There have been studies such as those of Sainsbury (1975), Mayer and Timms (1970) and Baker et al (1977), Thoburn (1980) which have highlighted the problems of assessing the effectiveness of social work and other researchers, Goldberg (1970), Mayer and Timms (1970), R.N. Timms (1977) have urged that the client opinion be evaluated. Rita and Noel Timms, (1977) (p.75) write that:-

"Social workers are deeply involved in the area of planning with people so that they can better meet their needs, attain their goals, serve their interests. In this kind of enterprise seeking consumer opinion is not a frill, not a public relations exercise, it is the heart of the matter."
Goldberg and Fruin (1976 p.8) suggest that "Studies of client attitudes and satisfactions could help to make social work more relevant and useful to clients". So it is in accord with the philosophies of these writers that this survey was designed and executed. There is no claim of any rigorous and exact measurement of the incidence of the parents’ opinions. The information given is qualitative rather than quantitative and was collected from parents who, either had not experienced much in the way of services or, who had been consumers of the services within the city, and in some cases elsewhere in the country.

An analysis of the data collected from the parents perhaps focussed most clearly around three areas which had implications for future practice. It is already well documented that the telling of parents must be done with great sensitivity and skill (D'Arcy (1968), McAndrew (1976), Kew (1976) ) and this is further reinforced by many comments from this group of parents about how they were handled at this stage. They thought that their attitude to the child and the handicap was considerably affected by the experience of being told. The message from these parents was that the telling should be done as early as possible with both parents together and with plenty of time available for talking about it.

It is to be expected that there will be a lot of stress within families created by having a handicapped member. This stress can be partially alleviated by the availability of a smoothly operating, well co-ordinated system of services. It is the hitches which may be either a major one of a delay in a school admission, or a minor one of a pile of wet washing on a rainy day, which strain a stressful situation to breaking point. In listening to some of the parents grievances it is possible to understand why there might have been these seeming delays in the bureaucratic procedures, and the reasons might have been very
sound within the administrative context. But the process might need
to be more personalised. There might be a role for the social workers
to ensure that the various services do work together and are amenable
to changes in the pace of operations should the occasion warrant it.
This is not to deny that there is a place for appropriately channelled
fighting for help which for some parents is important to their identity
and personality. But for those who are depressed and exhausted there
should never have to be a battle to achieve that to which they are
entitled.

The third area is to do with priorities and involving parents in
decisions about these. During the playing back of the tapes of these
interviews, I recorded several times unscheduled (in the sense that
they were not direct responses to a question asked, but part of the flow
of conversation stemming from other issues) comments about things which
had happened which the parents had found particularly helpful. Several
times these were references to the unexpected grant which the family
had received from the Joseph Rowntree Family Fund which had enabled
them to replace their worn out washing machine with a new automatic one
or even change their ancient car for a newer and more reliable one.
Nobody said that to have a caring contact with a key person skilled in
dealing with handicap was the most helpful thing to have happened to
them. Obviously a material aid is a more tangible thing to mention,
but because it was not specifically mentioned, it does not necessarily
imply that some parents did not benefit from this, the less tangible
type of help. But it does have implications for the future planning of
services.

As an example of this 45% of the parents recorded that they did
not consider a short term hostel type of care to be necessary (p.72)
This was at a time when a short term hostel had been established in
Plymouth where handicapped children may be admitted for a short time to give parents a break. At the time of doing the survey the hostel was very newly established and experiencing some teething troubles which soon afterwards were to be resolved. This might have affected the parents thinking, but when pressed to explain why they did not think this was a particularly valuable service they made comments about the fact that if there was money to be spent they could think of better ways of spending it. As an example of 'a better way' more than one parent said that to have a telephone installed and perhaps even the rental paid for would have helped them. One mother described how far she had to run to the public telephone kiosk when her handicapped child was ill. She had to leave him alone in the house with her other youngster knowing that this was risky, and when she got to the telephone often she would find it vandalised and out of order.

If as the Court Report (1976) suggests we include parents in the assessment, decision-making and management team of services for the handicapped it is more likely that the limited resources will be allocated to where they have maximum effect. Those who are external to the problem may not perceive need in the same way as those who are daily dealing with it. In this situation this means the parents and since the ethos of this project is to focus upon the consumer viewpoint, it is important to record that the parents have a wish to be involved in the decision making with regard to the services for handicapped children and their families.

The emergence of these three areas of need which parents earmarked as possibilities for improvement, i.e.
1) more sensitive telling of parents that their child is handicapped,
2) a minimizing of stress—especially in relation to obtaining goods or service,
3) greater parental involvement in decision making about the allocation of services and other resources indicated appropriate ways for social work intervention with the Experimental Group, and designated fairly clearly what the social work 'treatment' should be.

It was clear that if these three areas were to be tackled then the social work intervention would have to be with a wider circle of people than just the handicapped child and his family. Changes and modifications to attitudes and practice would have to be achieved with several key persons involved in providing services for these families, in particular, the medical and educational ones.

The interviews themselves created considerable interest amongst many of the parents. As the handicapped is an easily definable group they do tend to be a target for researchers in several disciplines. I did not want the gathering of information to be a one way thing, so when I had completed the analysis of the data I sent each family a copy of a short paper containing the salient points which had emerged. Although in the covering letter I invited them to comment further if they so wished, none did so. This might indicate a lack of interest, an unprovocative paper or parents not having time to do anything that they did not need to do in their very exhausting days. Likewise, although I sent copies to all the head teachers who had spent time showing me round their schools, only one acknowledged having received it and said she had sent a copy to her head office because she had found it so interesting. The same reasons for the lack of response as those proffered for the parents might again be applied to the teachers. An additional one might be added and that is to do with not being particularly interested in what the parents have to say. Overall the lack of response suggested to the researcher that the process of achieving change might be more difficult than had earlier been anticipated.
CHAPTER 4

Establishing the Experimental Group.
"Between the idea and the reality falls the shadow."


INTRODUCTION

Part of the academic culture is that knowledge has value for its own sake. How that knowledge is acquired raises certain ethical issues in social experiments and this is particularly important in social work where confidentiality and respect for an individual's self-determination are vital components of the practice. In setting up an experimental group to take the survey findings further it was important to satisfy myself that it was an experiment in which there would be no harm done but only differential levels of benefit provided to those families involved. Likewise if there were to be any handicapped children who, for whatever reasons, were not referred specifically to me it was important that their families still had the option of a social work service. If they were to be seen by a colleague there was likely to be a variation in the timing of the social work intervention because an essential aspect of this experiment was very early involvement, and this was not necessarily believed in by the other social workers. Similarly, there may well be less of a multi-disciplinary approach for those families which fell outside the experiment, but they were in no way at risk through not being participants. There was no known evidence at that stage to support early or later intervention as the more effective social work practice.

In the design and plan for collecting data it was vital that the privacy of the families involved was respected as much as possible. This was one of the overriding factors in the decision that only a lone researcher should be involved in all aspects of the project thereby ensuring that this privacy remained protected as time passed. In an
attempt to develop procedures to maintain the academic credibility and fairness of the experiment as it went along, in all my dealings with those involved with the research it was important for my social work conscience to be clear.

It could be argued that methodologically it would be unrealistic for one person to attempt to do all three things, i.e. to set up the experimental group of clients, to be the social worker involved in working directly with them and then to be the research worker assessing the work done and in some respects it was not ideal. In answer to this I would argue that to really understand a system, a problem, an area of practice, it is vital to be part of it. To be an onlooker, an outsider monitoring the action of others does not give quite the same degree of feel and understanding even if it does give a lack of bias. I believe we need to carry into our social work research an aspect of practice which may be getting lost in the stampede away from casework and that is the concept of continuity of care. Just as a person needs to develop a relationship of trust with a counsellor and real sharing can only take place very often within the context of a secure one-to-one relationship, so too will a person only be able to share precious or threatening experiences within the context of such security with the researcher.

The delicacy of the subject matter would have made it difficult for a stranger, a fact to be substantiated by several parents saying that it was only because it was somebody they knew and with whom they felt comfortable that they were able to respond to my eventual request that they answer a questionnaire form about their experiences. In contrast to the survey of the original group where I was a complete stranger to most of the couples and where the participation was 79% of the total requested, the final survey of this experimental group
had a 97% participation rate. The only parents missing were a couple with whom we had only a very short contact and who had subsequently moved to the Midlands. Furthermore it was the researcher and the parents evaluating an experience from a shared base, in the sense that they had both participated and were questioning this together that was to produce the richness of material.

Perhaps in the original survey there was a tendency for parents in their distress to latch on much more to the negative aspects of their experiences because this is a way that people deal with their feelings. In the follow up of the experimental group they appeared to present a more balanced picture in that criticism of what was done were offset by comments about helpful actions too. In no way was my presence to bring forth only praise and positives. Parents were able to criticize and explain about the bad aspects as well as the good. The fact that several of the figures in the follow up of the experimental group showed similar patterns to those discernible in the original survey must to some extent make plausible the continuity of one researcher whose way of asking the questions is likely to be fairly standard throughout the survey.

**THE APPROACH TO THE EXPERIMENTAL STUDY**

For one year I was attached full time to the social work department at Freedom Fields Hospital taking referrals of any newly born or recently diagnosed child who was thought to be handicapped, and where necessary, I continued working with these families on a part time basis for a second year. Although it was known to the hospital staff that I was collecting research data, to the parents I was the social worker who specialised in the problems of handicapped children. In line with the falling birth rate, improvements in amniocentesis testing for foetal abnormalities and genetic counselling, the number of handicapped
children being born is dropping and there were fewer children confirmed as being handicapped in that year compared with previous years. This downward trend in the numbers had been apparent in the records of the health visitor for handicapped children, where there had been a very marked decrease in the total referred to her between the years 1973 and 1974. Up to, and including 1973 she had had at least twenty new referrals each year. In 1974 this fell to seven, in 1975 it was ten and in 1976 it was only five. These were, of course, children under the age of five and I was taking a greater age range to include younger school age children in my sample. From a research point of view this fall in numbers was disappointing because it meant that the final sample was smaller than had been hoped for, and partly because of this I did take older children than I had originally intended. From every other point of view the fall in numbers is splendid!

The work flow was not such that it would warrant a full time specialist worker in normal circumstances, but it did enable me to be readily available. When I was not in hospital I encouraged my medical colleagues to contact me at home any time during the day or night or at the weekend, and apart from taking three weeks holiday during the twelve months I was 'on call' for referrals and discussion at all times.

The plan was that whenever a baby was born, or a child examined, and there was the possibility, no matter how slight, of there being a medical situation which could cause a handicapping condition, the doctor concerned would contact me either in the hospital or at home. It was important for the contact not to be delayed until normally recognised working hours but for it to be as soon as there was any suspicion of abnormality even if this was during the night. Obviously it would take time for the new way of working to be
established which was to call the social worker in at the very beginning and in every situation.

Initially, there was some apprehension, and even ambivalence, from the social workers about my attachment which had been agreed by the Principal Medical Social Worker and the consultants. Although there was enthusiasm for having an additional worker there was concern that I might be creaming off the most interesting cases. This was further aggravated by the already established linking of the paediatric social workers to respective consultants, thereby having created a way of working with which they were all familiar. My presence was cutting across the procedures on two scores, one being that I would work to all the consultants and the other being that I would take only certain cases. My earlier involvement with the department had been as a visiting tutor and one of the social workers was a former student, although not a personal tutee. To some extent this role tended to stay with me although I happily shared the students' room, filing cabinet and telephone. The only concession I had was that a secretary typed my case recording whereas the students had to do theirs in long hand. It was extra work for the secretaries who went out of their way to be helpful and facilitate a smoothly running research project. In the second year in particular when I was less frequently in the hospital they were most skilled at deciding when it was necessary to contact me and then in locating me. As time went by everybody settled with the situation and goodwill all round made it work, although somewhat guardedly on occasions.

It is already well documented that the telling of parents must be done with great sensitivity and skill as was mentioned in Chapter 3. The comments about being told of their child's handicap from the parents in the Contrast Group made links between the way they had been handled at
This stage and the attitude they subsequently were to adopt towards their child and to the handicap itself. The message which came out so clearly was that the telling should be done with honesty as early as possible, with both parents together and with plenty of time available for talking about it. A leader in a recent British Medical Journal states:—

"Telling the mother and the father is a horrid task, and however sympathetically done there is a feeling of incompetence. The essential motivation of medicine is to relieve suffering and here is a denial of that possibility. The response of all is usually to withdraw and not communicate, the well known phenomena of rejection. Often the persons most affected emotionally are unwittingly ignored."

As well as acknowledging that it is a "horrid task", implicit in this quotation is the need for additional expertise; no one person can have all the skills and knowledge necessary. The survey findings indicated very clearly that the actual telling of parents needed to be improved upon and it could be that by developing social work skills in this area to complement the medical involvement some of the apparent need may be met. There was much to suggest that a multidisciplinary approach might be required.

During the first year of my attachment to the hospital I was attempting to use the data from the survey together with conceptualisation concerning crisis, loss and bereavement (Caplan,(1961, 1974), Parad (1965), Murray-Parkes (1965, 1971, 1975), Kubler-Ross (1969) Hancock (1976), Pollack et al (1976), Rappoport (1965), Lindemann (1965)) as a basis for understanding and intervening at the time of telling new parents that their child was handicapped. It was an attempt to give a better service by encouraging joint work as a multidisciplinary team and then, in due course, to review whether or not this had been helpful to parents in their overall acceptance
of the situation. It necessitated the social work practice approx­
imating to the medical model of twenty four hour coverage rather than
the more usual office hour availability, and if adopted more widely
this obviously would have implications for social work departments,
such as a need to move moving towards rota coverage.

During the 1970's the call for multidisciplinary teams increased
as the interest of various professional bodies, and particularly those
within the health field, focussed upon the whole problem rather than a
section of it. Both the Court Report (1976) and the Warnock Report
(1978) recommended a team approach to the two areas of their enquiry,
this being a concept which may be readily acceptable to the social work
profession with its long history of teamwork organisations. In the
Introduction to Teamwork in the Personal Social Services and Health
Care (1980) Lonsdale et al write:

"The very commitment of human service professions
to a philosophy of help and care reinforces the
ethic of co-operative and collaborative working
especially where the well-being of the client
depends upon it."

However, as Kane (1975) has indicated, although much useful
dialogue has occurred, not nearly so much attention has been paid to
such issues as goal achievement through teamwork.

She made a study of multidisciplinary teamwork in the United
States over a ten year period which showed a diversity of team arrange­
ments and "a growing recognition that patients comply better with
medical requirements when they are satisfied with their interaction
with health personnel." (p.144).

Hiltner pointed out (1958) that tensions are part of inter-disci­
plinary work and a very important aspect of moving towards teams with
less clearly defined professional roles may be a reduction in that
tension. Implicit in this is a recognition of the importance of the
inter-professional interactions being relatively free of tension in order to help patients to feel more comfortable in their relationships with these professionals. One goal of teamwork then is for better communication because people feel more relaxed with each other in their interactions.

In the present research the role blurring which Kane described as part of the integrative team was not planned in working with the Experimental Group: it was intended to follow a "co-ordinate team" model as opposed to an "integrative team" model (Kane 1975) in which distinct professional roles would be maintained, and although the social worker would be the key person in assisting communication, the consultant was the undisputed leader by virtue of his medical authority. In Webb's (1975) taxonomy of teams this would be a 'complex team' in which both skills and tasks of the different members vary.

It could be argued that a co-ordinate model is not a real team model but just a group of professionals operating together because of a common interest. Earlier it was stated that the tasks involved in helping families with a handicapped child are too complex to be encompassed by a single discipline but that is not to say that by merging roles a better service is to be presented. It is reinforcing the point that the professional roles are complementary, that there is to be a co-ordination of various kinds of service and an approach to the care of these families on the basis that their problems are multidimensional. I believe it is quite appropriate for this co-ordination of a set of individual professional activities to be called teamwork, and that within this framework their roles should remain quite distinct.

Much of the thinking concerning crisis intervention which has permeated social work practice during the last decade stems from the work of Gerald Caplan (1961, 1964, 1974,) a psychoanalyst who has
specialised in child and family psychiatry. Caplan believes a crisis is basically idiosyncratic but affected by the environment. He regards it as a short period of psychological upset precipitated by a sudden and significant change in a life situation which creates problems temporarily beyond that person's coping capacity. In the normal mode of living individuals are continually faced with situations requiring problem solving activities which with adaptations and adjustment result in a state of equilibrium. In a crisis the problem stimulus is exaggerated and that person's normal coping repertoire is overwhelmed so that his usual pattern of functioning becomes disorganised. This Caplan refers to as emotional disturbance when a patient may be confused, irritable, angry, depressed, aggressive and frustrated. How the period of crisis is resolved may determine a move towards either mental health or mental disorder. This is very dependent upon the individual's problem solving capacities, his previous experiences of crisis, his age, sex and social status, and his resources within the environment.

Erikson (1950) divides crises into 'developments' or those precipitated by a new maturational phase in the psychosocial development, and 'accidental' which are brought on by life's unexpected events. These Caplan terms situational crises and highlights three main types which are caused by:-

(a) loss of a source of satisfaction of basic needs, e.g. loss of a loved person, or loss of a bodily function
(b) the danger of such a loss
(c) a challenge which overtaxes the person's capacities such as a sudden job promotion or demotion.

A complexity of factors affects an individual's ability to cope with the crisis. These are to do with the availability of the basic
physical necessities such as food and warmth, the psychological necessities such as interaction and affection, and the sociocultural necessities such as custom and values, all of which are valuable and will determine how the individual defines and attempts to overcome his crisis.

Perhaps the major criticism to be levelled against Caplen's theory of crisis is that he has worked out a model related to an individual in crisis, and given little specific guidance in working with groups in crisis. A family recently told that their child is handicapped might all be in crisis but individual members might be at different stages of behavioural reaction which makes for greater complexity in working.

It is becoming widely recognised by professional workers that brief intervention will be effective at the onset of the crisis period (Hancock 1976) and that the same intervention will have a greater effect the closer it occurs to the crisis (Wolkan 1977). It is recognised that during crisis the individual experiences a heightened desire for help and is more susceptible to the influence of this than during periods of stable functioning. It is a time of malleability and availability but it is also a time when many complex forces are interacting to cause the disequilibrium and therefore a person may be 'at risk' of not resolving the crisis in a way deemed to be healthy.

The intervention is modelled on the method first used by Lindemann (1965) in helping bereaved people to "mourn the crisis". He did this by engaging them in a process whereby their understanding of the situation was enlarged, by supporting them in expressing their own feelings, by helping them to see what was happening in a reality-based frame of reference, so that they could regain hope of being able to influence the outcome by their own efforts.
This technique of 'preventative intervention' during crisis can be supplemented by a technique of 'anticipatory guidance' which may be used when hazardous circumstances, which might lead to crisis, are expected. This has been developed by Kubler-Ross (1969) in categorising stages through which people pass and identifying these by behavioural manifestations, in anticipation of death, and similar responses are recognised by Murray-Parke (1971, 1975) in anticipating mourning of other significant losses. Further adaptations and development of this conceptualisation have been made by Polak et al (1976) on intervention in acute bereavement, Hancock (1976) in working in a newborn nursery intensive care unit, Bocian (1973) in working more specifically with parents of babies with chromosomal anomalies and Kannel et al (1970) on the mourning responses of parents to the death of a newborn infant.

It has been a theory primarily developed and used by the medical profession within this field and, as yet, although social workers seem to be aware of its existence and possible value as a method of intervention, they are tardy in applying it and reluctant to write about it. Within the context of an Integrated approach this project was an attempt by a social worker to use the theory of crisis intervention in working with families at the time they were told that they had a handicapped child.

When parents are told that their child is handicapped it is possible that they might face an emotional crisis as acute as any challenge which the handicap may present, and as much skill must be applied to the care of the parents as to the child's medical problems. The child who is handicapped is very much the patient of the doctors and nurses; the parents need the care of the social worker. To treat the family as a whole is beyond the expertise of either discipline so it needs to be a team effort in which the
medical knowledge is complemented by the social work skills. In this project the team was deliberately kept small and usually consisted of one of the paediatric consultants and the social worker joined by either the registrar or the houseman. Sometimes, if ongoing hospitalisation was going to be necessary, the Ward Sister was also involved.

In telling parents that their child is handicapped the crisis situation is predictable and its onset controllable. Until parents are given this information, even if they have had some anxieties, they are not strictly "in crisis". However, the content of this message is of such enormous significance that they are likely to be thrown into immediate crisis once they are told. So, with this degree of controllability it was important for the team to be operating at its most effective. Ideally the timing of telling the parents was carefully planned so that it took place as soon after the diagnosis was known to the clinicians as was reasonable, but when both parents were together. It was also important for those concerned not to be rushed so that the parents were given all the time they needed in the immediate situation.

Parents in a shocked stage retain very little of what initially is said to them (D'Arcy ('1968), Kew ('1975), Cunningham ('1979), McAndrew ('1976), Thomas ('1978)). so one of the reasons why it was important for the social worker to hear exactly what information was given was so that in the days ahead this could be repeated as the parents became able to absorb a little more. But the presence of the social worker at this key interview had much greater significance than merely being party to the medical facts. It was also intended to allow the social worker to begin to work with the parents at the time of their maximum disequilibrium when they seemed most in need of help and more amenable to influence. (Welkon ('1977), Hancock ('1976).)
Implicit in all this are ideas of malleability, of needing to strike while the iron is hot, and it was to be shown subsequently that a short period of work timed appropriately, was infinitely more effective quantitatively when compared with those situations where the parents were not seen at the crisis point and later were to need much more social work intervention. It will also be demonstrated that in those situations where the social worker came in after the news had been broken to the family it took much longer to establish what her role should be and the effectiveness of the intervention was felt by the families to be wanting, at least in the beginning stages if not throughout.

Handicap and mourning are inextricably linked. (Olshansky (1962)). The birth of an obviously severely impaired child is often accompanied by silence within the room followed by sotto voce discussion between midwives and doctors and a quick removal and separation of baby from mother. The mother, and the father if he has been present at the delivery, know something is wrong. Just how wrong they may have to wait to know, but from that moment a psychological process is set in motion. Parents begin a grief reaction to the loss of something they had been anticipating for nine months or longer, and that is a normal baby. (Olshansky (1962), Mowatt (1965), Kanner (1953), Hancock (1976)). Part of the process of telling parents was to facilitate the grieving process which followed the information being received, and the main role of the social worker was to help the parents grieve in a healthy way (Murray-Parkes (1965), Simos (1977).) Although the fear of abnormality may fleetingly pass through the mind of a pregnant woman the image of the baby which she carries is generally of a normal one. (Carr and Oppe (1971)). When she and her husband learn that this normal baby has not been delivered to them they experience a tremendous feeling of loss. They have a baby but it is not the baby they
had visualised and they mourn the loss of normal growth and development through childhood to adult life. Their hopes and their forward planning are shattered; they face a future dominated by fear of the unknown.

A very real factor in the birth of a severely handicapped child is that he may die during the neonatal, or immediate post neonatal period. (Kennell, Slyter and Klaus (1970).) These parents have to face two losses, one being the normal baby they had expected, followed by the death of the abnormal baby who was delivered to them. For most of these parents death of a close relative is a new experience. They are young, their own parents are alive usually and they have not encountered loss through death in their life experience, so they have little upon which to draw. Already they are in a grieving stage as they mourn the loss of the normal baby and suddenly, on top of this, comes a second loss which is more definite and final. As they mourn the first loss there is always a part of them which will hang on to the comforting thought that perhaps the doctors are wrong and it is not as bad as they say. It could be that their baby will make better progress than they had been led to believe. But when that baby dies there is nothing left to hope for and they are totally bereaved. Yet at the same time they experience ambivalent feelings for a part of them knows that death was perhaps the best way out, and a part of them believes that they could have done much for that child.

Inevitably bereavement is one of the severest forms of psychological stress (Murray-Parkes (1965).) It is the price that is paid for commitment and the pain of grief is as much a part of life as the joy of love. A couple may have committed themselves to parenthood only to find that very soon they have lost that status. The death is untimely as inevitably it is when any child dies, and the psychological adjustment may be less good than in timely death. There
is also very little to remember and memories are an essential part of the mourning process and something to which people in their grief can return. (Murray-Parkes (1965))

Death represents the ultimate loss and arouses powerful emotional states, not only in the immediate relatives, but in the staff involved with the caring. I found that sometimes the doctors and nurses looked to the social worker for support as well. Perhaps one of the benefits of my having a small case load when it did have a high proportion of grief and mourning, was that it did give me a chance to regenerate emotional energy between the cases. It was something which as a team we coped with by leaning on each other in times of exceptional sadness, and had we not been functioning in a multidisciplinary way perhaps we would have had to resort to the more traditional medical way of opting out. (Bocian and Kaback (1978)). For example we could have been very factual, giving the painful news in medical terms and being as brief as possible. We could have avoided the parents once they had been told, or we could have arranged for them to have had tranquillisers to dampen down their grief. But we knew that in the long term this was not likely to be helpful to the parents and that we should not protect our own feelings by not getting involved with theirs. It was important for the team to remain serene and for the social worker, in particular, to listen and to bear the repetition of the parents' reactions to their grief for as many times as was necessary for the healing process, to tolerate their anguish with empathy and without ever prematurely cutting it off. (Simos (1977)). We supported their expression of feelings and reassured them that it was normal. We encouraged them to regard it as a period of convalescence to an illness which would probably take them at least a month and often longer to complete. (Simos (1977), Caplan (1965)). The social work continued until the mourning period seemed
to be over and the emotional equilibrium well towards restoration.
The death of the child was never seen as the end of the episode.

The actual telling of the parents was planned very much according to the findings of the earlier survey. Our practice was to see the parents as a team and for the consultant to give the medical information with perhaps a few comments from the junior doctor or from me. Then I would stay on with the parents allowing them to grieve and sharing it with them. It was very much a time of being on hand, being readily available and giving fairly basic tea and sympathy. Some 12 to 24 hours later it was anticipated that the parents would be ready for a longer interview in which there would be much more discussion of the implications of the condition, perhaps a need to recognise that their baby was a person and not a thing, and that he needed a name and a place as a member of their family. As a team we tried to liaise closely and if there was any further information to be given the consultant would try to do it when I was with him.

RECORDING PROCEDURES

All my work at the hospital was recorded in the patients case notes which were filed in the social work department. They were used as a record and as a working tool and I recognised the importance of keeping them very up to date. They contained a social worker's assessment of the work being undertaken and in attempting to show social work in action they included the bad things as well as the good things that were done. One thing that seemed to have emerged so clearly from the original survey was the confusion on the part of the parents, and perhaps also amongst the workers, as to what the social work task might be. An important aim in writing a blow by blow account of the events was to try to unveil some of the mysteries of the practice of social work. It was far from perfect, but it was real and hopefully, an honest
exposition of the social work as it was done. An analysis of the hospital records forms the content of the next Chapter. (Chapter 5). Chapter 6 reviews the evaluation made by the parents at least 12 months and not more than 15 months after their first experience at the hospital. Three different questionnaires were used. For Group A it was the same questionnaire that I had used in the original survey. However, there was a difficulty here in that I could not use this questionnaire with the family of Sarah Roberts who had since died, so I had to use the one adapted for all the families where a child had died. As a result the evaluation by the Roberts parents is included with the Group B evaluation but care is taken to differentiate between evaluation about the work concerned with her death, and the work about her handicap that had preceded it. A third questionnaire was used for Group C where it was important to establish whether or not early intervention on the part of the social worker at a time of medical uncertainty had been helpful, or had created additional anxiety. If I was considered to be the special social worker for handicapped children did my presence and offer of help suggest a condition more ominous than it might be and therefore make the parents unduly worried? In testing out a hypothesis of the benefits of early intervention the feedback from this group was to be of particular significance.

Throughout this project evaluation occurs at many stages and at several levels. In the process of doing social work judgements are inevitably being made by the social worker as a self-monitoring process and a tool of the job. So the work done at the hospital with the experimental group contained much of this type of evaluation. Running judgements were recorded and the worker's comments were also written down at the conclusion of the social work involvement with the family. Clients also comment on the helpfulness or otherwise of the work, as
it proceeds, and these spontaneous evaluations are also recorded. It is likely that there could be discrepancies between judgements made at the time and those made in retrospect, as well as between the social worker's assessment and that of the client, so it was important for the recording in the diaries to be up to date and for this work to be written up before the final survey interviews were carried out. It is unlikely, for instance, that the social workers who had been involved with the parents in the original survey thought that their work was as poor as the parents had felt it had been, and certainly this emerged clearly in an interview with the then current Dr. Barnardo's social worker who revealed a much more positive assessment of the social work attempted compared with the feedback from this group of parents.

Stuart Rees (1978) indicates something of the discrepancies between worker and client evaluation of the helping achieved in social work practice and so, although this was not a principal part of this research project, it was important that the assessments by both parties to the interactions stood clearly apart.

The attempt to evaluate the experimental work which had been set up in response to leads provided by the initial survey and linked in with theories and hypotheses which seemed to have relevance, required the parents to accept a change of role from that of the social worker to that of the researcher. A weakness of this inevitably was that they could not easily divorce the two roles and might be inhibited in their criticisms, so it was important for the researcher to try to explain very clearly to them the value of an honest appraisal of their experiences. The social work had been a component of a multi-disciplinary caring process but the evaluation was intended to be of the whole experience. Parents recognised the value of honest assessments which might guide those responsible for an improved service, and were genuine in their concern for a better future for the next
generation of parents facing the difficulties created by having a handicapped child. I saw it as an essential part of these evaluation interviews to create an atmosphere in which honesty could take place.

All names are, of course, disguised, including those of the medical personnel who played a part in the experimental stage of the research.

THE EXPERIMENTAL GROUP

Forty one cases were referred to me during the twelve month period. Three handicapped children were referred to other social workers in the year and these have not been included in the project. The forty one divided into four fairly equal groups, although not all the medical conditions could be neatly categorised. The ones who died at an early stage clearly became one group, but differentiation between chronic and acute, impaired and handicapped was not easy and I tended to juggle the names back and forwards as medical changes occurred and as I tried to meet the criteria for medical categorisation. Because the outcomes were different it was necessary to adapt some sections of the questionnaire to suit the changed situation. (See Fig.8.)

The first group (Group A) comprised the twelve handicapped children who lived. It includes four babies with Down's syndrome, one of whom was not expected to live for very long, (Fiona Parker) but who was still alive at the time of the follow up interview so is justifiably included, and a second little girl (Sarah Roberts) who
was quite fit and well for nearly a year and then quite unexpectedly was a victim of instant cot death. The social work done in that year was geared to supporting a situation of having a handicapped child who would live and for this reason she is included here. In addition to these four there were two babies whose handicaps were apparent at birth. One was born with a defective foot and lower leg which would need amputation when he was a year old. This apart he was a normal, fit and forward young man, but his physical disability justified his inclusion. The other baby was obviously severely handicapped and it was thought unlikely that he would survive, but he did, and as the year went on it became even more clear just how very severe his handicaps were going to be.

The remaining six were those for whom the handicap only gradually became apparent. There should perhaps have been a seventh in that one little boy with a type of double jointedness and slow intellectual development would have been included if his parents had not so adamantly resisted the suggestion that he was handicapped, albeit mildly so. He was therefore included with Group C.

The group of handicapped children who died (Group B) included ten referrals. Nine of these deaths occurred in the neonatal period and another when the little boy was two. All these families were referred to the social worker because death was known to be imminent and this was the principal focus of the social work with reference to handicap being made hardly at all. A year after the death I made contact with all the parents and asked if I might do an evaluative interview with them discussing their experiences at the hospital at this time. One family had moved away and did not wish to be interviewed, but the rest were all willing to be involved, although one couple requested that I waited until their next baby was born and they knew that he was all right.
Group C comprised those children who were impaired but not permanently handicapped (see Chapter 3 for definitions). The greater proportion of these children were the babies early diagnosed as hydrocephalics who had had a shunt fitted and in due course seemed to be developing normally and manifesting none of the other features of spina bifida. A shunt is a valve fitted into the baby's head which allows the excess fluid to drain down an attached tube into the stomach, thereby preventing an excessive enlargement of the head. Another baby was born prematurely and was quickly transferred to the Special Care Baby Unit because of repeated apnoeic attacks causing considerable concern. Then came a dramatic improvement and she began to make progress and in due course developed normally. There were five other children with serious acute conditions which could have left permanent damage, and one boy who, immediately after birth, was sent to Bristol Sick Children's Hospital where a serious heart condition was diagnosed. By the time he was a year old he was a robust, energetic youngster with a heart appearing to be as sound as any other child of his age.

Eight babies who were referred were not truly handicapped, having only minor impairments or temporary conditions (Group O). Their parents were seen briefly and then medical treatment was discontinued fairly quickly so no evaluation interviews were carried out at a later stage because there would have been little upon which to make comment. Interestingly because it represents differing impressions of what the problem might be, this group included one family referred simultaneously to two social workers. The baby was born with the lower part of the fingers missing on one hand and because of this the registrar referred the family to me. The midwife referred the mother to the maternity medical social worker because she was unmarried. Neither the registrar nor the midwife was aware that the other had made a referral, nor did
each mention the alternative problem which had been their colleague's reason for referring to the social work department.

I was involved with all the families when the situation had looked at its blackest and had worked with them towards a recognition that things could go either way. Although there had been a need to continue working with some families for much of the second year, whereas other cases had been closed very quickly, twelve months later I saw all the families in Groups A, B and C (except Paul Smith's parents who had moved away) and discussed with them their experiences at the time of the crisis.

A further aspect of my social work practice during the two years I was attached to the hospital was to investigate in greater detail the provision of services for families with a handicapped child. One factor which had emerged from the original survey was a seeming complexity in the network of supporting services due to some extent to their piece-meal development and changes in Departmental responsibilities. In an integrated social work approach it is of professional importance to use skills in identifying anomalies and perhaps, even bringing pressure to bear upon the bodies which seem to impede the smooth running of a functional and efficient system. This has to do with the use of a social worker's skills in communication and liaison, and inevitably this means the social worker assuming the role of key person in the coordination of the services. It is likely that there will be links to be made between the clients and other agencies, with other material resources, with the medical and associated professions and also within the clients own family network.

DISCUSSION OF GENERAL FEATURES OF THE EXPERIMENTAL STUDY

The experiences undergone in hospital and soon afterwards by parents with a handicapped child appear to be vital to the parents'
acceptance of the situation and their early treatment of the handi-
capped child. (D'Arcy 1968, Farber 1959, Thomas 1970, Rizard and Grad
1961, original survey). Furthermore these experiences are likely to
have a bearing upon the parents' subsequent mental state (Ross 1964),
the child's own development and the parent-infant bonding process (Love
1970). As such their importance is immense and has warranted this close
study of the process. The comments made by parents in the earlier
survey provided guidelines and highlighted possible pitfalls as the
team faces the difficult task of informing parents of an unfavourable
diagnosis. But there could be no fixed rules for doing this; guidelines,
not tramlines, could be offered and there needed to be flexibility.
Obviously the number involved were small but the work recorded here
does seem to demonstrate the value of very early team interventions in
situations concerning loss, thereby enabling a family to mourn in what
may be considered a healthy way and to move towards an acceptance of a
new situation.

Generally the planning of telling the parents was carefully
followed and the team liaison was fairly good. In the group where the
babies died (Group B) although the original aim had been to concentrate
the social work intervention at the crisis point, there is evidence to
suggest that in some situations it may have been terminated too soon
and that the effects of the crisis were more enduring. Where a mother
was given an early discharge after two or three days in hospital, she
ought to have been offered a home visit very soon afterwards. The
follow up interviews, planned to occur a month later and to be
evaluating rather than therapeutic, sometimes indicated that couples
were still in need of help. One couple (Mr. and Mrs. Harris) clearly
would have benefitted from help at home earlier than they were given
it, and only after two overdue interviews did Mrs. Harris begin to
move towards an acceptance of what had happened. There is no way of knowing if the professional help she received had any effect upon the length of time it took her to mourn her loss, but perhaps better timing of it could have made her task less painful.

To some extent the apparent professional reluctance to extend the work into the home situation may have reflected another aspect of the original survey findings. Those parents who had had social work help were asked to comment upon it. Several of them had said that the social workers did not seem to know why they were visiting, nor when to stop coming. Although the social worker always said to the latter group of parents that they could always write or telephone, if the professionals could help them further in any way, with the exception of one father who made contact with the registrar about a previous pregnancy, none did so. It is possible that the difficulty of requesting something diffuse precluded them from actively seeking help, but if it had arrived on their doorstep it could well have been very acceptable. By contrast, in the families in Group A where the handicapped child was expected to live, the social worker was planning for on-going support, possibly for many years, and did not expose parents to the risks of too early termination. Telling parents was seen as the beginning of a process that would lead on to the involvement of other professional workers, with the social worker acting as a key person in making the links.

Another aspect that has emerged in writing up this work, particularly that with parents whose babies died, was the frequent apparent neglect of the fathers' needs. Mothers are in hospital because they are the patients of the maternity department; fathers come as visitors, continue their life outside and may not feel or be made to feel that they are so involved with the situation. It is believed that the bonding of fathers and offspring begins later (Kennel and Klaus 1970,
Blake Stewart and Turdan 1975) and perhaps because of both of these factors the mother is the focus of attention in these early post-partum days. Although it was always the intention of the consultant and the social worker to see both parents together, and at the beginning this was nearly always done, the subsequent work appears to have been done with the mothers and this may have reflected ease of access rather than need. In the recordings of the interviews it was notable how often it was the mother who did the talking and how often the father sat in silence. For example, the electroencephalogram result on one little boy (Paul Smith) showed that there was no brain activity controlling his body chemistry and it was likely that he would die within a few days. His mother showed very little emotion about the situation, whereas the father was very upset whenever we spoke to them. The parents in this case were always seen together, yet retrospectively it is clear that the amount of work done was geared to the mother's needs which were probably less than those of the father. Similarly with the Green family where Mr. Green's stated dislike of the hospital atmosphere meant that he did not come in very often. After Keith died Mr. Green was extremely upset and yet he was not seen again by the social worker who focussed the intervention on the mother in the ward. Mr. Allen was much more upset than his wife in the first interview and when they were seen a month after the baby had died he appeared to be defending himself still against the hurt caused by his loss. He was a naval father who said that he and his wife would prefer to deal with their grief in their own way, but it may have been that he would have been helped by more direct involvement on his own with the consultant. If Service life encourages men to be men and not to display their emotion in public, then perhaps the caring professions should respond appropriately by providing the opportunity for a man to man talk.
Whenever the relatives came into the hospital to support the parents at moments of crisis, they were involved with the parents consent, in any discussion. The team was very aware of the fact that parents were part of an extended family, and that family usually would have an important role to play in supporting the couple in their grief. It was here in particular that the flexibility of the hospital routine was so good. Grandparents, who are not usually allowed into the Special Care Baby Unit, were permitted to visit their dying grandchild and to touch the baby if they so wished. Rooms were made available for relatives to sit together and there always seemed to be kindly ward ancillaries about, who would make cups of tea at any time of the day or night.

One aspect of the work that parents did seem to find helpful was the explanation of what the team was trying to do. Frequently the social worker explained the conceptualisations concerning mourning and what was the task of each person in the process. It was not just some­body trying to be kind, but a person who knew something about the state that they were in and could predict how they felt and would feel as they lived through it. Likewise when there had to be a change in emphasis of intervention caused for example, by a handicapped child who had been expected to live becoming a terminal case, this was shared with the parents. There would be discussion on the work done towards an adjust­ment in their life to encompass the expected difficulties created by having a handicapped child within the family, and a recognition that now this had to be changed to one of anticipatory mourning as they faced a premature death. It was frequently at this stage that the parents' ambivalent feelings were overwhelming. Part of them felt saddened by the loss, part of them was gladdened by being spared future problems, but most of all they felt terribly guilty about having had
any feelings like this at all. It was very helpful to them to know that they were normal in this, that most parents felt the way they did, and that it was a common reaction which would resolve itself very soon. The apparent accuracy of prediction seemed to offer real security in the whole process of rehabilitation.

Teamwork and timing have been the two crucial factors. As the team learned to work together the skills and weaknesses of each member were recognised and there was a movement towards a functioning unit. It was fortunate for this research project that there was a group of consultants, registrars and housemen at the hospital in that year who were interested in trying new ways of working, and obviously the whole project depended very much upon their early anticipation and willingness to refer. There was not always complete agreement as to the moment of telling, but there was a willingness to be guided by the survey parents saying 'sooner rather than later'. There was agreement about honesty. Although the team tried to give bad news as gently and as kindly as they knew how, they did not seek to deliberately shield parents by withholding the whole truth as they knew it to be. Honesty was crucial to the development of trust and this they believed to be essential with those cases where there would be ongoing involvement for many years.

It would probably have been impossible to support the parents so much in the early days unless the members had been working as a team. Although it began by being a group of people with clearly defined roles it became much more of a unit in which members related well to each other and drew strength from the professional expertise of colleagues. At times they were very saddened by events but continued to be able to give real help to the parents because they had emotional support from a team membership. Bereavement and loss were discussed and feelings shared. It would be incorrect to say that they were not
emotionally involved with some of these families, but they were never emotionally incapacitated. In their professional relationship with the parents they were sustained by the knowledge that any grief reaction that might be experienced would be delayed, any tears to shed would come later and that metaphorically there would be a shoulder to lean upon.

If the professional people are sympathetic and helpful to the parents, the relationship formed during those first few days is very strong. It is important that the key persons who are going to give support and guidance over the years ahead are available during the time of initial contact. Professional bonding to the family may be equally as important a component of the rearing of a handicapped child as is the parental bonding. Many handicapped children are unable to show much response to their parents and the giving of emotion seems to be all one way. To sustain them in this one way relationship parents need to draw upon relationships elsewhere. It may sometimes be appropriate that they are supported in this by a middle aged consultant and social worker who care for them in a professional way.
GROUP A  Handicapped & lived
Stephen Archer
Paula Cann
Mark Cox
Matthew Dark
Norman Freestone
Jonathon Haig
Fiona Parker
Andrew Price
Patrick Richardson
Sarah Roberts
Peter Stephens
Anita Wrigley

GROUP B  Handicapped & died
Sally Allen
Christopher Cooper
Samantha Field
Keith Green
Tracy Harris
Amanda Old
Michael Thompson
Richard Thorpe
Susan Williams
Paul Smith

GROUP C  Impaired
Joanna Bates
Anthony Cooper
Ian Edwards
Roy Evans
Rachael Farmer
Simon Forster
Susan Hurst
Sharon Kendall
Kerry Maker
Nigel Stallman

GROUP D  Not handicapped
Robert Andrews
Philip Bassett
Jane Embury
Hugh Jones
Saun Meadows
John Phelps
Jill Rickard
Trevor Short

FAMILIES INCLUDED IN THE PROJECT WHO ANSWERED THE RESEARCH QUESTIONNAIRE

FAMILIES NOT INCLUDED IN THE PROJECT WHO DID NOT ANSWER THE RESEARCH QUESTIONNAIRE

Figure 8. The children who were referred to the Social Worker during the Experimental period.
**EXPERIMENTAL GROUP**

**Group A. Handicapped and lived.**

**Stephen Archer** 4½ years. One younger brother. Developed symptoms of a degenerative cerebral condition but no firm diagnosis was made.

**Paula Cann** baby with two older brothers. Down's syndrome.

**Mark Cox** baby - first child of youthful marriage. Severely handicapped physically and mentally. Gross abnormalities never firmly diagnosed, although put up for international identification.

**Matthew Dark** baby with an older half brother. At birth a heart condition was initially suspected but not until he became hydrocephalic at six months that a mass of abnormal blood vessels was discovered at the base of his skull. Massive surgery required.

**Norman Freestone** 14 years - one of five children. Sudden onset of sub acute sclerosing panencephalitis - a very rare terminal condition caused by the measles virus.

**Jonathan Haig** 2 years with one older brother. Developmental delay but no firm reasons established.

**Fiona Parker** baby with an older brother. Down's syndrome and major heart condition.

**Andrew Price** baby - first child. Congenital abnormality of the right leg.

**Patrick Richardson** baby with an older brother. Parents living apart. Mild cerebral palsy.

**Sarah Roberts** baby with an older sister. Down's syndrome. Died unexpectedly at 11 months of Instant Cot Death.

**Peter Stephens** baby - first child. Down's syndrome.

**Anita Wrigley** baby - first child and the reason for the parents marrying. Mother had severe psychiatric illness. Serious developmental delays caused by the premature fusion of the skull.
EXPERIMENTAL GROUP

Group B. Handicapped and Died.

Sally Allan baby - first child. Severe spina bifida. Died at five days.

Christopher Cooper baby with one older brother. Very premature. Weak heart and evisceration of the bowel. Died within two hours.

Samantha Field baby with an older brother. Gross abnormalities and odd chromosomal pattern. Died within 36 hours.

Keith Green baby with two older brothers. Born by caesarian section during which operation his mother was sterilised. Heart and lung abnormalities. Died at four days.

Tracy Harris baby - first child of anxious parents. Died at two days.

Amanda Old baby with two older siblings (one adopted). Extremely premature baby who appeared to have internal abnormalities. Lived in an incubator for a month then died suddenly. Parents refused a post mortem examination.

Michael Thompson baby with an older brother. Hirschprung's disease affecting the whole of the small bowel. Lived for three weeks.

Richard Thorpe 2 years with an older brother. Meningitis. Died within 36 hours without regaining consciousness.

Susan Williams baby and first child although second pregnancy. Spina bifida. Died at five days.

Paul Smith baby - first child. Cerebral abnormalities. Died at five days.

(Not interviewed.)
EXPERIMENTAL GROUP

Group C. Impaired.

Joanna Bates 4 years - an older sister. Late diagnosis of hyper-phosphatic rickets.

Anthony Cooper 12 years - an older brother. Meningitis. Responded well to drug therapy.

Ian Edwards baby - one older sister. Oesophageal atresia. Treated surgically.


Rachel Farmer 9 months. One older brother. Neuroblastoma - treated with drugs.

Simon Forster baby - first child. Severe heart condition suspected at birth. Later proved not to be so.

Susan Hurst baby - first child. Premature baby who had a series of apnoic attacks and initially showed some developmental delays.

Sharon Kendall 12 years - middle child of three. Relapse of acute lymphatic leukaemia. Died when she was 14 but after the research project had been completed.

Kerry Maker baby - first child. Born with a meningocele which was operated upon and a shunt fitted.

David Proctor baby with an older brother. Born with a hydrocephalus. Shunt fitted.

Nigel Stallman 6 years - one younger brother. Developmental delays. Double jointedness causing a certain amount of ataxia but emotional deprivation seemed more of a problem.
REFERRED BUT NOT INCLUDED

GROUP D.

Robert Andrews jaundiced baby. Earlier pregnancy had resulted in an abnormal baby who died.

Philip Bassett - mother's post partum anxieties very high. Envisaged abnormalities in the baby which did not exist.

Jane Embury - baby with missing digits on her left hand.

Hugh Jones - baby with a possible ventral septal defect of the heart.

Shaun Meadows - baby with slight talipes and hypospadias, both of which were operable.

John Phelps - baby with hypospadias - operable.

Jill Rickard - baby with slight respiratory problems which responded to treatment.

Trevor Short - baby with an irregular heart beat which settled down to normal.
Chapter 5.

The Experimental Group.
INTRODUCTION TO GROUNDED THEORY

Grounded theory is a term given by Glaser and Strauss (1967) to a process whereby theory is "discovered" from data. It is an approach of maximum value when dealing with qualitative data and it is therefore appropriate to use with case study material such as the medical social work records. In handling grounded theory a series of 9 stages have been extracted by Turner (1981) from Glaser and Strauss's account, and these are summarised in Figure 9. These stages were followed, to a greater or lesser extent, in this analysis of the social work records of all the work done with the families which comprised the Experimental Group.

Some fifty to sixty label cards were produced for each of the sub groups A, B and C. These were further sorted into constellations and given a category label. At this stage the categories of the three groups were compared and found to be so similar that for this part of the account the divisions into Groups A, B and C was abandoned.

Using these categories, the following theoretical account of the process of intervention was developed:

The intervention was seen to commence with the referral situation, prior factors feeding into this situation being the diagnostic background of the referral, variations in the particular initiator of the referral, considerations affecting the timing of the referral and the specific reasons which triggered the referral.

The referral situation normally also constituted the initial telling situation, where the parent or parents heard officially for the first time of their child's handicap or disability.

In this situation and subsequently the social worker adopted the key role of liaison person supplying role system information and sometimes dealing with difficulties arising from the dual role forced on
<table>
<thead>
<tr>
<th>Stage</th>
<th>Main activity</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Develop categories</td>
<td>Use the data available to develop labelled categories which fit the data closely.</td>
</tr>
<tr>
<td>2.</td>
<td>Saturate categories</td>
<td>Accumulate examples of a given category until it is clear what future instances would be located in this category.</td>
</tr>
<tr>
<td>3.</td>
<td>Abstract definitions</td>
<td>Abstract a definition of the category by stating in a general form the criteria for putting further instances into this category.</td>
</tr>
<tr>
<td>4.</td>
<td>Use the definitions</td>
<td>Use the definitions as a guide to emerging features of importance in further fieldwork, and as a stimulus to theoretical reflection.</td>
</tr>
<tr>
<td>5.</td>
<td>Exploit categories fully</td>
<td>Be aware of additional categories suggested by those you have produced, their inverse, their opposite, more specific and more general instances.</td>
</tr>
<tr>
<td>6.</td>
<td>Note, develop and follow-up links between categories</td>
<td>Begin to note relationships and develop hypotheses about the links between the categories.</td>
</tr>
<tr>
<td>7.</td>
<td>Consider the conditions under which the links hold</td>
<td>Examine any apparent or hypothesised relationships and try to specify the conditions.</td>
</tr>
<tr>
<td>8.</td>
<td>Make connections, where relevant, to existing theory</td>
<td>Build bridges to existing work at this stage, rather than at the outset of the research.</td>
</tr>
<tr>
<td>9.</td>
<td>Use extreme comparisons to the maximum to test emerging relationships</td>
<td>Identify the key variables and dimensions and see whether the relationship holds up at the extremes of these variables.</td>
</tr>
</tbody>
</table>

**SCHEMATIC LIST OF THE STAGES IN THE DEVELOPMENT OF GROUNDED THEORY,**
**EXTRACTED FROM GLASER AND STRAUSS (1968). AFTER TURNER (1981).**

Figure 9.
Looking more closely at the social work content of the interaction the characteristics of teamwork were of central importance in the situations under consideration. Whilst it was acknowledged that variations in social work styles did occur, there were also variations in style between the social worker and other professionals and an important element of the process was the search for a convergence or compatibility of styles amongst the professionals.

Within the context of teamwork, the social worker was found to engage in five major kinds of activity in dealing with the parents of handicapped children: activities which were concerned with integrating elements of the situation; activities which made use of the social workers authority in the situation; acting as a consultant to the parents; or engaging in social integrative aspects and evaluating the parents and the social worker's own reactions to the situation.

Each of these kinds of activity may be broken down into their elements: when integrating, the social worker may be communicating or encouraging communication, liaising, using the telephone, and contacting colleagues, clients and other agencies. When using authority the social worker may explore the client's new role, make contacts, adopt directive stances, give advice, manipulate clients, offer further contact, initiate follow-up interviews or attempt to deal with relationships with clients who are themselves professionals.

As a consultant, the social worker stays, talks and interprets, follows up information initially given, makes use of known social work concepts relating to mourning processes, the parents relationship with the dead baby and the stages through which crises develop. S/he may also be required to discuss the medical situation and its implications, or even inform parents that a death has occurred.
The social integrative aspects of the social work role are to do with the boundaries of the professional relationships and the permitted behaviour within it. It is a process which required the social worker to be available out of normal office hours, to carry out home interviews for which the clients often made careful preparations, to be ready to respond when the parents sought further contact with the social worker. It involved doing practical immediate things such as making cups of tea or serving cornflakes, answering questions about personal details, using touch, accepting cuddles and kisses and little presents from young children.

Finally, in this particular project, the social worker was not only assessing herself, she was also helping parents to appraise their situation, seeking their feedback about the nature of the social work involvement and involving them in planning for the future.

The project was conceived as being based upon teamwork, but there were also occasions, appropriate and inappropriate, when solo-work also took place.

Where possible, teamwork was sought in the initial telling situation and when this occurred it seemed to help the parents to understand the role of the social worker better.

Teamwork also required some attention to joint-interviewing as a technique and where this did occur, it seemed to encourage a greater willingness on the part of medical personnel to involve the extended family. A further occasion where teamwork commonly occurred was prior to a bereavement, where the professionals frequently felt that they needed each other's support.

When teamwork was taking place it was noted that it was important to ensure good quality recording of events to facilitate team communication.
When solo-work did occur it seemed desirable to regard it as a specialist contribution within the team. While it was sometimes necessary on the grounds of economy, it was also sometimes more appropriate particularly where the social worker took on the role of repeating a number of times for the parents the information which had been imparted but not absorbed at the initial telling situation. Some ill-advised solo-work also took place, as when one parent was informed of the handicap in advance of the joint interview.

In some of the situations conflicts arose, most commonly conflicts between parents, but also between parents and professionals and between professionals. In the situations on the project, conflicts between parents sometimes seemed to lead on to conflicts between parents and professionals but the intra-professional conflicts were kept separate from relationships with the parents.

Various types of client behaviour were encountered. Parents varied in their reactions to the initial telling situation, and in the extent to which they could draw support from their families, and they also varied in the amount of information that they could absorb in the early stages. Some reacted to the telling by shifting the spotlight onto themselves, while others queried the diagnosis. There were considerable variations in the familiarity which parents had with medical terminology which also affected their reactions.

When the child concerned died, parents were observed to be engaging in anticipatory mourning, to display a need for ritual in the mourning process to attempt to understand the meaning of death or to display extremes of grief. It was also noted that the stress of the advent of a handicapped child could lead to the emergence of other problems already latent in the parental relationship.
The preceding paragraphs have presented the general theoretical understanding of the processes of joint socialwork/medical teamwork in relation to dealing with the parents of handicapped children which has been extracted from the experimental phase of the present project. In the remainder of this chapter, this general framework is used to order the particular situations from which it was derived as some of the complexities of the various cases are unfolded, starting with an examination of the Referral situation.

A. THE REFERRAL SITUATION

Typically a family would be in contact with the medical staff because a child was manifesting some abnormal clinical signs which needed to be investigated. When the diagnosis, even at a provisional stage, indicated that this might be a handicapping condition (Diagnostic background history to the referral) the medical staff were asked to notify the social worker (Initiator of the referral). This was a new pattern of working in that the social worker asked to be involved at the very beginning and in every situation (Timing of the referral) wherever there was the slightest suspicion of a handicap. The emphasis also was on a medical problem rather than a social one. At this early stage the knowledge was of a potential medical crisis with no information about the family's strengths and coping repertoire. It was an assumption that every family in this situation should be offered a service and there should be no needs testing by any of the professionals involved. It was hypothesised that any family having a handicapped child would need help and that the evaluation later would give some indication as to whether or not this was so. The plan was that the doctor responsible (nearly always this was the consultant and only rarely did the registrar fill this role) would arrange that he and the social worker met together with both parents (Initial telling situation) he would give the medical
information and answer any questions, and then leave the social worker with the parents to discuss the matter further.

It took some time for this referral procedure to get established and for the three consultants, two registrars and their housemen to remember to notify the social worker in advance of any information being given and not, as had hitherto been their practice, to refer only when the parents appeared to be incapacitated by the information they had been given or when they appeared to have problems of a more social nature. In some of the earlier referrals (Sally Allen, Fiona Parker, Norman Freestone) there had been some brief talk with at least one of the parents before the organised joint session and on rare occasions the family was not referred at all. (Christopher Cooper, Roy Evans). One of the consultants (Dr. Fergus) seemed less willing to experiment but good liaison with an interested and social work orientated registrar (Dr. Martin) overcame this. In due course, and perhaps when some of the benefits of doing things this way were demonstrated, the co-operation was much better. The consultant who had first been contacted about the research project was the most frequent initiator of referrals, particularly when the prognosis looked grave and there was a likelihood of a death. Dr. Jones was responsible for referring over half of the families where the child was going to die. It might have been something to do with death being regarded as a medical failure, but there did seem to be a greater readiness to make contact with the social worker when this was likely to happen. In the other two groups the reason for referral was a potentially handicapping condition although there were isolated cases of acute conditions such as leukaemia or surgical conditions such as hypospadias being referred, often by the nursing rather than the medical staff.
As a result of this the Initial telling situation for the parents was set up. The participants would be the consultant, the social worker and both parents. Occasionally the registrar, houseman or the Sister would join in this session, although the aim was to keep the team small at this stage so that the parents did not feel overwhelmed by professionals. In spite of recognising that it was not ideal there were a few instances of one parent being given information alone.

The actual telling of the parents was planned very much in accordance with the findings of the survey, together with more recent knowledge of systems thinking and crisis theory. The practice was for the small team to see the parents and for the consultant to give the medical information with perhaps a few comments from the houseman or the social worker. Those parents who were aware that medical investigations had been going on were partially prepared for receiving the information, although rarely for the gravity of it. Others, and particularly the parents of the Down's syndrome babies, had not been alerted to the possibility and were ill-prepared to receive the shattering information. Nearly all the parents were confused about the medical situation and in their shocked state most heard very little of what was said to them. They might ask a few questions but usually all they were able to do was to sit in stunned silence or cry. After this preliminary conveying of information the consultant would withdraw leaving the social worker with the parents. This was very much a time for being on hand, readily available and giving fairly basic tea and sympathy. It was an opportunity for the parents to grieve and for the social worker to share this with them. On two occasions the team temporarily withdrew from the initial telling situation to allow the parents personal time to grieve together, and on another occasion, the parents left the emotionally charged situation and then returned to
continue the joint session. In these situations there had been nothing to suggest to the parents that anything was wrong and they were shattered by the information. Each couple had seemed to need a chance to share together the devastating news before they could face going further in exploring its implications for them.

Following the plan of intervening jointly as early as possible it was necessary to time the interview to fit in with the availability of both parents and the professionals' work commitments. Since it was vital to give time to the task and not to try to squeeze it in between other activities many of the initial telling situations tended to be during the evenings, early in the mornings or at the weekends. It is nothing unusual for the medical profession to be available at all hours, although a rota coverage enables individuals to have off duty time. In order that the joint early intervention plan should be implemented it necessitated that the social worker approximated to the medical model but in this case without rota coverage. So apart from three weeks holiday the social worker was 'on call' at all times and encouraged the medical staff to telephone at home anytime during the day or night, a thing which they were never reluctant to do!

Some twelve to twenty four hours later it was anticipated that the parents would be ready for a longer interview in which there would be much fuller discussion of the implications of the condition, perhaps a recognition of the need to acknowledge that the baby was a person and not a thing and that he needed a name and a place as a member of their family. This interview was usually done by the social worker alone. It was arranged with the parents at the end of the initial telling situation and was a continuation and exploration of the areas which had been established in the first session. It was a crucial interview for deciding whether or not there should be further social work
involvement. Unlike the medical profession social work does not have the same authority for imposing its service. Of course, patients can refuse medical treatment but as there are few alternatives they rarely do so. Social work is a less clearly identifiable activity and it may seem that what is being offered differs very little from the help which parents may derive from other sources and particularly their own families. However, having first met the social worker as part of a multidisciplinary service being offered as a whole, the refusals were few. Where they did occur were in situations when the initial telling had not been joint.

(Christopher Cooper, Joanna Bates, Amanda Old).

In summary then, the referral situation was dependant upon the medical colleagues diagnosing and recognising a potentially handicapping situation and making early contact with the social worker. That piece of communication was vital if the experimental plan was to be tested out. In the early weeks the social worker was so readily available that they could hardly fail to forget. She was on the ward, in the clinics and generally being very obvious. Once the service being offered was tested out and to some extent proven then she had more confidence in the doctors willingness to seek her out and felt less need to be under their feet. In all of the forty-one cases, the referral was precipitated by a medical situation and in thirty-three of these a handicapping condition was anticipated. The timing was generally early and flexibly during the day or night. Intervention was joint in nearly two-thirds of the cases.

So from the outset the patterns of communications were being established. Katz and Kahn's definition of systems theory as being "basically concerned with problems of relationships, of structure and of interdependence, rather than with the constant attributes of objects," is immediately applicable. The initial telling situation was the setting
up of a communication channel which would radiate into a network of supplies and resources as time went on. All social systems are open which means that they are in a constant process of change subject to the inflow and outflow of communicational stimuli, the main one being the exchange of information. Social work is primarily a lexical profession (Goldstein 1973) that relies upon communication exchange to carry out its function, so right at the beginning the social worker is establishing for herself an important role as the key person in liaison. If the exchange of information is fundamental to professional performance then very early on this task had to be established clearly and the social worker recognised as the person who was taking responsibility for gathering the data for it. Lennard and Bernstein (1969) refer to this as role system information and part of the social work task early in the contact with the parents was an explanation of the social work role and how it complemented that of the doctors or in some situations that of the educational psychologist and the teacher of the handicapped.

The whole relationship can be looked upon as one of communication. Relationship has traditionally been a concept more typically applied to two person systems because literally it does refer to the affinitative bond between two persons. This has been particularly true in past social work and basic to one-to-one practice, strictly referred to as casework. So in relating to larger units there is a recognition that there is a complex set of mutual relationships and inter-relationships among a number of persons. Part of the initial telling situation was the creating of a triadic as opposed to a diadic interchange, which it was hoped would alleviate some of the confusion of double telling. As in Greek tragedy where the bearer of bad news was slaughtered after he had delivered the message, so too did the consultant withdraw from the interaction once he had given the information, leaving the social
worker to carry the caring, comforting and supporting role. Sometimes the presentation of a person carrying a dual role, that is, having two functions to perform, creates difficulties and confusion for the recipients. The consultant comes with a mixed message: 'I have diagnosed that your child has been born with an impairment which will make him handicapped for life and this will have a profound effect upon your family life from henceforth; I am concerned about you all and will try to help.' Such a message could evoke fairly strongly ambivalent feelings which are confusing to the individual and particularly so in times of stress. If two people come and quite clearly delineate and carry separately the two parts of the message, then there can be a more structured polarisation of feelings which can make them more manageable and understandable to the client. Professional role division might usefully be employed in other situations where good and bad news have simultaneously to be relayed. For example, an accountant and a bank manager might share the bankruptcy revelation, the person and the general practitioner might share telling the family that the difficult elderly relative has died.

Returning to the initial telling situation the social worker is immediately confronting more than a two person social unit. The parents are a couple likely to have an extended family in a neighbourhood; the consultant is part of a hospital system some of whose members may be in the interview with him. The social worker, as well as being part of her own professional system which again is a subsystem within the hospital, by virtue of the fact that she has opted to take the key person role, places herself in a position that holds the possibility of some sort of relationship with each of the members of that unit, or as it may be regarded, a newly created social system.
It is important to recognise that some skill in relationship formation is crucial here. A medical consultant's training is with pathology rather than with personality. The so called 'bedside manner' is designed for other purposes and even in current medical training there is very little being done on how to speak with patients, or how to put them at their ease. Conversely much of a social worker's training is in understanding relationship formation. This is particularly relevant in situations where parents are given bad news for in a very brief time of contact they are being called upon to participate in a relationship which requires them to get involved more quickly and even with some risk because at that time they may feel very vulnerable and threatened.

The records made at the time and used for the present analysis were deficient in that they stressed only the communication which was going through the social worker, whereas it is important to remember that other contacts were also going on elsewhere, all around. The consultant was communicating with his medical system and writing records, although almost exclusively of medical content; the parents were communicating within their family setting and most probably not writing anything down. But because a social worker uses recording as a working tool these records are likely to be more far ranging in content and of greater detail.

B. SOCIAL WORK PHENOMENA

Perhaps the first and most important thing to establish here is the concept of style. This can be defined as the interplay of personal and technical factors which comprise professional behaviour. Ellenberger (1970) said it was impossible to ascertain in a man's thought what is truly his and what he has assimilated from events and persons around him. Likewise social work practice is coloured by the poverty or richness of the practitioner's own life and is bound to be influenced
to some degree by the perceptions that derive from these personal experiences. The technical factors link with the theoretical underpinning to that practitioner's work and which concepts that individual worker chooses to study and use.

This particular social worker was originally a geographer by profession so the cartographical background would make her especially receptive to the holistic concepts of an Integrated approach, i.e. the need to map out the problem and the communication patterns and to plan the possible points of intervention. But in order to be effective in all the functions noted in such an approach the social worker would need to be a complete generalist and this one was not, and it is indeed doubtful whether any one individual can be. Her professional training was in casework, although some small group work had been done.

The resultant practice with this experimental group of clients was an amalgam of the skills of these two methods. Only rarely was the intervention focussed on a single individual and when it did happen it was more likely to be on a colleague rather than a client. Parents were nearly always seen together and often with other members of their families. The social worker had had previous experience of working in a paediatric setting, had a particular understanding of crisis intervention techniques and the theories of loss and mourning, all of which were very evident in the recording.

Personal links with the medical profession made the communication here much more comfortable than it was with the educational psychologists or with the higher administrative echelons of the Special Education department. This has implications for a concept of compatibility of professional styles. When the interaction between individuals tends to reduce the dissimilarities in expectation, goals and behaviour, there is as a result a meaningful communication and pattern
of liaison. This property in systemic thinking is convergence; it is an index of the degree to which the system does or does not provide opportunities for the kind of interaction which would foster mutuality (Goldstein 1973). Seeking convergence using the skills of liaison is expected to be an important aspect of the social work phenomena. Compatibility of styles links with a third category - teamwork. In this project the team was a hospital one and did not include personnel from education and the now hospital based social services. The medical social worker and the doctors had a closer working understanding (compatible styles) and to some extent that made the team exclusive which may not have been to the benefit of the client.

It is useful to look at the Referral Situation where the social worker was shown to be the key person in the professional liaison, in other words, she was going to assume responsibility for linking the family which had recently acquired a handicapped child into a social system with which she herself was going to be very familiar. This would entail exploring the resources available to families within the area and visualising a map on which the principal boundaries, roles, properties and characteristics could be located. Very early in the research project it became apparent that there was a need to look at the work of the Health, Education and Social Services departments involved in order to try to understand their pattern of functioning and to locate where their boundaries were and if in fact they were impinging upon the systems with which they should have been in touch. This would give a structural appreciation of the situation.

The idea of teamwork was central to the analysis. A number of aspects of social work practice within it were explored. Five major kinds of social work activity were discerned, although the distinctions between them were not necessarily always clear cut.
1. Integrating Role

Integrating refers to those situations where the social worker needs to be a liaison or go-between person. Liaising is the intercommunication carried out by the social worker who is fulfilling a "key person" position. In the present context this refers to the behaviour which the social worker, as part of her professional role, engaged in when required to facilitate communication between the client and the resource needed to meet his needs. In this role the social worker presents herself as someone valuable less for what she can intrinsically provide, than for her ability to facilitate linking with the complex range of services which are potentially available to people but which in their distressed and ignorant state they themselves cannot readily contact. This activity assumes, clearly, that there is an availability of such a complex of services, and that the social worker knows her way around the bureaucratic maze of scattered resources.

When liaising takes place, typically, the family expresses a need in an inchoate form and the social worker translates this need into a form which enables it to be allocated to a resource and undertakes to make the contact on the family's behalf. Very often social work practice is concerned with enabling clients to do this for themselves, but when families are incapacitated by the distress of being told that the child is handicapped, then it is appropriate for the social worker to act on their behalf until they feel strong enough to assume the responsibility themselves. A further point to make is that resources are not necessarily readily available to, or the staff amenable to being contacted by the lay person. A less satisfactory result may be obtained by the families operating on their own.

Integrating tends to be in a single direction because part of the social work task is to act as the clients' advocate. But more than this
it is a very definite part of systemic thinking, that is in linking people into the social system and the network of resources, the results of which are likely to go directly to the client. The social worker is not usually the advocate of the other professionals. They have their procedures well worked out for communicating with clients; just occasionally these procedures need a gentle social work nudge.

The records show that the social worker on behalf of the families made contact with consultants and other medical personnel. For example, she asked the anaesthetist to explain to Richard Thorpe's parents why the ventilator had not been working properly, she spoke with the Ward Sister about mothers being discharged home, she telephoned headmasters and educational psychologists and made personal visits to naval consultants, administrators of Trust funds and to the Head of Special Education. The methods she used were writing letters, personal visits and, most frequently a telephone call. The use of the telephone was a very important part of the communication throughout the experiment; it was the means whereby a 24 hour coverage of the possible referral situation could be maintained.

The case where the Integrating activity of the social worker was most extensively employed was that of Stephen Archer. The degenerative brain condition was diagnosed when he was four, so as well as the medical component to his problem there was an impending educational one. Figure 10 illustrates the relatively simple network within which the Archer family functioned prior to Stephen's illness and then the complexity created by linking in with Medical, Education and Financial systems. In Figures 11, 12, 13, the communications flow lines for the medical, financial and educational resources are shown. These are important in that their direction needs to be understood for the effectiveness of intervention to be maximised. For example, if the social worker in Plymouth wishes to achieve an action from the paediatrician in London
Diagram to show the systemic development of the Archer family's life before and after Stephen's illness had developed.

Fig. 10.
Diagram to show the variation in communication flow patterns inter-professional and with the family, within the medical setting. 

Fig.11.
Diagram to show the variation in communication flow lines in a family's application to four sources of financial assistance.

Fig. 12.
Diagram to show the innovation in the communication flow lines in a family's application for a place for their child in a Special School.
she is more likely to do this by working through either the Plymouth paediatrician, or the social worker in London, both of whom are within her recognised communication flow lines whereas the London paediatrician is not.

Figures 14, 15, 16, 17 are diagrammatic representations following Buckley’s model (Buckley 1967) of the use of systemic thinking in the problem-solving process, again with special reference to those of Stephen Archer’s family. The medical and financial problems were easily resolved in contrast to the educational ones which focussed upon Stephen being given a place in a special school. In this process the social worker was instructed in the role of link person but as time went by and progress seemed slow it was felt necessary to reinforce this role by advocacy and by the use of the social workers authority as well. It became essential to know where to apply the pressure if change were to be achieved. In all, the social worker communicated several times with ten different persons involved in reaching the single decision of when Stephen could start attending special school. This highlighted the fact that once a child was already at school (for example Nigel Stallman, Norman Freestone and Sharon Kendall) transfer between school was relatively speedy. The special educational selection procedure is geared to the transfer of children already within the system. The S.E.1 form had to be filled in by a head teacher and then went to the Community Health Physician for the S.E.2, form to be completed before the psychological assessments contained within the S.E.3. and S.E.4. forms (See Figure 13).

Stephen Archer was not yet in the educational system and the existing procedures did not cover situations where a new child was being admitted. No head teacher could fill in the S.E.1. form which triggered off the completion of S.E.2., 3 and 4. After these
Diagram to show a very simplified model of a problem-solving process which can be applied to any system including social work. (After Buckley)
Diagram to show the application of the systems model to the medical treatment programme of Stephen Archer.

Fig. 15.
Diagram to show the application of the systems model to the requests for financial assistance by Stephen Archer's family.

Fig. 16
Diagram to show the application of the systems model to the request for a place for Stephen Archer in a special school.

Fig. 17.
difficulties were exposed by Stephen Archer's application the Assistant Director (Special Schools) agreed to a new "exceptional circumstances procedure" whereby the paediatrician could initiate the selection (Special Education) procedure by writing jointly to the Heads of Education and Health who would then start the process with the S.E.Z. form stage.

It was this experience which alerted the social worker to the need to anticipate educational problems particularly in those situations where the catchment hinterland of Health and Education did not coincide. Peter Stephens was a case in point. He lived just across the county boundary in Cornwall. It was within the Health area focussing upon the Plymouth Hospitals but the Educational responsibility was Cornwall's with the headquarters in Truro. Furthermore the special schools were located in west Cornwall which meant that the east Cornwall children had to be weekly boarders. Mr. and Mrs. Stephens were eager to battle for the principle that it was emotionally better for Stephen to live at home and travel daily to school in Plymouth. The issue was dependent upon Cornwall's attitude to financing this which cost effectively might be little different from transporting and boarding Stephen within the county facilities. At the age of one the issues pertaining to responsibilities for Stephen's future education were initiated.

It has already been stated that responsibility for the handicapped child and his family span three major departments - Health, Education and Social Services each of which is a system within its own right. However, 'no social structure is self-sufficient or self-contained' (Katz and Kahn(1969)). It needs to receive energy inputs from a variety of sources. In the past there has been a tendency for social workers to see a family as an isolated unit and for their professional input to be the main source of energy to allow the family to tackle its problems. Systems thinking encourages social workers to act as liaising
agents putting the family in touch with other resources which provide fresh inputs of energy. The social worker becomes an entrepreneur linking the system with the energy supplies needed.

If we accept that all social systems are open systems, which means that they are in a constant process of change subject to the inflow and outflow of communicational stimuli, then it is important that the boundaries of the systems are permeable. In an area of work which covers several departments it is of vital significance to establish the degree of boundary permeability between these departments. In the biological sciences permeability refers to the passage of fluid and porosity to the amount of fluid which can soak through. These terms may be applied analogously to social behaviour to try to explain why messages do or do not pass between different areas and why the amount of information or emotion which passes through varies from one time to another. In the case of handicapped children there ought to be an easy interchange between the Health Department and the Educational Department if they are comfortably to carry out their joint responsibility for special education provision.

It could be argued that their boundaries are more permeable at the point of contact with the clients and less permeable at the interface with the other major departments. Or it could be suggested that the permeability of the family's boundaries is more porous at times of crisis. Some would argue that these professional systems, and in particular the one of which the social worker is a part, are too ready to penetrate into families at times of heightened vulnerability or at crises, and that this having occurred leaves a family less able to initiate and call upon its own resources for energy. Some of the feedback from the parents indicated that they felt that help was thrust upon them. Mr. and Mrs. Williams were of this opinion and Mrs.
Richardson was inclined towards thinking that at times it would have been better for her to be left to get on with her own life.

So to deal with the transferring of energy from a source area to an area of need we are concerned with the whole process of communication. The liaising role of the social worker has been established; in this section we are looking at the wider issues of who needs to be interacting with whom and who is responsible for ensuring the inflow and outflow of communicational stimuli if there generally seems to be some sluggishness in the system.

(2) Authority Role

Authority and power have been widely discussed in social work, although there is relatively little literature specifically on this subject. Forrester and Bailey (1968) have argued that the social worker's authority derives at least as much from the knowledge base and professional skills that he himself possesses as from the power conferred upon him by society. It is something with which he may not feel comfortable and as a result of this, there is a distaste for the exercise of authority which seems to be common among social workers. For example, Clarke (1971) in his paper on the Analysis of Crisis Management by mental welfare officers indicates that they exhibit a very great reluctance to exercise the authority vested within them by virtue of their position. There is a duality of origin to a social worker's authority. It is derived from the institutional source which sanctions that professional to provide a service and from the professional's own personal competence. Blau (1964) writes about power arising out of the exchange transactions between persons when one of the persons has the competence, the commodities or the services that the other needs. This results in what he has termed "power-dependent relationships". There is an element of power dependency in all professional relationships but
in none more so than in those with the medical profession which bask
in its aura of power and prestige. To some extent a social worker
employed in a medical setting is going to enjoy some of this power in
her practice. This is a fact of life, for better or for worse, a product
of the imbalanced, unequal relationship which typifies professional
practice.

The records of the project present considerable evidence of the
social worker quite deliberately explaining her role, and spelling out
the things she might be able to do which could be helpful. The apparent
felt need to do this might have arisen from the section on social work
in the original survey where there was an enormous confusion amongst the
parents as to what it was that social workers actually did. In some
cases, the few social workers who were themselves involved may well have
been unclear as to what their function was in this rather specialised
area of work. This particular social worker felt confident that she
understood the general nature of the problems and she had skills to offer
but wished to make these quite explicit by spelling them out in detail.
From time to time as the focus and pace of work with a family changed,
for example, when Sarah Roberts died unexpectedly, it was necessary to
extend the explanation to incorporate another area of possible involve-
ment. Examples of this from the records include this reference from the
notes on the Freestone family:-

"I tried to establish a work plan with her and it
was impossible. Her response was 'You come round
whenever you want to.' I said, (I hope with care!)
that it was not my needs that were to be met but
theirs as a family with a problem and then I
mentioned a range of social work interventions which
might be appropriate. The only thing she was
interested in was material resources."
With Matthew Dark's mother there was this note:-

"I talked fairly briefly about the social work help and said that it was something she may or may not feel she needed. What we did want to ensure was that all mothers had the same offers of help and that she was not left out just because she was a member of staff."

The explanation of role usually happened in the first or second interview and was seen as an important part of establishing whether or not there was to be a working relationship. Perhaps the greatest testing out of this role comes with the work done with parents who themselves are professionals in related areas. Mrs. Dark was a nursery nurse on the Special Care Baby Unit. Mr. Bates was an administrative officer with the Social Services and one of the mothers whose child was referred but not impaired so was not included in the research write up, was herself a social worker.

It might be argued that the social worker felt too competent in the service she was offering and that the demands of the research project were instrumental in giving her a confidence in the value of the service. The case notes provided examples of the social worker being directive, being judgemental, manipulating and giving advice, all of which, hopefully, reflected nothing other than knowledge and authority in this area of work. There were few examples of the social worker and the parents agreeing contractually to a work programme, but a contract was used to establish a work plan with Mrs. Wrigley: there were problems in this family beyond those created by having a handicapped child, and to make the task more manageable it was necessary to agree the things to be tackled and the order in which this should be done. The social worker also contracted with the Kendall family to work with Sharon intensively over a short period of time.

(3) Consultancy Role

Linking with the use of authority is the social workers engagement
in consultancy. As expertise in working in an area accumulates the social worker builds up a reservoir of particular knowledge and skills.

The social worker needed especially to have a sound knowledge of the theoretical underpinning to her own professional practice. Particularly was this in evidence when she helped parents interpret their own feelings of behaviour and linked this with the adaptation stages through which people who are bereaved or in crisis do pass. Crisis intervention (see pages 103ff.) is a generally accepted mode of social work practice which has been developed particularly within the last decade, (Timms(1978)), although it has been a major component of medical social work practice for much longer. It involves "The active entry into the life situation of an individual, family group or other social system, in order, first to cushion in so far as possible, the impact of a stressful event that throws the person (or persons) off balance; and second to help develop and mobilise the resources of those who are affected directly by the stress." (Parad(1968)).

An example from the case records of the Stephens family illustrates this:-

"Mrs. Stephens spoke about some of the stages she had been through including disbelief since being told about Peter's condition and we related this to the mourning process. She mentioned a friend who had had a miscarriage very recently and who had been so depressed that they had driven her to see the doctor. We made links between mourning the loss through abortion and her own mourning the loss of a normal baby and that reactive depression could be a common factor in these situations."

Similarly in an interview with Mrs. Parker:-

"We looked at the original reason for my involvement as a social worker and how the situation had now changed and whether or not social work was of any help to them in a terminal situation. We talked about her earlier mourning of the loss of a normal baby when she knew that Fiona had Down's syndrome and now the loss that she was going to have to face when Fiona died, for her husband (She says that life has gone quite easily for him so far), this will be the first time that he
has lost anyone who is close to him whereas she has already lost through death a mother and a fiancé. Fiona's death will be the third time that she has lost a person whom she loved dearly."

Not only did the social worker develop a wider knowledge base relating to certain areas of social work intervention, but she also acquired a fairly extensive medical knowledge about handicapping conditions in the course of the project. This made her more competent to expand the medical information which the paediatrician had given, to answer related questions and to provide accurate information. But it could also have made for difficulties when she was party to some medical information, but unable to divulge it. There is a recognised ethical tradition that neither profession encroaches upon the others established territory. This social worker was convinced that it must be the consultant's responsibility to give medical information in the first instance. When Peter Stephen's parents were asked to see the consultant and the social worker had arrived before the consultant was available they became increasingly agitated as they waited. Psychologically they needed to have some information upon which to focus their anxieties which were in danger of becoming exaggerated well beyond the realms of reality, the social worker had that information and she was there. However, all she was able to do was to recognise their anxieties with them and make some tea.

Once the paediatrician had given the medical information then it was available to others for further interpretation and reinforcement. But to do this competently required the social worker to have a greater medical knowledge than that just derived from having heard what the doctor said. She needed to be able to answer the secondary questions which subsequently arose. She needed to read the medical literature which was relevant. Equally it was the general understanding that the consultant would leave to the social worker the more social aspects
of the problem of the handicap, but at times, and quite appropriately, they would each encroach on the others ground. Dr. Brown, in particular, was always interested in the family as a whole and liked to dabble his hand in things social, whereas although Dr. Jones held a similar interest he felt after years in practice that he had only time to do well those things that were clinical and that the rest should be delegated. (4) Social Integrative Role

The social integrative aspects of social work was given much prominence by the early charity and settlement workers who sought through "friendly intercourse" to "bridge the gulf between the classes". (Woodroffe 1962). The integrative and relational input remains a common one amongst social workers, a

"profession which concerns itself with the facilitating and strengthening of the basic social relationships between individuals, groups and social institutions." National Association of Social Workers, New York (1959).

This relational helping process involves the social worker's empathetic self in a positive bond and encounter with individuals and families. Through relationships there occurs an exchange of acceptance, respect and affection (the agape or caritas of altruistic caring).

A social worker carries into the professional relationship a native ability to respond with positive and genuine regard for another person, yet at the same time imposes certain beliefs about how persons should act in relation to each other and to her. The imposition of the worker's professional value system may be attributed partly to the authority of the role and partly to her own personal needs.

Although this social worker believed in open door consultancy and made herself very available to families by night and by day, she had certain expectation of limits of that relationship. There is, for example, a trend in vogue for social workers to be on christian name
terms with their clients. Although there may be advantages in this practice, the disadvantage is that the other roles such as authority and consultancy may be more difficult to comprehend if there is too much familiarity. It can be argued what is in a name, but certainly the use of a surname is likely to reinforce the aura of expertise.

Unlike the other social workers in the paediatric department, this one always addressed all adult clients by their surname and had an expectation that they would similarly address her. Only Mr. Kendall in the last interview used her Christian name and he was reprimanded for doing so by his wife. Similarly all doctors and nurses were addressed formally when in the presence of patients and clients although Christian names were frequently used in the ward kitchen or Sister's office. Any personal information asked of the social worker was always given, but never expanded upon. Mrs. Roberts asked if she had any children and Mrs. Freestone asked if the doctor she had heard of with the same name was related in any way.

Within the constraints of this aspect of a formalised relationship there were many other parts which were very informal and seemingly fairly uninhibited, particularly in relationships with the children. The social worker enjoyed being with children and spent quite a lot of time on the ward playing with them. Stephen Archer was in hospital on many occasions and perhaps more than any other child in the sample. When he was well he would race around and land the odd punch or two; when he was poorly he just wanted somebody to sit and cuddle him. He frequently had convulsions and when he came round he always asked for cornflakes. It was an important part of the social work task to take him to the kitchen and provide him with a bowl of cereals. He gave her many kisses during these sessions and it was a valuable yardstick to measure how ill he was. When Stephen was well he did not enjoy
too much kissing; when he was feeling ill the kisses were prolific.

An analysis of the case recording revealed that, to her surprise, this social worker used a lot of touch in her communications with clients! Often all that sick children seek of adults is to be cuddled, to have their hands held or an arm around their shoulder. In times of stress when an adult may be grieving tremendously it is normal for that person to regress to a more childlike pattern of behaving and similarly to respond to the comfort of a shoulder to cry on, an arm to support him or a hand to hold. When Peter Stephen's grandmother was told of his condition she took hold of the social worker's hand. After Sarah Roberts had died her mother could only respond to the social worker's arm around her shoulder. Mrs. Kendall broke down when the doctors were having problems in getting the needles into Sharon's veins and when the social worker put her arm around her she leaned against her and wept. When the social worker quietly suggested to Mr. Kendall that he took over the holding and comforting it was to have an outcome of greater significance than the social worker realised at the time. That afternoon they went home and went to bed together for the first time for many weeks. Mr. Green was the only father to whom the social worker actually, rather than metaphorically, offered a shoulder to weep upon and this might have been the social worker's cultural norms overriding emotional need. Perhaps the only time when the social worker had any qualms about the use of touch was in her work with Norman Freestone. In the 18 months that she was working with the family, Norman physically matured through puberty while simultaneously he mentally regressed and as a result his behaviour was fairly uninhibited. The early gentle taking hold of the social worker's hand when he was walking and became unsteady, changed to incidents of heavy pawing and strong physical contact which required a fairly phlegmatic professional response to be cultivated.
All the practical things which the social worker did could be included in this role - the numerous cups of tea made for grieving parents, acting as chauffeur when no family transport was available, doing some home visits when it was easier for the parents, changing nappies and giving children drinks. They may not specifically be recognised as the core of social work practice but they are the facilitating factors in relationship formation.

An extract from the case recording of an interview with Mrs. Roberts the day after Sarah died perhaps reflects something of this particular role:

"She said that it was so much easier to talk to somebody outside the family who did not steer her away from 'the things she wanted to talk about but which made her cry'. She again spoke of how she had felt when I had walked into the room the night before; she had been so glad to see me but had felt all her grief welling up which was why she had said 'don't say anything'. When I had put my arm round her she knew that I had understood."

Most of the examples from the recording are of the social worker reaching out to the families. There are times when the families were seeking the social worker and making an overture to her. They called in to her office and went to quite elaborate preparations for home interviews.

(5) Evaluating Role

Finally, there is the evaluating role. It has been stressed earlier that the social worker's case record is a working tool and throughout all the notes there is considerable evidence of the social worker writing "memos to herself". There are comments about the way that people are behaving and pointers to factors to which the worker should be alerted. There are value laden judgements about people, statements of the social worker's reaction to some patients and there are summaries of where the worker thinks the case is at and where she thinks it should be heading.
There are reminders of things which need to be done and deadlines for certain actions to be achieved. Such notes occurred much more extensively in the records of the cases in Group A compared with Groups B and C, perhaps because there were many more facets of the system to handle and keep tabs upon. Children who were impaired and placed in Group C did not have the extra handicapping features so fewer links had to be made with other networks. Similarly with the families whose child died, the contact was more sharply delineated and generally of shorter duration, and there was not felt to be a need to keep current thinking linked with forward planning.

The notes provided evidence of appraisal and evaluation with the parents and feedback from them at stages in the case development were recorded. A more major attempt at evaluation was to come with the questionnaire completed a year after their first contact, but, prior to this, where parents spontaneously made comments about the service these were written down. Mrs. Williams mentioned that she thought the social worker was wrong to raise the issue of a postmortem on the telephone, and also said that she felt the hospital put pressure upon her to go to see Susan and she thought this was quite wrong. These comments made the social worker particularly careful in handling these two areas with subsequent parents. When parents made comments about colleague's performances the social worker was very careful not to agree with any of the criticisms that were adverse, nor disagree with any which were complimentary.

C. TEAMWORK AND SOLO WORK

(1) Teamwork

The core assumption of an Integrated approach is that professional action is interactional rather than individualistic which means that it can only be implemented by groups working as a team rather than
as separate individuals. A team in this sense is a group with a distinct structure, identity and way of functioning. Members belong to it by virtue of their roles and the resources they offer, but need to be able to demonstrate flexibility to shift roles if the need arises. It is a recognition that an individual cannot do everything all of the time. Members need to be competent in interpersonal relationships and to be able to work harmoniously and efficiently to further the work. It may need to engage in joint support in building up expertise to tackle broader strategies of intervention.

Kane's (1975) definition of teamwork requires three conditions, i.e. (1) a common team purpose, (2) distinct roles for team members toward achieving the common purpose, and (3) a communication method among team members. All these conditions would be met by a type of practice which Evans (1978) has defined as an individual form of teamwork. It is a group of people who have a common interest area but who divide the work within it and take personal responsibility for their own sector possibly with very little intercommunication going on between all the parts. Evans related this model to the organisation of social work within social services but it might be equally relevant to a hospital setting.

Medical social work is usually allocated on the basis of one worker attached to one or more consultant firms. "Firm" is the medical jargon for the hierarchy of consultants, registrars and housemen who work to one specialism. From them, and from the nursing staff working on the wards in which the consultant has his beds, the social worker picks up referrals of various problems for which professional help might be offered. There may be opportunities for interprofessional discussion and times when patients may be seen jointly, but more generally, the problem area is apportioned and the work upon it individualised.
If the thinking behind an Integrated approach was to be applied in the present project then the experiment required the medical staff to move from the model of an individualised form of teamwork with which they were developing a familiarity to a model of joint teamwork, which not only was alien to them but was being requested by somebody who was not part of the hospital staff and with whom they had not previously worked.

The previous section has indicated the various integrative and liaising activities of the social worker which were directed to keeping communication channels open, enabling people to be party to relevant data and, at times, applying professional clout when obstructions to processes seemed to be developing. There was little to suggest that this particular activity facilitated teamwork or that all the members collectively threw all their expertise behind some considered endeavour. To some extent it happened when the social worker orchestrated the negotiations concerning Stephen Archer's school entrance but this was rare. There were occasions when something closely approximating the joint model occurred but many more times when team members were acting as individuals sometimes appropriately and more often in ways that were not entirely desirable.

The joint model was perhaps best developed in the referral situation or in working with families where the death of a child was the likely outcome. It was less likely to occur in a quickly changing medical situation for the obvious reason that the rapidity of change often necessitates speed of action which does not allow for time-consuming communicating to take place. Another factor might be when a professional did not feel very confident in what he had to do and did not wish to expose this to a colleague. This is most likely to have been the reason why Susan Williams' parents were told by the houseman in advance of the social worker's arrival, although it was
known that she was on her way into the hospital.

The procedure for the initial telling situation has been explained in more detail elsewhere, and this was probably where teamwork was at its most effective. The parents were seen together by the consultant and the social worker, sometimes joined by the junior medical staff and the ward sister. The value of this was that the team was paraded as a whole and offered to the parents as a helping resource. It emerged later that the role of the social worker was less baffling to the parents if she was first encountered in the team situation rather than as a solo worker at a later stage. The importance to the social worker of being at that opening encounter was that she heard exactly the medical information that was given to the parents and was able subsequently to reinforce this which was an important aspect of teamwork.

Team consultation occurred quite frequently and particularly so when a bereavement was imminent. No matter how many times one has done it, nor how remote one is from the situation, telling parents that their child is going to die is one of the most harrowing of professional tasks. For those professionals who were parents themselves inevitably there was a slight degree of identification. The social worker felt that it was the joint support of another professional in going into this situation which enabled a more caring and involved strategy of intervention and this view was shared by one of the registrars and the housemen, and possibly others but they did not say so.

Every member of the team felt saddened by the death of Richard Thorpe, a beautiful fair haired two year old whom we never knew in a conscious state. Over some 30 hours the team of four had much contact with the sorrowing parents and grandparents and were able to let themselves get close because there was so much mutual support. The day Sister on the Intensive Care Unit said to the social worker when she had gone in
early in the morning, "If you're the social worker thank goodness you've come; they're in a terrible state." This may be interpreted as a way of saying that they were doing everything that was medically possible but that further role functioning within the team was needed. Once that was achieved the work with the family as a whole burgeoned. Mr. Thorpe could not settle in one place for any length of time and had restlessly to keep walking around the Unit. The nurses tried to persuade him to go out or to sit on a chair but when the social worker explained to them the necessity for his hyperactivity they were readily able to accommodate this within their nursing activity. After the electroencephalogram had shown that there was no brain activity the timing of switching off the ventilator was fully discussed by the consultant, registrar and social worker. The parents had gone home for a break and although it was quite inconvenient to the consultant to wait he agreed to do so, rather than send the police round to the house which would distress the parents even more. We expected that they would meet their other son from school and then return to the hospital and this, in fact, they did.

Joint interviewing often stemmed from the team consultation and again this tended to occur most frequently with bereaved families. At midnight following Sarah Roberts' death the registrar and the social worker interviewed both parents for over an hour and then took them to say goodbye to their little daughter. Because it happened in response to an emergency, it was not and could not have been, a planned interview, but by this stage in the experiment these two professionals felt very comfortable in working with each other and had developed some expertise in complementary roles. When it was known subsequently that Sarah had died of Instant Cot death the consultant and the social worker went together to tell the parents at home. All too frequently parents have been summoned to the hospital to save medical time; in
this situation there was a recognition of calling these parents back to the place so soon after the horror of their last visit and therefore a willingness to go out to them. When Norman Freestone became difficult to control in an outpatient clinic the consultant and the social worker agreed that in future they would see him at his home. These frequent joint visits in addition to making life easier for the family, also provided an opportunity for Norman to be seen in his familiar setting.

Joint interviewing in one family situation was carried out by the social worker and a consultant who was not part of the paediatric team. Mrs. Wrigley's medical condition required her to have regular consultations with the naval psychiatrist and he invited the social worker to join them. This enabled him to keep in touch with Amanda's medical situation and made it possible for the social worker to be fully aware of the limitations in parental functioning caused by this serious illness. It was not teamwork as previously designed but an indication of how far the network of communication has to be extended to involve effectively all aspects of professional involvement with one family situation.

Another variation of joint interviewing was for the social worker to see together two mothers with whom she was working and who had formed a friendship while they were both on the ward caring for their children. During this period these mothers became close companions, discussed their children's medical situations and generally supported each other through various crises. Mrs. Maker and Mrs. Farmer were alone together in the mothers' room when the social worker went to the ward, and it seemed appropriate to interview them together. It was a useful session in which comparisons and contrasts were elicited and each was able to express some anxiety about the treatment, which they might not have been able to do without fellow support. Such contacts were not always
successful however, although Mr. Parker was keen to meet other parents of children with Fiona's condition when I introduced him and his wife to Mr. and Mrs. Cann (having earlier sought their permission to do so) during an outpatient clinic, the meeting did not appear to achieve any of the things for which Mr. Parker had hoped. Mr. Cann was reluctant to extend the contact beyond the introduction and saw no purpose in mixing with parents who were similarly placed, nor in comparing the milestones in their daughters' respective development stages. The mothers talked together quite amicably but obviously it was to be an isolated occasion and the social worker did not proceed any further with this contact.

Perhaps one of the secondary developments from the teamwork approach was an apparent greater willingness for the consultants to involve the extended family if they so wished. Traditionally medical etiquette has tended to confine discussion to the immediate next of kin. A husband alone would be told of his wife's medical condition, parents would be given information about their child. As the paediatricians moved towards involving other professionals in their important information giving sessions they tended to move away from a pattern of excluding the other relatives. If young parents are sitting with their own parents and in-laws then it makes sense to share the critical information with them as a group. The same argument could be applied as the one used to justify the social worker's presence. Parents in a shocked state "hear" only a small part of what they are told. The relatives, although shocked themselves may not be quite so emotionally involved and are more likely to "hear" and subsequently reinforce what has been said. Both sets of Samantha Field's grandparents were included in the later discussions and grandparents and an aunt heard Dr. Jones suggest that the ventilator should be turned off and Keith should be allowed to
die in peace. Although Peter Stephen's grandmother was in the hospital she did not come up with the parents to see the consultant. Following Mrs. Stephens' request that we told her because she was too close to her to do so herself, we included the grandmother in all the subsequent sessions.

(2) Solo Work

It is important to stress that it would have been quite inappropriate for every interview to be joint. This would have been enormously extravagant of professional time and would have negated the value of the different roles and resources. The value of teamwork is in the understanding of the member's individual contributions and a recognition that these often will be carried single-handed. But the concept of teamwork depends upon the ability to integrate the parts in a holistic way at the crucial stages. It would be a barrier to communication if on every occasion the whole team had to be assembled before anything could be said or done. Equally the group gathering together could be taken by the parents as a sign heralding doom and despair. Parents can be very perceptive and it soon was recognised that the larger the team the greater the significance of the information.

It has been mentioned elsewhere that on occasions when the consultant gave the first information about the medical condition to the parents on their own, it was difficult subsequently for the social worker to become completely familiar with the situation. More significant were the rare times when the consultant gave information to only one parent which at the time caused considerable distress and ultimately resentment by the parents and to some extent the social worker (e.g. Canus). From the earliest contacts with Mr. and Mrs. Cann it was very clear that they were a closely interacting partnership but one in which the husband took the dominant role. Mrs. Cann leaned on him for support and for
decision making. Clearly it was ill-advised solo work to select out the wife alone and to tell her that her newly delivered daughter was permanently handicapped. Perhaps the problems were further compounded by the fact that to the social worker this consultant seemed the least comfortable of the three in telling parents about that particular condition. This was something which she discussed with him at one stage, because in talking about Down's syndrome, he seemed to be quite different to what he was when he discussed, as an example, meningitis. He was surprised to learn that his approach did seem to vary, as he was to be told that the Canns were distressed about not having been together when the news had to be given to them. Their situation obviously called for greater skills than one professional person carried. In due course, many more hours of professional time had to be spent in retrieving the situation and even then this was never very satisfactory.

In other cases, some information was given in the first instance by the consultant (e.g. Freestones, Prices, Archers) but at the same time, a joint interview for much fuller discussion was arranged.

Although the doctors were willing to accept that generally telling one parent alone was not desirable there were situations where this was necessary. Mrs. Richardson was living apart from her husband, and although he came to see the baby, his wife did not allow him to be much involved. Mr. Dark and Mr. Cox were both in the Navy and not immediately available at the crisis point. Mr. Green disliked hospitals and after the initial telling situation avoided coming in. Mrs. Proctor was told on her own and retrospectively said she preferred it that way and then she chose how and when to tell her husband. He was another father who disliked the hospital atmosphere and came in as infrequently as he could.

An important aspect of the teams communication is the recording process. The consultant and his junior doctors wrote notes in the
medical records of the patient. These were kept on the ward and were available to other staff but not to the patients or their families. The social worker could look at these and learn the bare bones of the medical situation. Only rarely did she write anything in the medical notes but they were available to her if she had some important information to add. Social work recording was much more extensive and was held in the social work department. Theoretically it should be available to the doctors; in practice, it was not used by them. Consequently it was important for the social worker to take responsibility for summarising the significant data which she had and for making it available to the doctors. Usually such summaries would be contained in a letter to the consultant and such contacts helped to link solo work with teamwork.

Konopka (1959) wrote that teamwork in a professional undertaking demands high competence of each individual team worker as well as the capacity to use this competence in a joint undertaking. Krakow (1964) referred to it as a process involving "joint thinking and planning by the social worker and the doctor on the patient's behalf."

Earlier in this account (p. 103) there has been reference to the two opposing patterns of teamwork as described by Kane, i.e. "co-ordinate" and "integrative" and a recognition that in this setting the teamwork was of a co-ordinate kind. In many respects it fell short of this. The medical "firm" is a hierarchical team, well established within the hospital setting and with an almost omnipotent consultant as leader. It can operate quite adequately with all the medical aspects of handicap and although a social worker would hope that it will not be equally competent, it can tackle some of the social problems as well. On the other hand, a social worker is completely lacking in medical skills and offers only a small area of expertise in the total problem situation. Perhaps because of this social workers seek to promote the teamwork
concept to give them security to operate. They may seek the mantle of medical authority by closely aligning themselves to the doctors.

It was not easy for this social worker to establish a position within the hospital. She was not a permanent, salaried member of staff. There was some resentment at her presence from the other social workers, and the doctors had established a way of working with the social workers which initially they did not see any need to modify. It called for a slightly impertinent approach from the social worker in that she said she had additional expertise to offer and it would necessitate her becoming more involved with their work and the establishment of a team. The part of the work which the doctors tended to shun was the giving of bad news, the management of people in crisis and the coping with grief. Perhaps this was their Achilles heel but this was where the social worker got into the area of work and because what she contributed appeared to be effective, she was allowed more freedom to operate. It would have taken longer than the two years to really establish the teamwork concept but the seeds were sown and towards the end of the research period there was evidence on occasions of it working very well.

D. CONFLICTS

Under certain situations conflicts arose. These conflicts were of the following kinds:-

(a) between parents

(b) between parents and professionals

(c) between professionals.

Those in category (a) were the most common. Inevitably, where there had been disharmony in the marriage the stress created by having a handicapped child precipitated further conflict. This was most in evidence in two young naval families where in each case a pregnancy, which had forced the parents into matrimony, culminated in the birth of a severely handi-
capped child and greatly increased the discord. Mr. and Mrs. Wrigley quarreled over money, over responsibility for the child, over involvement with the in-laws, over household chores and their social activities. To a similar range of arguments, Mr. and Mrs. Cox added those pertaining to extra marital affairs. Mr. and Mrs. Old were another service family, he was an army officer and their strained marriage was severely disrupted by the arrival of a very premature and potentially handicapped baby.

Marital stress was from time to time evident with the Freestones, the Stallmans, the Kendalls and the Parkers, but all recognised, acknowledged and associated it with the stress of the medical condition. These marriages were likely to survive the crises but those of the Wrigleys and the Coxs showed all the signs of an early and permanent break up, which subsequently did happen.

Some of the stress precipitated conflict issues between parents and the professionals. For example, Mr. and Mrs. Kendall wanted to hang on to a complete parental monopoly over decision taking, whereas the professionals pushed a view that since it was her life that was at stake Sharon should be allowed to be more involved. Sharon herself had several minor tussles with the junior doctors over treatment issues and with her parents over family attitudes. After nine years of intermittent suffering with leukaemia she was not always recognised as being quite an authority on the subject, and more especially on the subject of side effects.

Mrs. Bates was perpetually in conflict with the medical profession because of the delay originally in diagnosing Joanne's condition, and nothing in their present competence in treating it was ever going to atone for this. So too with Mrs. Stallman who felt that everyone was professionally incompetent in their apparent slowness in diagnosing in her son a condition that was going to be acceptable to her. She was also
openly in conflict with her son and honestly confessed to not liking him, but this did not make it any easier for her to accept that part of his condition was emotional deprivation which was tending to exaggerate a not particularly serious physical unco-ordination.

It would be considered in breach of professional etiquette for a doctor to criticise another doctor and to some extent this holds true for social workers. However, it was necessary for this social worker to telephone and mildly rebuke a social worker in another hospital who on three occasions did some work with a family without first checking if those families were known to another department. Such an action can cause confusion to patients, as well as being considered professional bad form. There were more strongly worded telephone calls to the educational psychologists and with the senior administrators responsible for the allocation of places in special schools, the conflict issue being the length of time involved in the decision making process. Any differences of opinion between the team members were rare and always kept from the patients.

E. CLIENT’S BEHAVIOUR

The ways that people respond and behave are the communication stimuli to the pattern of professional practice. Yet, inevitably this is a two way process, for the reception which their behavioural manifestation receives will inevitably affect the subsequent course. Similarly that which the professional perceives in a client’s behaviour is influenced by his own observations and feelings and by the particular role that he is carrying at that point in time. That of the client’s behaviour which a social worker chooses to record has been filtered and selected out by her own heightened perceptions of what is considered to be expected or not expected, or what is relevant or not relevant.

It is already well documented (D’Arcy (1968), Cunningham (1979), Thomas (1978), McAndrew (1976), Kew) that the telling of parents must be done with great sensitivity and skill, the inference being that the
information given is so devastating that parents will respond in extreme ways. Implicit in this is the suggestion that when parents are told that their child is handicapped they face an emotional crisis as acute as any challenge which the handicap may present, and as much skill must be applied to the care of the parents as to the child's medical problems. Although parents may have had some anxieties created by suspicions, until they are given this information they are not strictly 'in crisis'. However, the content is of such enormous significance that they are likely to be thrown into an immediate crisis with a pronounced behavioural expression.

Some of the parents in the original survey spoke of doctors being paternalistic and trying to protect the parents' feelings by cushioning the information in more optimistic terms than was known to be true. To counteract this, our plan was for the consultant to be honest and to try to paint neither too dismal nor too euphoric a picture of the real situation.

Whenever the social worker was present at the initial telling situation she recorded information about the parents' reaction to the facts. Typically in the first instance some of the parents appeared to be completely stunned. They acted as if they had not heard, seemed dazed and gave an impression of having gone blank. (Mr. and Mrs. Stephens, Mrs. Cann, Mr. and Mrs. Roberts). Some of the parents showed their grief almost immediately. Mr. and Mrs. Stephens had to be left together to cry alone before they could discuss the matter any further. Mr. and Mrs. Roberts cried while we were in the room. Mr. and Mrs. Thorpe were crying together when the social worker went in and continued to do so for much of the time until Richard died. The Archers and the Harrises cried freely, the latter in a way which to the social worker appeared to be very exaggerated. Mrs. Foster wept throughout the first interview. At some stage in the initial telling situation nearly all the
mothers cried, the exceptions being Mrs. Freestone, Mrs. Smith and Mrs. Cox. The first responded with non-stop talking and the other two with very detached expressions. At no stage did we see any of these mothers cry.

We expected that the parents would hear very little of what was said to them in the first session and this was in fact true. It is possible that nature prevents the pain of shock hurting too much by anaesthetising with a form of amnesia. Things are told to parents but in their shocked state they do not hear them and so there was a need to retell. This was the reason for arranging a follow up interview some 12-24 hours later. The "anaesthetic" was wearing off by then and although the pain was beginning to be felt there was a readiness for knowing more about what was causing it. One of the ways of testing out how much the parents had retained was for the social worker to ask them what the doctor had told them. Frequently the parents were quite confused about this. To some extent this was due to an unfamiliarity with the medical terminology although this, quite deliberately had been kept to a minimum.

Dr. Fergus was involved in telling two sets of parents that their respective children had Down's syndrome. In both cases in the first interview he drew detailed and highly competent charts of chromosomes to show the translocation of trisomy 21. It was a quite inappropriate response to the parents' question of 'what causes it?' but would have been ideal had one of his housemen or a medical student asked the same thing. One could describe this as the consultant being on an inappropriate wave length and this is likely to trigger off a different behavioural response in the parents. In both these situations the two fathers involved were angry and continued to feel this way for a very long time. Other studies of crisis work and the stages in a mourning response suggest that feelings of anger will appear at some point and that this might be projected in all directions and at anyone regardless or not of their involvement. Each of these fathers was
angry with the consultant which the latter might have felt was inappropriate, and yet it was probably a very helpful thing for the fathers to be able to do. It was important for members of the team to recognise that anger is part of the mourning process and that it requires a sympathetic hearing rather than an irritated response. In the case of the Williams family the anger of both parents was directed against the social worker and this channelling of emotional responses made it possible for Mr. Williams to have an interview with the registrar in which he was able to talk about two previous pregnancies with which he had been involved and which had both resulted in the birth of an abnormal child.

Close families draw support from their members. Distressed parents can lean on their family networks and draw from them the resources they need when the professionals are no longer involved. Whenever the members of the extended families were in the hospital and the parents wished it, these relatives were included in the discussions. The ways that these family members interacted together in the crisis situation indicated to some extent how this family was likely to tackle the problem of having a handicapped child. If there was caring and support being offered then it was likely that this pattern of behaviour would be repeated in their interaction with the child. It was important that at a very early stage this was allowed to happen.

How much information the parents were ready to receive had to be gauged by their questions. Some needed to be told everything at once (Freestones), others could only take in in instalments (Harris, Cann, Richardson). In all of these situations the diagnosis and the prognosis was clear cut and precise. Where there were doubts and uncertainties the parents' acceptance of the information was affected by the anxieties of the unknown. The precise nature of Mark Cox's very severe abnormalities was never fully understood and his parents tended to block out
the knowledge that he was mentally handicapped and to hear only that
there were physical abnormalities. In other situations anxiety caused
parents to fantasize, to have phobias or to become superstitious.
Following Sarah's epileptic fit Mrs. Roberts was apprehensive that some­
thing was wrong because this was the 15th and it had been on the 15th
six months earlier that they had been told that their daughter had Down's
syndrome. Mrs. Harris was sure that her baby would be a cabbage because
her sister-in-law had had a child with a spina bifida. Mrs. Forster
said that Simon's heart condition was the result of a curse put on them
by her mother-in-law, and Mrs. Roberts wondered if they were such wicked
people that they were being punished for their sins. Mr. Parker had
fantasies about Fiona becoming normal as a result of a specially designed
programme of education and that this would be the making of medical
history.

Occasionally the reaction of the parents to the initial telling
situation was to shift the spotlight onto themselves. The Kendalls spoke
of marital stresses created by having a child with leukaemia and wondered
how they were going to manage; Mrs. Forster asked for tranquillisors to
help her bear the problem. The parent who particularly used this ploy
was Mrs. Stallman who always insisted that her own earlier personal
experiences be discussed in detail with very little reference to the
present situation created by her son's minor impairment. Mrs. Bates
reacted to her daughter's hereditary rickets by being extremely negative
and particularly critical of the medical profession, and by blaming her­
self unmercifully for being the carrier of the condition. She said that
had she known that she would never have had Joanna and suggested that
the last straw for her was to be offered social work help which rein­
forced her feelings of inadequacy.

Frequently parents queried the diagnosis even when it was a very
firm one. Mrs. Freestone did this on several occasions especially when Norman lived longer than had been expected. The request for a second medical opinion was never dismissed by the consultants as being unnecessary or seen as a threat to their personal diagnostic abilities. In this situation the request was followed up with letters and test results to the leading authority in the country on the condition and a consultation in London was offered but not taken up.

The Kendalls had had so many years contact with hospitals and medical treatment programmes that they appeared to understand fully the medical jargon and the reasons for giving each of the many drugs and to know all the possible outcomes of the actions that could be taken. Other parents were more confused about the medical situation. Mr. and Mrs. Cann, although intelligent parents, struggled to comprehend the causes of Down's syndrome and preferred to collect odd pieces of information from well meaning relatives and neighbours. Information from these sources was not always accurate but it was presented in a form that was meaningful to them. Although Stephen Archer's mother was a nurse she kept searching, at times quite wildly, for possible diagnoses, and would present two or three daily during the initial stages. When their dog, which they had had for 10 years, became aggressive and the veterinary surgeon diagnosed a degenerative condition in the brain and recommended that the dog be put to sleep, they saw parallels with their son's situation and wondered if he had caught anything from the dog.

Some parents were unable to look to the future, some looked too far. At a very early stage Mr. Parker was asking about marriage prospects for Fiona, about private education, a need to move houses and 'if Fiona was a cracker with good legs was she likely to get pregnant' which has links with some of his other fantasies.
Crisis intervention has been defined elsewhere and the theoretical overview drew upon the work of Lindemann and Caplan. It is particularly relevant in providing an understanding of the ways that parents behave when they are coping with crises created by loss through death. Not all stressful events lead to crisis state and not all parents who lose a deformed or an acutely ill baby necessarily find that their usual steady state is thrown into disequilibrium. Perhaps such an example would be Mr. and Mrs. Field who although saddened by the loss of their daughter did not show any signs of extreme psychological upset. Likewise Mrs. Green was not so much upset by Keith's death as by the fact that because she had been sterilised she would never be able to have the much longed for daughter. Loss of babies was not a new experience to either of these families and they appeared to function much as they usually did throughout the time of their bereavement.

Sometimes the professionals would think individuals were exhibiting quite extreme grief reactions although at the same time accepting that 'everyone can master a grief but he that has it' (Shakespeare - Much Ado about Nothing). Mr. and Mrs. Harris after being told that their baby's slightly increased respiratory rate might be due to a heart condition were at once extremely distressed and wept in each other's arms "wishing the baby to die rather than be a cabbage". The bed was littered with masses of lilac tissues and there seemed to be nothing that the professionals could do, or say, that would assuage their grief. This behaviour was to make the professionals somewhat apprehensive about going back to tell these parents that Tracy's condition had suddenly deteriorated and that she might not live. The 'usual' or the 'normal' grief reactions the team felt able to handle; the extreme ones were more problematical for them. Although this happened early on a Sunday morning and the social worker had gone home, some 14 miles from the
hospital, the houseman, despite the serious clinical situation, waited for her to get back to the hospital to share with him the task of telling these parents that in fact the medical problems were as serious as the parents had anticipated. But by this time these parents had emotionally prepared themselves to some extent for this information. They wept profusely; Mr. Harris climbed on to the bed and lay crying beside his wife, but they were able to decide that they would like Tracy to be baptised and in due course, they were able to come to the simple ceremony and stay with the baby until she died. It is reasonable to assume that some of the emotional responses of these parents to this situation were coloured by Mr. Harris having a younger sister seriously handicapped with spina bifida. So too in Mrs. Roberts' grief reaction to Sarah's death she was also mourning other losses, including the loss of a normal baby which she experienced a year ago when she was told of the Down's syndrome, her brother's loss of health through cancer, her grandfather who was very near to death and an uncle who was currently undergoing major surgery. Mrs. Parker's mother and fiancé had both died at an early age and as she prepared to lose Fiona she mourned other losses of people she loved. Multiple grief reactions are almost inevitably part of mourning any loss. A primary loss brings secondary loss in its wake for it is never quite clear just what it is that has been lost. The death of a child may trigger off the earlier unmourned loss of a person who has been meaningful to that parent and the grief is an expression of a multiplicity of sorrows.

For many of the parents whose children died this was their first close encounter with death. They were overwhelmed with feelings and emotions which they found difficult to control and which at times were of such intensity that they were momentarily fearful of becoming psychotic, particularly in families where other members had a psy-
Some of the parents tried to understand the meaning of death and several like Mrs. Roberts saw it as a punishment for their own wickedness. Others asked about the worst that could happen but then did not want to look further at this. Mrs. Forster said 'will he die?' but when she knew that he might she did not want to be told any more. As Mrs. Freestone worked through the stages in the anticipatory mourning process she was able to look realistically to the future. She could talk about death about heaven and a life hereafter, and as she grew stronger in her belief she was able to involve Norman in this, although by this stage his powers of comprehension were considerably diminished.

At times there was a need for ritual. Families which normally would not have contemplated having their child baptised asked for it to be done when death was near and they themselves participated in the ceremony. (Harris, Thompson). Mrs. Roberts who had not bothered to have Sarah baptised during the first year was very distressed after
she had died about not having done so and asked the social worker if she believed that unbaptised babies went to heaven.

It was to be expected that the stress of the situation they were experiencing might expose other problems in the lives of these families. These were the cracks which in normal life were papered over but which in extreme conditions would be reopened. In particular marital stress was very common and much of this was due to the problems associated with having a handicapped child. Mr. and Mrs. Kendall were better than most parents in sharing the work created by having Sharon in the state she was and seemed to pull together well, but there were several flash points during the months. In the write up following one interview at home the social worker recorded:-

"The stress of the last few weeks had really built up and the relationship between the two was very strained. My presence seemed to act as a catalyst and they really let fly at each other which perhaps needed to happen. It focussed on small things like use of the car, who slept with who and that he never took her out without the kids or the dog. It also tends to be predominantly one way but Mr. Kendall did come back at his wife more than he is supposed to do.

We looked at the stress, the constant fear of death with which they lived and their own guilt feelings about being angry with Sharon when she would not smile at them or even speak to them at times. At the moment, she is very much a Mummy's girl and Mrs. Kendall finds this difficult and wishes that she would become a Daddy's girl which is what he wants. They know that their marriage will survive; it is long established and they feel that the basis is still sound, but they both confess to it going through the roughest patch that they have ever known."

Mr. and Mrs. Old's marriage was virtually ended before Amanda was born but her deformities and the anxieties created by her clinging to life for so many days destroyed any vestiges of the marital relationship. On the other hand, there were several references like those made by Mrs. Allen to the marriage having become closer since they
had been exposed to the stress of having a handicapped child.

It has been mentioned already that the Kendall family showed an equal division of labour and this could be said of the Bates, the Canns and the Stephens. Mr. Freestone was a long distance lorry driver and away five days a week which meant that his wife carried the lion's share of the care and control of Norman, but when he was home he did take a turn. If there was an unequal distribution of the labour then the mother tended to bear the brunt of it as for example did Mrs. Parker, Mrs. Maker, Mrs. Proctor and Mrs. Richardson. It could be argued that this was due to their husbands employment but this was only a contributing factor. Some fathers might be regarded as being selfish or frightened by the demands made on them. At the height of the crisis with Anthony Cooper it was the father who was most involved in sitting with Anthony and caring for him.

The inequality in the carrying of the work load implied a variation in the parental involvement in the situation. This might be further linked with the parents being at different stages in their acceptance of the condition. Mrs. Parker was always much more realistic than her husband in appreciating the implications of the medical situation, and the same could also be said of Mrs. Wrigley and of Mrs. Cox. Mr. Parker seemed to need his fantasies to protect himself from knowing the painful reality of a future fraught with difficulties created by having a child with Down's syndrome and a very defective heart condition. But as he dreamed of a future when Fiona would be normal he could give his wife little support in the anguish of today and the marital stress between them was considerable. Mr. Cann on the other hand was so much further ahead of his wife in understanding and accepting their lot that he entirely commandeered the role of family spokesman and as a result had an almost disabling effect upon his
wife. Some parents wished to have contact with other parents who were similarly placed; others could think of nothing worse.

Nearly all the children who comprised the experimental group were babies, some 25 being in their first year, another five being below school age and only three being older than this. The implications for social work practice of this fact are quite considerable. Three quarters of the group were too young to become clients in their own right, and a further five children were too young for the social worker to do anything with them other than play although this was a very valuable way of forming a relationship with them. One of these children was unconscious throughout the brief contact and 9 year old Anthony Cooper was unconscious throughout the crisis period and when he fully regained consciousness there was little further work to be done with the family. So only two of the children (Sharon Kendall and Norman Freestone) were chronologically of an age to become possible clients and sadly Norman's deteriorating brain functioning made it impossible to have very much verbal rapport. Sharon was intellectually alert and as a young teenager the team thought she had some rights to decision making, a view which created something of a problem for her parents. They had developed a strong nurturing parental behaviour pattern through the years of illness and they found it extremely difficult to mature in the parental role to a stage of allowing Sharon some freedom. The social worker had contact with the Kendall family for five months, during which time there was a significant week when intensive work was done specifically with Sharon. She was depressed and this was discussed with her parents during a joint interview. It would have been possible to have given her anti-depressant medication but since it was believed to be a very understandable reactive depression and it was known that taking more pills would increase her general hostility to treatment it was
agreed that some intensive work with the social worker should be offered to her. Sharon said that she would like to do this. The extract from the social worker's records covers the work done together in that week. There was a movement forward from being a patient in nightclothes at home to being a young lady who made an appointment to suit her convenience with a worker at the hospital. Although the progress was not maintained, and had not been expected to be, Sharon for perhaps the first time ever found that it was safe to talk about death with somebody who would allow it to be mentioned.

Summary

This chapter has been concerned with an analysis of the social worker's case recording to reveal something of the processes of intervention which developed with the Experimental Group. A total of 41 cases were referred to the social worker but eight of these were not included in the project because the child's medical condition was not relevant. So the analysis has been of the recording of 33 cases, and obviously some were in much more detail than others because more work was done with them. Considerable use was made of the nine stages extracted by Turner (1981) from Glaser and Strauss's account of Grounded Theory which established five major categories. Of these the most extensive is that concerned with social work phenomena, and although teamwork and solo work is a separate category there is some overlap between the two.

There was some difficulty in grouping clearly what were either activities or attributes of the social work role. To some extent this may be a problem of applying Grounded Theory to data being gathered for other purposes. For example, combing through the data revealed a high incidence of reference to the social worker using the telephone. This would be recorded in the notes to show that contact was made,
but that as a letter was not written there is no copy letter conveying the content of the communication. It also may suggest that, with all its advantages and disadvantages, this particular social worker was more inclined to liaising by quick telephone calls rather than by writing letters. As such it links with the concept of style which is the opening section on the social work phenomenon.

There is evidence in this section of use of both the traditional methods of casework intervention and of the implementation of some of the concepts of an integrated approach, particularly with regard to problems encountered in obtaining a place in a special school for one little boy. The variety of roles a social worker carries became apparent although it was not always easy to categorise every aspect of this. The authority role was fairly clear as was consultancy, but there was a third role which created more difficulty. It is finally labelled social integrative aspects although originally it was called a socialising role. However, the confusion with the sociologists' perspectives of socialization made for difficulties as did the layman's perception of socialising. Humanising was considered as a suitable term but rejected in preference for a social integrative role (Siporin (1975)) which appears to be the term most closely allied with the activities of this category. The main disadvantage of this term is that it closely resembles in name that of the first category.

There is an assessment of the teamwork and the solo work and a recognition that the concept of teamwork was in practice somewhat patchy, but had potential for the future. There was evidence of some conflict situations and considerable references to how and why clients behaved as they did.

It must be stressed again that the hospital records were the social worker's personal working tools. They existed to guide her
practice and an analysis of them as much as anything else has exposed the idiosyncracies of her individual style. The factors which seemed important to her are recorded but equally valuable would have been the information which either consciously or subconsciously, was filtered out and not mentioned. The significance of this may become partly apparent when the questionnaire evaluation of the parents' experiences is studied.
CHAPTER 6
Survey and Evaluation with the Experimental Group.
In your service of others you will feel, you will care, and you will be hurt, and you will have your heart broken. And it is doubtful if any of us can do anything at all until we have been very much hurt and until our hearts have been very much broken.


INTRODUCTION.

A year later I made contact with all the families of children in this Experimental Group and asked if I might visit with a questionnaire form to evaluate their experiences with the hospital team twelve months earlier. With the exception of Paul Smith's parents (in Group B) whom we had had only a very brief contact and who had subsequently moved to the Midlands, all agreed to do this. For those families whose child survived (Group A) I used the same questionnaire form as had been used in the original survey, but for those families where the child had died it was an adapted version focussing in particular upon loss through death aspects (Group B). The parents of the children who subsequently were considered not to be handicapped (Group C) had a further adapted questionnaire designed specifically to try to elucidate whether the early intervention before the medical condition was fully understood, had been helpful or unhelpful. Copies of the three questionnaires are to be found in the Appendix.

I asked the parents' permission to tape record the interviews and all were agreeable to this being done. At the beginning of the session I explained that we were trying to improve the service given to families with a handicapped child and one of the best ways of doing this was to seek consumer opinion upon the subject. It was very important for us to have their honest opinion and for them not to tell us what they thought we wanted to hear. In these interviews, I was trying to adopt a different role to the one they had previously known me in because
now I was the researcher actively collecting data. For this reason I would ask them questions about the social worker in the third person and encouraged them to tell me about the work their social worker did, forgetting that that person might have been me. In many ways this seemed to be much more comfortable for the parents and although a few lapsed into saying 'you did something...', the majority tended to keep to the convention of talking about 'my social worker' or 'the social worker'. Occasionally when I thought they were glossing over some aspects of the work which I felt had not been done well, I would interject some derogatory comment on the social work and challenge them to substantiate their earlier comments. By and large I think the parents' assessments were fair and appropriate. It was not quite ideal to have the same person 'working with' and then 'evaluating' but the advantages of doing this, explained in Chapter 4, were felt to outweigh the disadvantages.

The families of thirty three children comprised the Experimental Group and thirty two of these were included in the evaluation by questionnaire. The average age of the parents was 28.9 years. All but two of the fathers were in full time employment whereas only six of the mothers worked and these were small part-time jobs. Each family was actively caring for the child at the time of the survey, although in one situation this was likely to change very soon and it was probable that the child would be received into care. Six of the children were only ones, twenty three had older siblings and three had younger ones. When the survey was carried out seven of the eleven mothers whose children had died were pregnant. Three families could not have any more children because; in one case a 1:4 risk of recurrence was felt to be too high, in the second case the wife had been sterilised before it was known that this baby would not live, and in the third case the husband had had a vasectomy because of his wife's poor obstetric history.
INITIAL TELLING SITUATION

Of the total, 88% of the mothers and 69% of the fathers reported that they were told by the doctor at the hospital. A further 3% of the mothers and 16% of the fathers were told by their spouses. A small percentage of the mothers - 6% and 9% of the fathers thought they had never been told as such. Nearly half (47%) of the mothers and a quarter of the fathers (25%) said they were told on their own while 44% of the mothers and 56% of the fathers were told with their spouse. A small proportion of the parents (mothers 9% fathers 3%) thought they were told only once whereas 84% of the mothers and 72% of the fathers recalled being told more than once. For 69% of the mothers and 56% of the fathers the time of telling had been night but for 28% of each group it had not. In comparison with my case records these figures have two discrepancies. Every parent was told of their child's condition. It might be that there was uncertainty about the diagnosis and the lack of precise information was interpreted as never having been told. The other area of difference, although impossible to check out accurately, is the high proportion of parents who said they were told on their own. The agreed policy was for joint telling yet nearly half of the mothers said they were told on their own. It may be that the team believed it was doing the initial telling but in fact, there had been a partial leakage of information prior to this which raised the mother's suspicions to the extent that she thought she had "been told".

The parents who felt that they had not been told at the right time were the ones who had a poor experience of being told in that the planned joint intervention procedure was not followed. I have written earlier about the problems created for Mr. and Mrs. Cann by being told separately. A year later it still rankled with them. Mr. Cann said:
"I was particularly concerned that Mary was told and I was not there. Paula was born soon after 8 a.m. and the midwife said that she wasn't too sure about the baby and she was going to get the doctor to look at her and he would be down in a minute to see us. When he didn't come we went to chase it up and find out what it was all about and ask if the doctor had seen her. The nurse said that the hands were a little bit blue but she was much better and they brought her in, but obviously the doctor had not seen her. I stayed at the hospital for most of the day and then I went home to take the choir practice. At 7.45 p.m. Dr. Fergus came in and told Mary that the baby was a Down's syndrome. Mary knew there was no way of getting me because I was with the choir. I didn't get back until 9 p.m. and then she couldn't get the trolley 'phone so Sister let her use her 'phone in the office. She was on her own for over an hour, not able to get me and not able to discuss it with anyone. I couldn't see any reason when it had been left all day why it couldn't have been left until the following morning when I was with her. At that stage neither of us knew what it meant. I asked for information but at 10 p.m. Dr. Fergus was not available but his houseman came down. He was in a bit of a predicament because he thought Dr. Fergus would want to tell us himself but he told us basically what Down's syndrome was in general terms. Obviously he didn't tell us very much about our case. I think Mary ought to have had a night's sleep because neither of us slept that night."

Mrs. Can added that she thought they could have been told within an hour or two, as soon as they suspected anything, but having left it for twelve hours leaving it a bit longer would not have made any difference. She said very firmly that:

"I still think the earlier the better."

Likewise with Mr. and Mrs. Parker who felt that they had been told "at the right time but at the wrong moment". They both thought that it was about the appropriate length of time after delivery but that there was too much going on in the ward at the time and they could not settle quietly to talk about it. The problems were further compounded by some earlier 'leak' of information. Mrs. Parker had suspected it as soon as Fiona had been put into her arms and had asked the nurse if she was a mongol baby and had been told, "Well you know I can't comment until the specialist has seen her." That made Mrs. Parker so suspicious
that she asked them to telephone her husband and ask him to come in.

Mr. Parker continued:

"I'd got some flowers in my hand and the priest came out of the room and he looked at the flowers and he looked at me and he didn't say a word and I knew something was wrong. And then Sister said, 'Fiona is a mongol', full stop, just straight out with it - it was an awful shock."

One couple were not agreed about the way they were told. Mr. Procter thought that he should have been there when the information was given whereas his wife had liked the way it had been done so that she could explain the situation to him. Even so, having thought that way, she did say:-

"It was 5.50 p.m. on the Thursday evening and my husband came in 10 minutes later. I had been looking forward to having a visit. I watched him come across the yard and wondered how I was going to tell him."

The Evans both thought that they should have been told together.

Mr. Evans: "I came in with her case to take her home and they said I could take the wife but the baby was not allowed to go. The wife was in tears and I said 'What's the matter?' and she said 'there's something wrong with the baby. Then Sister came in and pulled the curtains round and had a talk: then the paediatrician came down and explained to us what was wrong. They said that the baby's head size was too big - frightened us to death. First thing you think of is a mongol child. They showed us a shunt, after losing one child already we were frightened. We were very upset that it could be a spina bifida - you wonder if it is ever going to walk."

Another moving account of how they were told came from Mr. and Mrs. Allen. They thought they should have been told earlier although in fact they had their first information very soon after the baby was delivered. They could not recall ever having been told that their baby was going to die, or "be left to starve to death" as Mr. Allen put it with some feeling. "Nobody actually said that this baby will die or we are not going to do anything and because of this it is going to die. (This comment differs considerably from what the social
worker had recorded in the case notes where the consultant said clearly and more than once that the baby would not live). Therefore, you might take the view that it might be a week, a month, two months or whatever... If only someone had said we don't know how long it will take but she will die. I was terrified of being left with a baby who was still alive a year or two later... when they said that it had a massive spina bifida too large to operate upon, we got the hint quite soon that it was not going to survive." Mrs. Allen continued with this theme: "Nobody told us when she arrived that it wasn't quite right. It was a breech and they said that as a breech usually has to be resuscitated Peter was sent out of the delivery room. I never cottoned on, but you know how you have your legs up for the birth and they put a cloth up so that I couldn't see it being born and immediately it was born they took the baby next door. They were all chattering away and everything and I said, "What have I got?" and nobody said anything to me. Then they said, "Oh we've just taken it next door to have a look at it." It was ages and I was asking questions and asking questions and saying, "Is the baby all right?" and he kept on sewing me up and when he had finished stitching me I said again, "Is the baby all right?" and the nurse said, "Well baby is not quite right; your husband will be in to see you in a minute."

Mr. Allen took up the saga from there; "There was no set up to tell me immediately, I was sitting in the corridor about half an hour after the delivery. Then a Sister walked straight out and passed me without looking and I thought there is something wrong; everyone was rushing around and I knew that something was wrong. In the end the bearded young paediatrician told me and asked who I would like to tell my wife and I said that I would like to. ... When I said to the doctor, 'What sex is it' he said that he did not know. That was worse, we thought 'My God it is so deformed that you can't even tell that.' I was
expecting something far, far worse."

The Bates' said that they should have been told years before because it should have been possible to diagnose that condition soon after birth. Mrs. Field complained about the staff avoiding answering her initial enquiries about the baby being all right.

Generally the parents had been satisfied with the timing of being given information and thought they had been given sufficient. Their recollections as a group of what was said to them were generally rather vague and for most parents it was just a memory of being given bad news, as it was for Mrs. Edwards.

"I couldn't understand why they had taken him away so quickly, but I knew they couldn't suck him out. I just kept smiling because I had got a little boy ... Sister said that something was wrong and that he'd gone to the Intensive Care. After quite a few hours we went to S.C.B.U., we sat down, I held Mike's hand. Dr. Brown wrote on a bit of paper; he drew it and what was missing. I knew that something had gone wrong, that's all I remember. I knew something was missing - didn't remember any more. He did explain it but I couldn't take it in. It didn't register; my mind was a blank. It was just a horrible sensation."

So much depended upon whether or not the parents felt that they could relate to the doctor. If they had faith in him as a person as well as a clinician this affected tremendously their attitude to the whole problem created by their child's medical condition. This came out so clearly when the Kendall's spoke of their contact over many years with Dr. Jones and his several registrars and housemen. The ward door was always open to them whatever the nature of their problem. It was to Dr. Jones that they first turned when a few years previously they had discovered that Mrs. Kendall was pregnant again. He said that he would speak to the obstetrician before they went to see him to request an abortion. Unfortunately the appointment came up before he had had a chance to do so.

Mrs. Kendall:
"When I arrived I was on the bed, he came in didn't say good morning or good afternoon or anything; he said 'Ah you have a child with leukaemia who is going to die, this one will replace it.' Those were his very words and you can imagine how I felt - I just broke down. He examined me and said 'right you can get up and come into the other room. He called Jeff in and said 'You're wife is pregnant. I will book her a bed and after I will sterilise her.' I asked him how was it that a prostitute on the street could come in and have an abortion and I could not and he said that that was out of wedlock and mine was in. He went on about booking a bed and in the end Jeff said, 'Hang on, you can stuff your bed, stuff your sterilisation ... I was in hysterics. Later I saw another obstetrician but he said he would only do it once so Jeff had a vasectomy."

At one stage, Mrs. Edwards talked about 'sarcastic doctors and nurses who make you feel inadequate' and Mr. Proctor referred to one doctor 'being superior to everybody and talking down to people.' The Stallmans described their experience which embody the same feelings:

"We hear the specialists talking amongst each other and we're sitting back there and they're using these long words and we wonder what they're talking about and they just say 'we'll see you in six months time ... where is it getting us? It makes you lose interest, what's the point ...?'"

Perhaps the inferiority feelings came out most vividly when the Bates described their visit to an orthopaedic consultant:

"He sits in this enormous room with one desk in it and his secretary is sitting there - a vast place, and you walk across this room and your knees are knocking and you sit down. He dictates vast notes with copious latin names - I thought his secretary was snooty too ..."

Although generally this group of parents was satisfied with the overall help they had received from the hospital staff, few of them specified anything in particular as having been especially helpful at the time. None of the families thought that it would be possible to have too many offers of help, but it did tend to be those who had been reluctant to have help who felt that help had been lacking. Mr. and
Mrs. Bates had not wished to see a social worker and tended to be fairly critical of most of what had been done at the hospital; it was they who did not think that they had had any help from the hospital staff and that included the paediatrician. Twenty eight mothers and fathers recorded that they had sufficient help, four mothers and two fathers thought they had none and two fathers said it was not very much. As these parents reflected back upon their situation a year previously there was a higher felt need of help among the mothers in comparison with the fathers. Twenty four mothers and fifteen fathers recorded that they had felt they needed helping with the situation. The most common criticism which emerged was of the extended family not being allowed near a very sick baby and where the baby was going to die a much closer involvement of the relatives had been wished for and apparently not allowed. This was an interesting variation on the situation as perceived by the social worker. Whenever she had requested that a relative be allowed into the ward it had been willingly agreed. It appears that without her mediation, or that of the other members of the team, it was not readily happening.

In the families where a child had died there was considerable variation in the time required to adjust to the death. Five couples said that it took them six months to get over the loss; the other replies ranged from 'next morning', 'two weeks' or 'as soon as we conceived' to saying that no time span could be put upon it. For the mothers to know that they were getting over it they recorded personal milestones such as:

- Stopped crying myself to sleep each night: 3
- Sleeping better: 2
- Started to socialise again: 1
- Wanted to get pregnant: 1
With the fathers it was events like:—

Returning to work 3
Reduced my drinking 1
Reduced my heavy smoking 1
Bought a car 1
Bought a cat 1
When the next baby was born normal 1

As far as long term regrets were concerned the following were mentioned:—

Not possible to have any more children 3
Anxiety extremely high re pregnancy 3
None - mothers 5
None - fathers 5

These comments suggest that individuals react in different ways and over varying lengths of time to the personal disasters that occur, although women record that crying and disrupted sleep feature more commonly in their grieving. Men seem to find returning to work has a therapeutic effect upon them.

Such varied responses make both more difficult and more interesting, the task of offering help, because it has to be tailored to individual needs and experiences.

Professional workers may be well equipped with models for intervention but their skill in operating is so much geared to the flexibility in applying what they know to the uniqueness of each and every situation.

FAMILY STRESS - PARENTS

I asked the parents about their marital relationship since they had been through this experience. In every case this was a joint interview
and this matter was jointly evaluated. Seven couples were agreed that it had made no difference and six said that it had caused tensions which had not been present before or had aggravated and made worse tensions which did exist. The remaining nineteen couples said there was now a deeper relationship and closer understanding of each other, although two said that there was also increased tension between them as well.

Mrs. Proctor:

"It wasn't the best of pregnancies and then to have this at the end. We got a lot closer and more understanding of each other. It made a lot of difference to us ... we got engaged when I was 13½ and married when I was 16, he was the only boy for me."

Mrs. Kendall:

"All right our marriage isn't perfect and we're both very different people but we both feel the same that marriage has got to be worked at ... We had a very rough patch when we had the abortion. For 12 weeks I don't know how he stuck me ... I nearly packed my bags every day, I threw things at him and never once did he lay a finger upon me. I was a real horror."

Something of the paradox of emotional gain coming from personal loss seems to be revealed here. By far the larger proportion of the parents admitted to an improved relationship with each other as a result of the experience they went through and less than a fifth thought there had been an increase of tension between them.

**SIBLINGS**

There were no significant ill effects reported in the siblings but most were too young to understand what had happened. One five year old brother had told his parents to make sure that their next baby did not have the same thing as Richard had.

**THE PROBLEM AND THE RESOURCES**

Since only eleven families had a firmly diagnosed handicapped child the section on Resources comprises only a small sample which makes for difficulties subsequently in comparing with the Contrast Group which was much larger.
Table showing the Families Attitudes to the Need for Resources

<table>
<thead>
<tr>
<th>Services</th>
<th>Not necessary</th>
<th>Important</th>
<th>Essential</th>
</tr>
</thead>
<tbody>
<tr>
<td>Financial</td>
<td>4</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Aids and Appliances</td>
<td>3</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Nurseries</td>
<td>3</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Hostel Care</td>
<td>7</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Parent Support Groups</td>
<td>8</td>
<td>3</td>
<td>-</td>
</tr>
<tr>
<td>Counselling/Information</td>
<td>-</td>
<td>6</td>
<td>5</td>
</tr>
</tbody>
</table>
At this early stage in their life as parents of handicapped children the majority of these mothers and fathers were finding parent support groups, hostel care and financial help not to be necessary, whereas they were seeing nurseries, aids and appliances and counselling/information giving as being essential. In fact, there is probably not all that much difference in real terms between nurseries and hostel care, except for the availability of overnight accommodation, nor between financial and aids/appliances except one is provided as money and the other as goods. Yet as far as the parents were concerned, they felt very different and affected their rating of them as a resource. It is possible that in later years they might have assessed these resources differently and this will be looked at when the findings of the two surveys are compared.

**SOCIAL WORK**

Twenty eight mothers and twenty four fathers recorded that they had had contact with a social worker. Two fathers said they could not remember:

"I can't remember because I saw so many people."

"I couldn't sort out the different faces."

Two mothers said they had seen a social worker but both were referring to a health visitor. When I clarified this with one of them she replied "Well, I don't know the difference, is there any?"

Neither of these mothers associated me with being a social worker. One did not appear to recognise me and the other, although remembering me well, thought I was a doctor.

The other parents appeared to remember accurately and exactly when it was they had first seen the social worker.

"Right at the very beginning when Mark was first born."
"From day two of Peter's life."

"Wednesday morning with Dr. Fergus."

"We were introduced to one on the day that Dr. Jones told us about Sharon and she sat in with the consultant."

Again they were quite specific and fairly accurate about the frequency of contact.

"Three to four times including two home visits and an out-patient appointment in the summer."

"Every day I think when I was in hospital and three to four times in the year since."

"Very frequently at the beginning, each hospital visit and twice at home."

"Once at hospital, once at home."

"Whenever we needed her, several times."

This may suggest that people are more attuned to remembering the event rather than the nature of it.

In an analysis of the service they had received there was a much greater variety of viewpoint ranging from being satisfied to being quite disenchanted with it.

"Very helpful: when I didn't understand what the doctors were saying she put it in a better way that I could understand."

"She said if there was anything we didn't understand she would interpret and ask questions for us and that felt good."

"It was very good because she was the only one who told us anything."

"Bridges the gap between the medical staff and the layman ... we can say something in our language and she can explain it to the doctors in their language."

This role of interpreter appears to have been important to the parents. They were told many things by the medical staff, but not always in language they understood, and this might account for some of the discrepancy between the team thinking that the parents had the information
and the parents claiming that they were never told.

The value of having somebody to talk with was often apparent in the comments.

"I was grateful to have her to talk to like a mother."

"Helpful to have somebody to talk to, not to be given advice."

"Helps get it off your chest ... a brick to sit there with somebody booing their eyes out."

"Sometimes it helped and sometimes it didn't. Personally I think sometimes you want to be left alone to sort things out but it's nice to know that there is somebody there if you do want to talk. She knew everything about Patrick and could explain it in proper English instead of all those medical terms. Doctors do talk to you in all those medical terms and you don't know what they are on about half the time."

Mrs. Edwards, having had experience of five social workers in the eighteen months or so since Ian had been born with oesophageal atresia, was perhaps something of an authority on this subject:

"I felt annoyed because a social worker was coming to see me - only going to be nosey and want to know this and that. I saw her two or three times in three weeks, then a male social worker from Social Services, then a Miss something or other, then Miss Phillips and of course Miss Evans in Bristol who was marvellous. The first two helped me with my talking but never got anything done, and then Miss Phillips came along and she got us everything - washing machine, liquidiser, drier. But talking and getting it off your chest is quite useful ... It's been hopeless in the last year; they'd ring up and say do you need us and I'm not going to say I do because I'd look stupid."

Two parents had "a job to remember really" and for another pair it was "O.K." but for Mrs. Stallman it was far from satisfactory:

"Where's it getting us to? All we do is talk. We're talking a lot, you're getting my feelings and learning about me, but we're not learning anything about the medical side. It makes me wonder if the social worker comes here to see if I'm treating him right?"
ADEQUACY OF SERVICE

Many said the service had been good enough and nothing more could have been done. Mrs. Old and Mrs. Williams both said that they could get over things in their own way and it had not been necessary for the social worker to come and talk to them. Mrs. Williams added that she did not think the social worker knew enough about the case. Mrs. Edwards found the service to be patchy and Mrs. Bates said it had not helped her at all. Those parents who did not think they had seen a social worker said they would not have needed one because they had their family.

Mrs. Wrigley who had been transferred to the Dr. Bernardo's social worker when Anita had started at the nursery was a little critical of the service from then on:

"She seems more interested in Anita than in Phil and me. I sometimes feel that she does not want to know."

The feedback from this respondent raises questions about the professional judgements made in decisions about transferring clients at crucial stages even when administratively it is correct to do so. When asked if any more could have been done it was Mrs. Wrigley who replied:

"I find it difficult to say. I don't know who I should turn to, the psychiatrist, Anne, the other mothers ... The Samaritans are quite helpful just to talk to somebody at times."

Mrs. Richardson wanted the one thing that could not be given and that was false assurance:

"Somebody to say that Patrick's going to be all right; that's all I wanted at that time."

But for Mr. and Mrs. Dark there was a time when the service was excessive.

"It was too much when Matthew was so ill ... couldn't think straight let alone recognise who it was coming in. Peter very nearly told everyone to go. We felt ... well, we'd met you at the beginning, we knew you and that was fine. Then you were away and in came Meg..."
Williams and then Joan Burrows... good God another one to tell your tale to - here we go again and we didn't even know if he was going to live through it."

**SOCIAL WORK STYLE**

Some of the parents answers may reflect the social worker's style, that is the interplay of personal and technical factors which comprise professional behaviour.

"None of us knows anything about social work until this happened. A go between us and the doctor. Easier to talk to her than to the doctor, almost feel like calling them sir 'cause they make you feel small. I hardly call anyone sir but they make me feel that I should call them sir. A social worker never makes you feel like that..."

Mr. and Mrs. Harris had appreciated having an opportunity to talk with the social worker and, at a later date with the health visitor, "As soon as they come in they don't talk about little things, they get right down to the heart of the matter." When asked if that was helpful they replied, "Well it depends - it takes you by surprise; you've never had anything like it before. Nobody round here mentions it; the neighbours avoid saying anything and then the social worker says how about Tracy right out - but it is the only way."

Similarly with Mrs. Cox who at times must have felt exasperated by all the professional helpers who bombarded her life with their offers of help, spoke warmly about the social work component:

"Helps us with sticky situations. Puts us at ease when we are all tensed up. Information - understanding as well, a shoulder to lean on and cry on and we've often done that."

Other comments included:-

"More human than the doctor is, spares more time than the doctor,"

"Have her to talk to like a mother."
Mrs. Roberts’ reply focussed upon the value for her of being able to talk to somebody and for that person to listen:

"I've spoken to her so much and I've had all the help I needed. It was there for the asking and when I needed her she came. I suppose you could say that I had a social worker for the year of the baby's life. She was there at the time of telling us that our baby would be handicapped, there at the death and she came afterwards. I needed to talk about things and the social worker was ready to listen and it was helpful to me to do that."

This aspect of social work practice was also clear in Mrs. Stephens' remarks and suggests that parents are not always seeking answers to their anxieties just somebody with whom they are able to share them.

"As for the social worker, I don't think we could have got through this year without a social worker and come through it as well as we have. It's a very useful non medical backup, a good listener, somebody who knows what she is talking about without being medical. She sits and listens and doesn't try to answer everything. Friends are very good, they don't interfere but they do tend to keep coming back and saying, 'oh yes but ..."

For Mrs. Kendall the age of the social worker had always been important and this was evident in her following remark:

"Having the right one is so very important. If I'd had Sue there I'd have resented it no end ... I still feel maternal to her because she is so young and I don't think I can get from her what I got from my first social worker. She has no children, she is not married; how can she understand our problem? My social worker was a mother figure to me that I could lean on mentally and physically. I couldn't have done that had I seen a young girl then ... whether it is because she was there first ..."

Perhaps she was also recognising that the attachments made in times of crisis are stronger bonded than those made when the crisis is over. People in crises are more amenable to help and if that has been a positive experience they are likely to feel warm towards those who offered it.
Replies from some of the fathers contained interesting comments reflecting their personal attitudes to social workers in general and to this one in particular. Mr. Parker said:

"She made me stronger because she was there. I couldn't throw my arms round my wife which I knew I should have done because I'm not that sort of person. I'm not a lovey-dovey sort of person but because she (social worker) was there I felt a lot stronger in myself. It made me feel good and I knew that somebody's got to be strong in the family and it had to be me."

In contrast, Mr. Allen got nothing from the contact with the social worker because he thought the support should come from elsewhere.

"I think they are there to support those families which can't support themselves in a moral sense. A family should do the job instead of a social worker; basically the social worker is standing in for the old family unit as it used to be. Let's take us; we lose a baby. Let's assume we are a highly emotional pair, we're very sad and the social worker comes along and gives us all the support that we need and we end up needing to have a little social worker and suddenly we find we like it, it's nice, we can lean on our little social worker. Then we find that we are leaning on her for the next six months whereas if we had been left for the twelve hours we would have found that we had to get cracking and we'd never have needed her at all. There's the stigma too; social workers are for problem families - even if we had needed it I'd have been tempted to say scrub that. I don't like the idea of social workers; it's not my scene and I don't want to be involved."

Finally, there was a long answer from Mrs. Freestone. The social worker had not found this mother an easy person, either to relate to or to work with, so it was a somewhat humbling experience to hear what she had to say. It came out fluently with virtually no pause for thought and apparently refers to the experience which she had had in the last year. What contact she had had with social workers in the past I did not find out but would think that over the years there must have been some, if only because a son of Mr. Freestone's first marriage was in care.
"Helpful in a constructive way, well my social worker is. I don't know what others are like. When things get on top of me she is always willing to spend an hour with a sympathetic ear and some very constructive views. We never feel when she leaves the door that things have been left unsaid that should have been said. I think she gives me the courage to carry on and I feel better about everything. A cheerful attitude but can be very serious and understanding as required. She's available when I need it but she doesn't intrude. She says the right things at the right time. We get depressed and low and then she says the right thing at the right time and it gives you that little bit of a push to go on."

When it came to the question of what was their impression of what a social worker did there was an interesting range of replies but two clear themes. One was that you would not know if you had not had any contact with one and the other was the value they placed on the liaison work done by the social worker with other key people.

Mrs. Hurst who could not differentiate between health visitors and social workers and who did not think that she had ever seen the latter, said that she had no idea what they did but it was a good job and she thought they would help a lot of people. Similarly for Mrs. Farmer who thought the health visitor was the social worker; her reply was:

"It's hard to say. She's nothing to do in our circumstances and she hasn't helped us; when it did really matter they didn't call."

Two families with low incomes laid emphasis on the access to resources.

"They bring us something you don't think about; can be helpful with things like transport."

"Oh gosh! The first impression is that they are going to be nosy. They could be more helpful in giving more details about things available for example car transport."

Mr. Maker said that:

"You've got to have dealings with them before you know what they do. I don't think I've had any contact with one. What are social workers? Are they W.V.S. ladies?"
Mrs. Forster also mentioned not having had any previous contact:

"I've never had any contact before - read about them but our contact with the hospital social worker has been our only one. They are understanding, helpful, sit on the shelf, say a few things but don't interfere. It's nice to have a good cry and a talk to somebody outside the family who is not going to talk to the neighbours."

Mr. and Mrs. Cann replied that if they had been asked what was their impression of social workers eighteen months ago, they would have said that they were well off ladies with nothing to do other than going round dishing out alms to the poor and needy. Then Mr. Cann added:

"But now we've met one and experienced the very specialised and professional work which goes on with the problems which can develop from illness, we have a very different impression. We've had advice, help, reassurance, moral support and perhaps most important, we've had information. She was the only person who really gave us any information; the only person who told us what it would be like. It's been good."

When I put this question to Mrs. and Mrs. Stallman who up to that point in the interview had been honestly critical of the services they had had, an interesting dialogue was to develop between them which was taped and is of value to record in full.

Mrs. Stallman: "She makes me talk a lot - mind you I feel good talking to her about how I feel with Nigel because if I talk to one of my relatives about it they think ..."

Mr. Stallman: Does it do any good?

Mrs. Stallman: ... I'm hard and they just don't understand. She makes me feel comfortable when I tell her...

Mr. Stallman: Yes that's O.K. but ...

Mrs. Stallman: I don't know what the social worker thinks of me ...

Mr. Stallman: Yes, but when that social worker has gone do you know how to handle Nigel?

Mrs. Stallman: I tell you the way I feel but you don't understand.

Mr. Stallman: It hasn't solved the problem has it?
Mrs. Stallman: No it doesn't solve no problems but it gets it out of my system how I feel; when they've gone I'm back to my usual routine ...

Mr. Stallman: Where is it getting us?

Mrs. Stallman: It doesn't get us anywhere but it makes me feel good, I've had this bottled inside me for six years and I've not been able to express my feelings to anybody which is what I want. I mean if I tell my Mum she thinks I'm hard, 'don't be silly' she says. If I tell Frank he says, 'don't be so silly, he's a lovely boy. They don't understand how I feel unless...

Mr. Stallman: I understand how you feel and I've got stronger feelings for Tristan I must admit...

Mrs. Stallman: You feel sorry for him; yes I feel sorry for him in a sense especially when he goes through all these tests. I mean that sometimes I could cry with all these injections and blood tests which he has - I could really cry for him because to me he is being used as a guinea pig. That's my impression...

Mr. Stallman: Perhaps you were used as a guinea pig when he was born...

Mrs. Stallman: ... to me it seems that Nigel is being used as a guinea pig and it's good for me to get it off my chest about the way I am feeling to somebody who will listen. My relations just think I am hard... "

This dialogue seems to demonstrate the difficulty of proving the value of social work support. Earlier Mrs. Stallman had been critical of just talking with the social worker and it not getting anywhere. Yet here Mrs. Stallman describes how she had felt it was helpful to talk to somebody outside the family network and that was really as much as she ever saw the social worker doing. For Mr. Stallman, who saw no change in the situation as a result of the social work, it was a case of questioning the worth of the time being spent upon it. What neither of them realised was that the social worker was at the same time working with the educational psychologist, the consultant and the teachers in the school, persuading them not to force the issue of transfer to special school because this might well cause a total rejection of Nigel. Mrs. Stallman, and her parents, were adamant that Nigel was not to go to a special school. They would rather pay for him to go to a second
rate private school thereby causing themselves considerable financial hardship. So although Mr. Stallman saw no change in the situation the social worker was beavering away on the side lines to prevent the situation being, as they would have viewed it, made worse. In time the nature of Nigel's disability would cause him to fall so far behind his peer group that his parents would probably come to accept the necessity for special education, but at this time they were not ready for it and educationally the situation was not desperate.

However, this dialogue encapsulates the dilemma of measuring such intangible elements in social work as 'listening', 'ventilating' and 'support'. For those who may be having it, it feels helpful; for those who look on it is baffling. It also showed some ambivalence about it on Mrs. Stallman's part. She was critical of nothing seeming to be achieved, but when her husband began to query its value she tried to explain that it felt good even if she could not explain what had been done.

Although for some parents there had been confusion about my role and two mothers did not remember ever having seen me, the majority appear to be clear and accurate in their understanding of what I had been attempting to do. Previously I have written that one of the areas of concern about very early intervention in situations where there was so much medical uncertainty about both the diagnosis and the prognosis, was that the arrival of a social worker might be almost precipitating alarm. To some of the parents at the hospital she was already labelled "the social worker for the handicapped", so if, with such a tag, she began to work with a family it could, although incorrectly, convey to the parents that a handicap was suspected in their child.

There was no evidence from the answers to the questionnaire, nor from the more general discussion which was tape recorded, that this
had ever been the case.

The only family which had found the intervention totally unhelpful were the Bates. They had been referred at a late stage and had some fairly strong views about who needed social workers. Mrs. Bates comments about the referral are of significance:

"I got a bit frightened to think that I needed a social worker. But then I kept bursting into tears every five minutes. I felt she was asked to come because I was getting myself into a state and I needed somebody to get me out of it, and that was what really frightened me that I could get into that situation. I felt I was heading for a nervous breakdown if I got to that stage. It pulls you up a bit and makes you realise..."

Although the contact had felt unhelpful, in another way it had brought Mrs. Bates to her senses and made her realise that if she did not start to cope with the situation she would become 'a case' which for her would be very degrading. In some respects I was surprised that they agreed to do the research questionnaire, but they welcomed the opportunity to explain their attitude and felt as did many of the parents that it was a chance to do something to help the hospital, and this gave them considerable pleasure. Another mother, Mrs. Proctor called in to see me at the hospital a few days after doing the research interview to tell me how much her husband had enjoyed taking part in the survey. He had never liked the paediatrician and she felt he had almost a slightly warped view of the hospital care, but during the evaluation he had come to appreciate how much we were concerned with doing the best we could for the parents. He felt flattered that we should want to seek his opinion.

Since there was no evidence in the research survey to suggest that early contact caused increased anxiety, and in fact the parents generally had found the social work intervention to be helpful, there would appear to be no major reasons against offering social work help
early. If parents, during times of medical uncertainty, are anxious and under stress than it is more likely that they will be receptive than, to offers of help, rather than later when for better or for worse, the problems are being resolved. This would fit in with the research findings of Wolken on early intervention in crisis situations being more effective, and the findings of this limited sample would justify the extension of the definition of crisis to include stressful events of a more indefinite nature.

DISCUSSION

The evaluation in this chapter has concentrated upon the social work input. References to what the doctors did were only incidental in that it was a component of the initial telling situation on another part of the teamwork process. I had no permission from medical colleagues directly to seek feedback on their performance and it would have been quite wrong for me to have done so.

Generally the social work input had been favourably received but this response needs to be viewed with caution because it might have been affected by the researcher being the social worker responsible for the service. It may be easier to say something positive rather than negative when the person involved is sitting opposite asking the questions. So ideally it might have given a truer picture if another person had evaluated with the parents the social work input. That is not to detract from the value of evaluating from a shared basis some of the most painful parts of the experience, nor neglect the fact that some parents said they would not have participated in the survey if they had been asked by a stranger.

What the parents said happened, and what the social worker recorded as having happened, were sometimes at variance. An example is the Allen's experience of being told (p.199) when they do not remember
hearing it said that their baby was going to die yet the social worker had recorded that they were told that the baby would not live. Either party could be right. The significance is that in times of stress there might be discrepancies in the recollections of what occurs and this requires greater sensitivity and care in repeating information.

The parents need to be given information in terms that are understandable to them come out many times, as did the need to convey it early. Parents recall picking up messages from the general atmosphere of tension in the ward and sensing that something was wrong. Once their own anxiety levels were heightened their responses to the situation might get out of all proportion.

Nobody had objected to being offered help. This is important for those professionals who might hesitate about the issue of 'the right to intervene in another's life.' An offer of help is not an intrusion provided it is made in such a way that it can be rejected comfortably.

Perhaps the most important fact to emerge from this survey was that there was not such a greatly improved service as the professionals would have wished. The social worker may have felt more confident of the success of the experimentation than was in fact warranted. In the areas where numerical measurement was possible, i.e. in the initial telling situation, nearly half of the mothers and a quarter of the fathers reported having been told on their own. In a system where joint telling was professed to be every team member's ideal this was far less satisfactory than had been expected. On the other hand, there is generally far less aggression being channeled to the supporting services, in particular the social work and medical, than was the case with the original survey of the group.
CHAPTER 7

Discussion of the Findings.
"The impact of the arrival of a handicapped child on the life of a family is tremendous, sometimes overwhelming."

Eileen Younghusband.

THE PROBLEM

Introduction

"The care of handicapped children is an area of service divided awkwardly between education, health and social services." (Sainsbury, 1977). At the very beginning of the research project there was clear evidence that no one Department assumed total responsibility, because a central register of handicapped children did not exist. The special schools had lists of the children who attended, the Area Health Office had records of those children referred by the hospital for allocation to the health visitors; the Social Services had a few children on its Disabled Person Register and the hospital had the medical notes on the children the paediatricians were treating, but none of the agencies was taking overall responsibility and inevitably there were several children who did not belong in any category and were slipping through the net. The compartmentalisation into different areas of professional responsibility meant that handicap was not seen as a whole problem, but as a fragmented one for which each Department took partial responsibility. The Education Department thought in terms of the special educational requirements, the Health Department considered diagnosis and prognosis and the Social Services seemed even less certain of its function but offered some counselling and access to some material resources. Although the exchange of information was adequate and good informal links of long standing existed, no one agency was taking the key role of being responsible for the child in his family and organising the resources to meet the needs of that unit. Whether or not this would happen if a central register were to be created is open to debate, but such a
register would lead to some measure of centralising and focussing of information which seems to be essential. I had to compile my own register by consulting every known list of handicapped children and there were several instances of lists not tallying and children being known to only one agency.

Partly in response to my research having exposed a deficiency and partly in response to internal developments a meeting was held while I was at the hospital to try to establish a process whereby such a register could be created and kept up to date. It was finally decided that it would be held by the health visitor for handicapped children and information about any newly diagnosed handicapped child was to be fed to her. Although, at the meeting it was considered that she was the most suitable person, the obvious disadvantages of this arrangement are that she is likely to pick up only the under 5 year olds and that the whole scheme is very dependent upon the voluntary action of very many colleagues.

The Warnock Report recommends that there be a Named Person and suggests the head teacher fills this position; the Court Report envisages a District Handicap team with the Consultant Community Paediatrician fulfilling this key person role. Each reflects the terms of reference and the focus of their respective area of attention. Equally it could be argued that there is immense value in having a social worker acting as a key person. Whoever it is, the move that seems to be needed is towards the team model of service delivery which must be co-ordinated by a leader with an ability to understand all the multi-disciplinary components of handicap and weld the fragmented wisdom of three disciplines into a specialised service for handicapped children and their families. Such a move towards a greater sharing of the task would require a major shift in attitude, particularly perhaps on the part of the medical profession where there would need to be an adjustment in their hitherto somewhat
hierarchical pattern of operating in relation to other professionals to one of more equal partnership.

Other professionals are beginning to realise from their own experience that they must include knowledge beyond that of their narrow practice base. Dr. Mia Kellmer Pringle has written:— "In the past thirty years a revolution has been brought about in the health and physical development of children by applying new medical and scientific measures. In the next thirty years a similar revolution ... could be brought about in their mental health by applying new social, psychological and educational knowledge." (1966). She takes it for granted that no one of the helping professions can operate in isolation and that multi-disciplinary actions are essential if we are to counter successfully personal and social problems. The tendency for the disciplines to work separately in the Plymouth field of handicap was early apparent and this tendency made further difficulties for the families as they struggled to counter the problems of handicap. As an example, getting a handicapped child to an out-patient appointment is not an easy matter and if the family does not possess transport then it is even more difficult. Several parents told me that they would receive a whole series of dates and times to see various para-medical specialists for a range of testing. Often these would be in the same place, the Child Development Centre. If only the Community Health Physician, the speech therapist and the educational psychologist could synchronise their timetables and call one child for one session and do all the testing at the same time, not only would this be economical of professional time, it would save the parents hours of exhausting travelling and waiting.

During the course of the project there emerged some early signs of closer co-operation, a little of which emanated directly from the work I was doing, and much more from a natural process of realisation that
there is value in the caring professions co-ordinating their expertise.

The ratio of impaired children to the normal child population remains approximately 3:100, but because the national birth rate is reducing, the number of these children being born is also falling so the absolute total is smaller. In addition the early detection of abnormalities by amniocentesis testing and the widespread disinclination now to operate on severe spina bifidas has contributed to a reduction in the numbers of abnormal babies being born or living beyond the neonatal period. But, to counter these factors vastly improved infant resuscitation techniques and sophisticated neonatal baby care is reducing the neonatal death rate, and ensuring that several handicapped children, who previously would not have survived, now live to childhood and beyond. Such an example is Mark Cox who was most rigorously resuscitated four times in one afternoon and thereafter had no further problems with his breathing and lived. Another baby (Amanda Old), although finally she did die, lived for very much longer than would, until recently, have been thought possible. She was one of the smallest and most premature babies to be born in the hospital and by using some of the most up-to-date knowledge and equipment she was kept alive and even began to gain a little ground for nearly a month. Had she lived she, like Mark Cox, would have been handicapped.

So over the three year period of the research there were trends developing which had an effect on the total problem. For some mothers who had not been considered at risk and eligible for amniocentesis and then whose babies were born with abnormalities, the knowledge of the limited availability of these diagnostic aids made for some bitter feelings. Susan Williams' parents were upset about many things, and a failure to detect their child's condition early in the pregnancy rankled with them. In their next pregnancy Mrs. Williams had the test and both were delighted to know at an early stage that not only was the baby developing normally but that it was a boy. Conversely Mark Cox's
father was angry that the superior resuscitation techniques used on his son meant that he lived to be nothing more than "a guinea pig for the medical profession" and a terrible burden on his parents. He argued strongly that nature intended that Mark should die when his breathing stopped and that this should have been allowed to happen. In situations such as this it seems that medical advances may add to the problems which the parents of handicapped children have to face.

A comparative examination of the data provided by the Contrast and Experimental Groups.

The two groups had much in common. All of the parents had a child who was handicapped, but the nature of the handicap, the varying family backgrounds and resources, and the experiences of professional care which they had were not all the same. Some of the Contrast Group had had a mild dose of social work treatment; all of the Experimental Group had had a planned programme of social work availability. Not all the families wanted or needed on-going help. From the evidence provided by this research it does not appear to be true that "all families with a handicapped child need a social worker." Some families do cope and from these we learned much about what is necessary and needed to meet the challenge. Perhaps the most important message was the ability to let go of some of the responsibility for caring for the child, to share the burden either in the extended family or by making use of alternative short term care, not necessarily always within the state provision. Some relatives appeared to be marvellous at helping out and where there was a young, active maternal grandmother who played a vital part in the caring role, the situation seemed to be eased considerably. Where the parents enjoyed a close relationship with each other and shared the burden, it seemed to augur well for the future and it also helped to be financially reasonably well off. But perhaps the most important
factor was the personality of the parents. If they had the emotional resource to rise and meet the challenge, to be able to laugh at it occasionally, instead of always weeping and to seek for some positives in the situation, then these parents appeared to be able to manage.

1) Attitudes to resources

This research has indicated that individual family needs vary considerably and that a wide range of facilities are necessary. However, there are certain resources which seem to be more popular than others and there was a discernible trend common to both the Contrast and Experimental Groups, although there were minor variations within the whole. The composite tabulation of the additional help which respondents believed should be made available to families illustrates this. (fig. 19). There are three clear constellations of similar percentages which suggest that most parents find the availability of nurseries and playgroups to be essential; that short term hostel care is not thought to be necessary by over half of them; and that counselling and information giving is seen as important. The contrast in parental attitude to nurseries and short term hostel care is interesting and although I pressed the parents to explain why they felt so differently to the two, I really did not get any clear and rational explanations. Replies tended to be like these:

"Oh I wouldn't like him to be away at night."

"It wouldn't feel right if she had to be away so that we could enjoy ourselves."

These may be expressions of guilt at offloading responsibility and the hostel care might be seen as 'putting away' in the sense that day care is not. Interestingly, it became obvious so many times during the survey that parents could more easily let go of some of the responsibility of caring for their normal children but found it well nigh impossible to do the same with their handicapped one. Perhaps what also holds parents
like this back is the feeling that if they do relinquish the responsibility, even anticipating this to be for only a short period, they will never be able to take it on again. It may also be that they cannot believe that anyone else could care for their child as they have learned to do. To some extent this may be true, because each individual child needs to have a very specialised and personalised programme of care, but it is unlikely that they would suffer too much from a slight upheaval in their routine.

Seemingly there is some irrationality in the parents response to the availability of this resource, but in addition, those who tended to record hostel care as 'not necessary' were those who had never tried it. Ignorance of a facility may therefore contribute to its relative unpopularity. When the Beckley Unit first opened as a short term hostel there was a slow response from the families to its open door policy, and apart from peak holiday periods there were nearly always vacancies. One incident was exaggerated out of all proportion as a reason for not using the unit. A three year old boy was picked up out of his cot by a fifteen year old Down's syndrome girl and dropped so that he got a little bump on his head. The boy's parents complained, the other parents panicked and there were enquiries carried out. Three years later this is still an important issue but it has also become something of a power struggle between those who run the Unit and the parents of this boy. He now spends time at the Franklin Hospital in east Devon because his parents cannot be sure yet that "It is safe for him to go to the Beckley". Other parents wait for these ones to give them a lead, and the latter seem to almost enjoy their prestigious position. Gradually the hostel is becoming more popular but it still tends to be used a lot by a few families.

The variations which occurred between the subgroups are worthy of comment. As explained in the earlier part of this thesis the Contrast
Key to Abbreviations in Figure 19

**Group 1** Families which had the Dr. Barnardo's social worker and the Health Visitor for handicapped children.

**Group 2** Families which had the Health Visitor for handicapped children.

**Group 3** Families which had never had any social work or specialised health visiting and would have liked to have had them.

**Group 4** Families which had never had any social work or specialised health visiting and would not have wished to have had them.

**Group A** Families in the Experimental Group which had a handicapped child who lived.

- **F** Financial
- **A** Aids and Appliances
- **N** Nurseries and Play groups
- **H** Hostel care for short stay relief
- **P/S** Parent support groups
- **C** Counselling and Information giving
Figure 19. Table showing Parents' Opinions of the Relative Importance of the major resources available to families with a handicapped child.
Group was made up of four subgroups to ensure that the sample contained reasonably equal representation of the varied services which existed.

The fifth group includes the families of the handicapped children from the Experimental Group. There were fifteen families in each of the first four groups and eleven in the fifth. The figures are given in percentages to make comparisons easier.

Understandably financial assistance by way of the Attendance Allowance, Mobility Allowance and grants from the Rowntree Family Fund are considered by most parents to be important or essential. Groups 2 and 3 record similarly high percentages (80%) yet Group 4 is only 33%. This figures suggests that the self coping mechanism which made social work unnecessary applies also in their attitude to material resources. The classification of the fathers' jobs might mean that this group was marginally better off and better able to do without. Likewise Group A comprising families which only recently acquired a handicapped child and perhaps have not had long enough to experience the financial drain which can occur, do not rate financial help as a high priority. The father's job classification did not indicate an affluence greater than the other groups, but none of the families was in the lowest of the Hall-Jones classifications. Overall this group records the lowest percentage for essential (27%) and the highest for not necessary (36%).

Group 1 had a very high percentage of parents assessing nurseries and playgroups as being an essential provision, but these are the families whose children were attending the St. Nicholas nursery provided by Dr. Barnardos and who were clearly satisfied with, and extremely dependent upon that service. Another interesting figure is that slightly over half of the parents in Group 3 recorded hostel care as being essential. This stands out far ahead of any other group in its felt need. Group 3 would also have liked to have had social work help; this figure
might be suggesting that they have felt a need of other services too and because of the apparent failure to be put in touch with them, they are very exhausted by the battle of bringing up their handicapped child.

Many parents honestly admitted that the financial help sweetens the bitter pill they had had to swallow in having a handicapped child and that this is something of a compensation which accrues to all the family. The grant from the Rowntree Family Fund which had enabled the family to buy a reliable car meant that all the children went for the outing. In one family if one of the siblings grumbled about having a handicapped brother who prevented them going in to the funfare, the parents pointed out that it was his handicap which had got them a car and that it was really Colin's car which had made it possible for them to come to the beach in the first place. Undoubtedly there is extra expense and this was usually because of the exceptionally heavy wear on some handicapped children's clothes, especially shoes, special diets and the washing powder needed for additional laundering. On the other hand, some parents pointed out that there were some expenses which they would have expected with a normal child and which they would never have with a handicapped one. As one father, a keen sportsman himself, said with considerable regret:

"I'll never have to buy him a pair of football boots or a cricket bat."

None of the parents in either survey saw parent support groups as being essential and the parents of Groups 4 and A tended to say that the parent groups were not necessary. These were the ones who had not experienced parent groups, but to the most active group members some of whom belonged to two groups, their existence was important. As with examples mentioned elsewhere it might be another indication that ignorance of a facility can depress demand and provision of that facility can increase it. Groups 1 and 2 seemed to contain the majority
of parent group participants, and they said that they went less for the support and more for the information about what could be obtained. To some extent it is a sad indictment of the services, that information about them is not readily available to the parents, a fact further substantiated by the importance given to 'Counselling and Information giving'. The second aspect seemed to be the more vital part of the category to consumers and perhaps the two terms should not have been linked together on the questionnaire. There is a danger that the counselling aspect could be overrated as a resource by being combined with straight factual information - giving, which, for most parents, is the thing they most seek. Perhaps it is an indication also that the purpose of groups may be perceived differently by consumers and organisers, and suggests that if parents had been more actively involved in the planning of the services the emphasis of the provision might have been different. It also calls for a much more rigorous publicising of resources and services, and although it is known that the uptake of benefits always falls below the potential total of those who qualify, in a group so small and so clearly identifiable as this it is not unreasonable to suggest that a maximising of resource uptake is feasible. It also points to a vital role that a social worker can fill, by being a reliable source of such detailed information.

There is some evidence in the replies in each of the surveys to suggest that having once tried it the parents felt more positive about an area of additional help. This is the same reasoning which explains why the provision of new services so frequently is followed by increased demand. It happened, for example with N.H.S. dentures and spectacles and with the children in care after the Children Act 1948. Likewise where a facility had not been tried there was sometimes complete rejection without even considering the idea. Short term hostel care can
be for as short a period as half a day, and as such is no different in kind to the nursery provision, but some parents would not even think about its possibilities. Parents of handicapped children seem to feel more guilty than other parents about not being able to cope, and therefore appear to drive themselves to extraordinary lengths. Several of the parents in the first survey said they never went out to any social events and would have loved to do so. It would seem unlikely that anyone would condemn them for arranging for their child to be cared for in the hostel for one evening while they enjoyed themselves, yet for many it seemed an impossible arrange­ment. They would say that it would be different if they could have a special baby sitter who would come into their home and be responsible and this perhaps adds weight to the feelings of stigma about 'doing away with him' for just an evening. Again it could be that if they once let go of that res­ponsibility they may never want to resume it again. Not only does it seem to take time, it also appears to be virtually impossible to convince many parents that these areas of additional help exist because they are con­sidered to be required, and that the use of at least some of the facilities may help to recharge their emotional batteries.

2) Initial Telling Situation

Many of the parents in the original survey reinforced with their com­ments the already well documented evidence that the giving of information about the child being handicapped must be done with great sensitivity and skill. The clear message from the parents was that the telling should be as early as possible, when both parents are together and with plenty of time available for discussion if they feel like it at that stage. So with the Experimental Group we tried to do that, but having three consultants with different approaches inevitably meant that there would be variations.

Certainly the telling was attempted at an early stage, but unfortunately it was not always done with both parents together and the social worker present,
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<td>41</td>
<td>47</td>
<td>28</td>
</tr>
<tr>
<td>With spouse</td>
<td>28</td>
<td>33</td>
<td>44</td>
<td>56</td>
</tr>
<tr>
<td>No information</td>
<td>6</td>
<td>16</td>
<td>3</td>
<td>7</td>
</tr>
</tbody>
</table>

**Figure 20.** Table showing Parents' Assessment of with whom they were told.
**Figure 21.** Table showing Parents Assessment of by whom they were told.

<table>
<thead>
<tr>
<th>By whom told</th>
<th>Contrast Group N = 60</th>
<th>Experimental Group N = 32</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mother</td>
<td>Father</td>
</tr>
<tr>
<td>Doctor</td>
<td>68</td>
<td>37</td>
</tr>
<tr>
<td>Told by spouse</td>
<td>6</td>
<td>42</td>
</tr>
<tr>
<td>Not told</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>No information</td>
<td>16</td>
<td>11</td>
</tr>
<tr>
<td>How often told</td>
<td>Contrast Group N = 60</td>
<td>Experimental Group N = 32</td>
</tr>
<tr>
<td>---------------</td>
<td>-----------------------</td>
<td>---------------------------</td>
</tr>
<tr>
<td></td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>Once</td>
<td>40</td>
<td>30</td>
</tr>
<tr>
<td>More than Once</td>
<td>50</td>
<td>40</td>
</tr>
<tr>
<td>Never told</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>No information</td>
<td>-</td>
<td>20</td>
</tr>
</tbody>
</table>

**Figure 22.** Table showing Parents Assessment of how often they were told.
Table showing Parents Assessment of when they were told.

<table>
<thead>
<tr>
<th>when told</th>
<th>Contrast Group N = 60</th>
<th>Experimental Group N = 32</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mother</td>
<td>Father</td>
</tr>
<tr>
<td>At right time</td>
<td>54</td>
<td>45</td>
</tr>
<tr>
<td>Not at right time</td>
<td>36</td>
<td>28</td>
</tr>
<tr>
<td>Never told</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>No information</td>
<td>17</td>
<td></td>
</tr>
</tbody>
</table>

Figure 23.
<table>
<thead>
<tr>
<th></th>
<th>Group A</th>
<th>Group B</th>
<th>Group C</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N = 11</td>
<td>N = 10</td>
<td>N = 11</td>
</tr>
<tr>
<td>With whom told</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never told</td>
<td>-  -</td>
<td>-  -</td>
<td>1  1</td>
</tr>
<tr>
<td>On own</td>
<td>6  3</td>
<td>5  3</td>
<td>4  3</td>
</tr>
<tr>
<td>With spouse</td>
<td>4  6</td>
<td>4  5</td>
<td>6  7</td>
</tr>
<tr>
<td>No information</td>
<td>1  2</td>
<td>1  2</td>
<td>-  -</td>
</tr>
</tbody>
</table>

**Figure 24.** Table showing the breakdown of the information from the three subgroups of the Experimental Group with regard to with whom they were told.
<table>
<thead>
<tr>
<th>By whom told</th>
<th>Mother</th>
<th>Father</th>
<th>Mother</th>
<th>Father</th>
<th>Mother</th>
<th>Father</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Doctor</strong></td>
<td>8</td>
<td>5</td>
<td>9</td>
<td>8</td>
<td>10</td>
<td>8</td>
</tr>
<tr>
<td><strong>Told by spouse</strong></td>
<td>1</td>
<td>3</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>2</td>
</tr>
<tr>
<td><strong>Not told</strong></td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>No information</strong></td>
<td>2</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

**Figure 25.** Table showing the breakdown of the information from the three subgroups of the Experimental Group with regard to by whom they were told.
<table>
<thead>
<tr>
<th>How often told</th>
<th>Mother</th>
<th>Father</th>
<th>Mother</th>
<th>Father</th>
<th>Mother</th>
<th>Father</th>
</tr>
</thead>
<tbody>
<tr>
<td>Once</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>More than once</td>
<td>8</td>
<td>7</td>
<td>8</td>
<td>7</td>
<td>10</td>
<td>9</td>
</tr>
<tr>
<td>Never told</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>No information</td>
<td>1</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>-</td>
<td>1</td>
</tr>
</tbody>
</table>

**Figure 26.** Table showing the breakdown of the Information from the three subgroups of the Experimental Group with regard to how often they were told.
<table>
<thead>
<tr>
<th>When told</th>
<th>Mother</th>
<th>Father</th>
<th>Mother</th>
<th>Father</th>
<th>Mother</th>
<th>Father</th>
</tr>
</thead>
<tbody>
<tr>
<td>At right time</td>
<td>6</td>
<td>5</td>
<td>7</td>
<td>6</td>
<td>7</td>
<td>6</td>
</tr>
<tr>
<td>Not at right time</td>
<td>4</td>
<td>4</td>
<td>2</td>
<td>1</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Never told</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>No information</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>3</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

**Figure 27.** Table showing the breakdown of the information from the three subgroups of the Experimental Group with regard to when they were told.
Figure 28. Table showing Parents' Assessment of the effect upon their marital relationship of having a handicapped child

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>No difference</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improved</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Strained</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>A</th>
<th>B</th>
<th>C</th>
</tr>
</thead>
<tbody>
<tr>
<td>No difference</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improved</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Strained</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

CONTRAST

EXPERIMENTAL
### Figures in percentages

**Figure 29** Table showing the Parents' Assessments of having felt in need of help.

<table>
<thead>
<tr>
<th>Felt Need</th>
<th>Contrast Mother</th>
<th>Contrast Father</th>
<th>Experimental Mother</th>
<th>Experimental Father</th>
</tr>
</thead>
<tbody>
<tr>
<td>Help not needed</td>
<td>30</td>
<td>48</td>
<td>27</td>
<td>46</td>
</tr>
<tr>
<td>Help needed</td>
<td>70</td>
<td>30</td>
<td>73</td>
<td>27</td>
</tr>
<tr>
<td>Very rarely</td>
<td>22</td>
<td>7</td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td>Occasionally</td>
<td>22</td>
<td>12</td>
<td>18</td>
<td>9</td>
</tr>
<tr>
<td>Often</td>
<td>20</td>
<td>8</td>
<td>46</td>
<td>27</td>
</tr>
<tr>
<td>Very frequently</td>
<td>7</td>
<td>2</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>
although the consultants said that this was always their policy. Occasionally little snippits of information leaked to the mother prior to the joint session, or, as in the case of Mrs. Cann, she was told on her own with neither her husband nor the social worker present. Although we knew that the pain of knowing would be eased by careful telling, and we had an agreed programme to try to implement in all cases, there were occasions when errors of judgement were made.

The figures for the Contrast and Experimental Groups (Fig. 20) show that in both slightly over half of the mothers said they had been told on their own but a reduction in numbers had been achieved with the fathers which suggests that more joint interviews with parents was occurring.

This links with the higher percentage of the fathers (56%) recording that they were told with their spouse, and a slight increase (28% - 44%) between the Contrast and Experimental Groups for the mothers. However, these are figures which relate specifically to the handicapped section of the Experimental Group and if the figures for the other two sub-groups i.e. those whose child died and those where child was impaired are included, the average for the total Experimental Group is higher with 44% for the mothers and 55% for the fathers which is a significant improvement. All these figures suggest that it is difficult to protect the mothers who are patients in the hospital from picking up small amounts of information which alert them to something being amiss so that they ask the nearest, and seemingly most appropriate people, the nursing staff. But the doctor continues to be increasingly the key person responsible for conveying the information, (Fig. 21), although it appears from both groups that there is still quite a marked tendency for the wife to be told on her own and then for her to tell her husband. Nearly half the fathers in the Contrast Group were told by their wives but there was a much lower percentage in the Experimental Group. It is of significance
that the social worker had recorded a higher incidence of joint telling and was not aware of how much information was filtering through at an earlier stage.

The number of times parents were told and remembered being told was higher in the Experimental Group (Fig. 22), but when it came to an evaluation of the actual timing, the differences are less marked. (Fig. 23). Parents were asked if they thought they were told at the right time. In the Contrast Group 54% of the mothers and 45% of the fathers considered that they had and in the Experimental Group the figures were 67% and 59%. Figures for not being told at the right time do not vary very significantly. If the figures for Group A are compared on their own with the Contrast Group there is a remarkable similarity which is worthy of consideration.

There are various interpretations which can be put upon these figures and they only become really meaningful when accompanied by the fuller data from the tape recordings at the time of the interview. The dissatisfaction being felt by the group who had a handicapped child was sometimes due to being kept waiting for information - even half an hour is too long when suspicions have raised anxieties. More parents said that it was because they were not together. But perhaps it is not as simple a cause and effect as that. In the Experimental Group sub-groups B and C recorded much higher totals for being told at the right time which accounts for the higher overall total. (See Figs. 24, 25, 26, 27.)

In fact the planning of the telling of these two groups was similar to that for Group A, and if anything I would have said that Group C had a less good experience because there was so much uncertainty and confusion about what they were being told. It could be that because they are being given an unending burden to carry there never is a right time for some parents of handicapped children and the stress this creates
is projected as anger or general dissatisfaction with every thing that goes with it, including the experience of being told. It is impossible to measure such intangible factors and it yet again raises issues about whether or not there can be any means of connecting outcome to treatment given. Patrick Richardson's mother was kept fully in the picture from the very first convulsion, yet she thought she had been told far too late and in fact doubted if she had really been given any concrete data. She was only slightly nearer accepting Patrick's disabilities at the time of the research interview and her resistance to knowing his limitations may well connect with her attitude to those who told her.

Not one of the 92 sets of parents said that they had been told too soon, and even for a few of those where we thought we had intervened very early, it was not soon enough. Mr. Allen was talking in terms of a half an hour delay being 'too late'. The fact that none of the Group C parents complained of being given over pessimistic news too early supports the hypothesis that very early telling of parents is the more appropriate way of dealing with the situation.

3). Effects upon Relationships

Having a handicapped child creates stress within most families, mostly due to the arrested family development. One of the most reassuring aspects in facing a difficult phase in a normal child's development is that it will pass. But that is not going to happen with a handicapped child and as one of the fathers said:

"As you and they get older it gets harder."

There is no end to the continuing dependency and demanding of attention and except for the most resilient of parents this is emotionally wearing. Furthermore parents become fixed at one level of parental development, i.e., having a very dependent child, and in relation to this child never develop any further. Some of the friction caused by this carries through into
other relationships and the parents often find their marital relationship is affected. (Fig. 28.)

In the Contrast Group 28% of the parents said the problems of having a handicapped child had made no difference and 17% said that it had led to an improvement in their marital relationship. However, 55% recorded a strained relationship. The figures for the Experimental Group make for some significant comparisons. Of the total 18% said that there was no difference and 60% said that their marriage had been improved. Only 22% said there was strain and tension directly caused by having this handicapped child. Looking at the breakdown of these figures between groups A, B, C it is interesting to note how the parents whose baby died were drawn closer together, a similar trend also being found in the group where the children were impaired. It was in the group where the handicapped child lived that there was a slightly lower percentage of marriages where the relationship had improved and a slightly higher percentage experiencing strain and disharmony. Again there can be no way in which outcome can be linked with certainty to the treatment given. There could be many explanations to these apparent trends and perhaps the most obvious one is that the parents in the Experimental Group just have not had the child long enough for the grinding down effects to be really felt. If this is so then it would be reasonable to expect to be able to detect this by looking at a breakdown in the figures for the Contrast Group. Two groups clearly have a high percentage of strained parents - 1 and 3. The former had had the help both of the social worker from Dr. Barnardos and the health visitor for handicapped children; the latter was the group which would have liked to have had social work help and never were offered it. In other words the most professionally helped and the least helped were the groups experiencing the most marital stress. Group 1 had the youngest average age of handicapped child (4.0 years) and Group 3 had the oldest
(9.8 years) but then it is important to consider that Group 4 with perhaps the least stressful marriages also has a higher average age of child and therefore, presumably, an almost equally long period of being exposed to the effects of handicap. Group 4 had not had and did not want social work help. As was shown in other areas they seemed to be managing well on their own.

However, it is important to emphasise that there has been an apparent improvement in the marital relationships of the more recent generation of parents of handicapped children. It could be that the casework, having an important relationship component, enables other close relationships to burgeon. It could be that social work intervention in the servicing systems makes life for these families less fraught so there is a reduction in the amount of stress that expresses itself in marital conflict. Possibly the medical profession is becoming more humane and parents are made to feel more comfortable with their problems; it might even be that in that particular year the population which became my sample happened to be unusually lucky and satisfied in their marriage. Equally it could be argued that the original sample just happened to pick up an excessively large proportion of precarious marriages. It just has to be acknowledged that there is a noticeable difference between the two groups, and without being able categorically to explain the reason, it is worthy of comment and some rejoicing that this is so.

4) Expressed Need for Help

One of the most important questions asked of the parents was if there had been times since having a handicapped child when they had felt that they needed help. Throughout, the replies indicated that fathers admitted less often to needing help compared with their wives, but overall there was a widespread expression of felt need. Need is felt in a variety of ways; for some of the parents it is for material resources,
for others it is for help by way of moral support. But for a few it is much less tangible - a feeling of something being missing but a vagueness about what that might be and what could be provided to fill that gap.

The original survey revealed a high percentage of felt need amongst the mothers, (Fig. 29). It was this figure of 70% which was an important factor in deciding the form of the latter part of the project. It suggested that although there had been a quite indifferent response by the Contrast Group, the help needed appeared to be so great that a further attempt to provide the service of a caring and helping profession should be made. What is very significant is that the Experimental Group which had had as far as we know, every known helping facility made available to them, yet they still had a strikingly similar numerical expression of felt need.

Furthermore, although the totals are very comparable the frequency with which the help was felt to be needed showed that nearly half of the Experimental mothers recorded this as 'often'.

It may be that these figures are another reflection of the tendency not to miss that which has not been experienced. Mr. Allen spoke about the risk of finding one liked having "the little social worker" around and the needing her for another six months. So it may be with all other resources. Perhaps of much greater importance is the stark fact that a large proportion of the mothers of handicapped children find the task so burdensome that they freely admit to needing assistance in carrying it out. The lower percentages for the fathers' felt need is more likely to reflect their lesser involvement in the daily grind rather than their greater resilience.
1) Introduction. Parents experiences of Social Work

The feedback about their fairly limited contact with social workers from the Contrast Group of parents indicated that they felt generally that they had a poor service with only isolated instances of helpfulness. Yet at the same time there was a high percentage of parents, mothers in particular, who were expressing a need for help. It could be that the way the social workers had intervened was not the most appropriate method and that had they used other techniques they might have been considerably more effective. Perhaps the extreme example is the student social worker who went regularly every week, had a cup of tea with the mother and presumably thought that she was engaging in "supportive casework". The mother felt that she could not discuss anything of significance with her and was glad when she went back to college. Other parents complained of social workers coming once or twice and then never appearing again. If these reports are true, they might suggest that the social workers had so many demands being made upon them that their handicapped clients were a low priority. (Social Service Teams. H.M.S.O. 1978.) Equally it could be argued that the social worker may cease to visit because of personal feelings of futility at not being equipped to be particularly effective.

So, in spite of the poor response to social work intervention as experienced by some families in the original survey, it was important to gather more information about it before attempting any further assessment of its effectiveness. Furthermore, whereas less than half of the parents in the original survey had had any contact with a social worker, all the parents in the Experimental Group had had some involvement following a planned pattern of intervention.

There was considerable confusion in the Contrast Group about what social workers did and frequently they were not differentiated from the
The raison d'etre of the medical practitioner and the health visitor is very clear to most members of the public, and the role of the first, in particular, is eminently respectable. The stigma of a social problem is not apparent in most health matters. To some extent the health visitor traverses the two fields but because she calls on all children under the age of 5 her role is more acceptable than that of the social worker who visits 'problem families'. There is a general lack of clarity of purpose and function of social work which is not helped by the workers themselves not being precise and specific about what they do. The whole situation is aggravated by a bad press and a poor image projected by the media. Certainly several impressions of what social workers do, recorded by the Contrast Group reflected what the parents had seen on television rather than something they had personally experienced. Another factor which is of significance was that the experience of social work was by a large number of parents, being compared with the very good impressions they had of the health visitor. She had been in the post 8 years and they all knew her well: in the 3 years that St. Nicholas nursery was in existence Dr. Barnardos had had four different social workers attached and three of them were young and recently qualified. Time and time again parents spoke of not being able to get on with young social workers, particularly the "unmarried, straight from college ones". The health visitor was unmarried but her middle age more than compensated for this and none of the parents seemed to notice that she was single.

The need to experience it before knowing what social work is really like was stressed several times in the Experimental Group evaluation. Mr. Kendall had wondered why a social worker was with the consultant for the first interview, because he thought they "were to do with money matters". It was unfortunate that he had come into the room after Dr.
Jones had explained my presence to his wife, and none of us thought to repeat this for his benefit. When he later experienced a range of social work practice he was the one who kept saying:

"Why haven't we had anything like this before? We've had all these years of Sharon being ill and only once before did we see a social worker..."

Mr. Parker associated social workers with social security and felt slightly insulted initially, that it should be thought that he needed that kind of assistance. In the research interview he was able to explain that having a social worker there had made him strong in the subsequent time of crisis. Both the Allens and the Bates associated social work with stigma and indicated clearly that they therefore had grave reservations about it. Mrs. Bates found the trauma of being considered 'a case' sufficient of a shock to make her cope again, but to have nearly been one of the families with which her husband's colleagues dealt was a frightening event. Mr. Bates thought that she should see a social worker but that he did not need to do so. For the Allens there were slightly differing responses. Mrs. Allan had found the social work intervention helpful and recognised this as such; Mr. Allen had been alarmed by feelings of dependency which were comfortable, when every bit of his cognitive reasoning was telling him that social workers are for problem families and his family should not be involved. Mrs. Stallman was critical of the 'just talking' that went on with the social worker and did not seem to be getting them anywhere, but when her husband began to take this line too, Mrs. Stallman began to raise points about it being helpful to talk to somebody outside the family and it 'felt good' even if she could not explain what had been done.

In view of the repeated comments about age it was perhaps as well that the research social worker was middle-aged! But the comments are not just to do with her age.
"I could speak to her like a mother."

"... motherly rather than clinical."

These parents are experiencing relationships with their handicapped child which are abnormally ill balanced towards continuous giving from them. It helps them to sustain this emotional drain if they are 'parented' by a consultant and a social worker who can give them professional care and support. Although the services they have to be involved with are becoming more complex as the care of the handicapped child becomes more sophisticated, parents still need a personalised service and certain key persons to whom they can relate and know well. If we use systemic concepts, the parents and the professionals are ideally parts of a system in easy communication which enables positive feedback and parental reinforcement to be given. It is good to hear a most highly qualified consultant say to parents, "I don't know; you tell me because you are the experts with this child." Later these same parents were to say to me, "He's so good because he always listens to what we have to say about it and treats us as equals." Another father who used to take a day off from emptying Plymouth dustbins to take his son up to one of the main London teaching hospitals told me that the doctors up there made him really feel that he was a colleague dealing with the handicap. They would all sit in a big circle and he and his wife would be part of that circle and they would all talk together. The doctors did not use long names that they did not understand and if the father was not clear about something he would ask them to say that again. He always came back feeling that the long journey there and back in a day had been well worth while and that he had given as much to the doctors as they had given to him which made him satisfied.

These comments link clearly with the Integrating activities of the social worker (Chapter 5) and in particular with the communicating
and encouraging communication aspects of her work.

2) The Integrated Approach

In the opening chapter the Integrated Approach in social work was explained as a conceptual framework for the assessment of problems and the planning of 'interventive' techniques. It is a way of thinking, an analysis which accommodates knowledge from many sources and incorporates all known methods of social work intervention. It gives ample opportunity for one to one work but also encourages much greater flexibility within this way of working, so that for example, time limited, task orientated approaches and behaviour modification are considered alongside the long term supportive interventive techniques which hitherto seem to have been most extensively used. As well as work with individuals intervention may be with small groups, large groups and communities and the person presenting with the problem is not necessarily going to be the client with whom the worker principally engages his professional attention. As yet an Integrated Approach is very much a theoretical model little tested in practice but, as was suggested at the beginning of this thesis, it might be a way forward in helping families with the problems created by chronic conditions.

As it is a way of thinking it cannot be tested using the clinical trial model. But the researcher/social worker was able to look at the problem with the framework put into her mind by the Integrated Approach. This approach suggests a particular style or mode of intervention and it is this particular style which to some extent was being tested and evaluated. The project and its results comment only indirectly on the Integrated Approach to the extent that the mode of intervention 'inspired' by it is judged to be good or important, or to the extent that this mode of intervention can be directly demonstrated to be due to the theoretical view taken.
In applying an Integrated Approach to the area of handicap a more versatile appraisal of a range of social work interventions was possible. The first survey had indicated that the time when parents were told was a traumatic one, so it was likely that one to one work would be most appropriate here, particularly modelled upon crisis intervention techniques. Two further potential crisis stages were likely to occur when the child started school and then when he left and went to the Adult Training Centre or just came home because there are insufficient places for all the handicapped adults. The second of these is outside the brief of this research project, but the first did prove to be a difficult time, not the least because the Education Department seemed to have blind spots. Inevitably very little work was done directly with the child because he was either too young or unable to communicate with a stranger, but to some extent he was reached by working with the rest of the family. The exception to this was Sharon Kendall who in her grave medical state became very depressed and was able to use the social worker in a way which she could not use her parents because they were so close to her. In fact her family was one of the most receptive to family group work being done especially when the family dynamics became fraught. On the other hand the Freestone family fell apart during the declining months of Norman’s illness but Mrs. Freestone was reluctant for the social work to be with anyone but herself and sometimes her husband. Much marital work was to be expected. The referring point was a handicapped child but the stress that that could generate seemed to gravitate into the marriage and for many of the parents there were times when we dealt only with their personal relationship and made no mention of anything directly to do with the handicap. Mr. and Mrs. Kendall’s marriage was so soundly based yet at times they reached breaking point and had to be helped to get back to their normal functioning pattern.
The Coxs fought and argued throughout the first year of Mark's life; they might have done in any case, but there was a justifiable focus for it in their grossly abnormal baby for whom they had had to get married.

I went to many parent group meetings and at times became identified as a champion of their cause. The parents often saw me as a person who had the facts to back their argument on an issue, or as somebody who would question the apparent clumsiness of some procedures and not accept as a sound basis for practice, that it had always been done that way. In all these interventions the triad of one to one, small group and community methods was considered and selection made as seemed appropriate for a way of working. But not only were the parents and their families the clients, so too were some of the other professionals. It could be argued that a client may only be so with his knowledge and consent. If one used the term unit of attention then one is much more free to locate the social work intervention where it seems to the worker to be needed. Several interviews with the educational psychologists brought benefits ultimately to the families. The nurses were helped with their feelings of grief and loss which ultimately meant they could risk getting closer to the families and thereby be of more help to them. The consultants modified a little their mode of telling parents about their child's condition and in listening to arguments for early telling helped the parents by improved practice. Ward sisters allowed distressed parents to behave and act out their emotions in ways not quite compatible with the smooth running of the ward, but of great help to the mourning process. And, because I was part of an inter-disciplinary system, I also received support and help on the very many occasions when I too needed it.

This may sound as if an Integrated Approach requires a social worker to be rather unattached, freefloating, chameleon-like, when in fact, it is offering an opportunity to systematically organise the
modus operandi according to the nature of the problem rather than the
monomania of the worker. However, because I was attached to the
hospital, and the referral point was when a handicap was suspected, a
large proportion of the work done was crisis intervention.
3). Crisis Intervention Work.
Social workers tend to feel good about crisis intervention because
they can see results, and as a method its significance may be exaggerated.
People do cope in crises and perhaps too much is claimed for its effect-
iveness. Mr. Allen said, "If we'd been left for 12 hours we'd have
coped with it." But several of the parents said that they had found it
very helpful to be told that some of the extreme emotions they were ex-
periencing were normal and would pass. To have been given a reasonably
accurate time scale for this was very comforting. Another aspect of
the crisis was that in their shocked state parents were often only
'hearing' about 25% of the information which they were given. It was
helpful to have that information repeated as many times as was necessary
for them to absorb it. On the other hand there was some distortion of
the messages they had received. The Allens claimed that nobody said that
Sally was going to die, when in fact Dr. Brown had said simply, clearly
and repeatedly that she would be given clear fluids and made comfortable,
but that she would not live. Mr. Allen did not 'hear' this or perhaps
it was that his anger at losing his daughter was still being projected
at seeming incompetence. Or, it could be argued that consultants tend
to use euphemisms in their wish not to hurt people, and although it is
splitting hairs perhaps parents need to hear the word 'die' rather than
'not live'. Mr. Allen had not been helped by sensing an atmosphere of
'something wrong' and not having this explained to him early enough.
His wife was always more accepting of events than he, possibly due to
the slight post-partum euphoria protecting her, and when her personal
crisis developed there was help around which she chose to use. Several of the parents said that the social worker was "the only one who gave us any information". Of course this was not true; the consultant also gave them information, but it was because the social worker had repeated the facts at a time when they were receptive to hearing it, and in simple language which they could more easily grasp, that they remembered it coming from her.

If parents were not seen at the crisis points they were subsequently in need of much greater inputs of social work time. It was to be demonstrated that in these situations where the social worker came in after the news had been broken to the family, it took much longer to establish what the role should be and the effectiveness of the intervention appeared to be less good. This was clearly so with Anita Wrigley when compared with Mark Cox. Both were very young naval families with the parents forced into marriage by an unwanted pregnancy. Anita's mother was told on her own in an out-patient clinic and a letter was sent, in due course, to the social work department. Mark's parents were told together by the consultant and the social worker right at the very beginning, and it was made clear why the social worker was there. Although Mark was much more severely handicapped far fewer social work man hours were put into the case. There were additional problems caused by Mrs. Wrigley's psychiatric illness, but hours more time was invested in this case in helping them to move towards accepting that Anita was not normal. I was not in at the beginning of the contact with Stephen Archer and Norman Freestone's parents; it took longer to make clear to these parents the role of the social worker than it did with Mr. and Mrs. Kendall. The late referral of Amanda Old's and Christopher Cooper's parents resulted in no effective social work being available to them in their bereavement, yet Richard Thorpe's parents were able to use the social work for the agonising 24 hours or so until Richard died. Mr. and Mrs. Thorpe had
a very supportive family around them and said later that they would have coped in any case, but it had made that task a little easier for them. On the other hand there were times when the social worker assessed that the crisis work done had been effective and well timed, yet a year later in the research interview the clients could not remember ever having seen a social worker! Mr. and Mrs. Field could not recall having seen a social worker, did not recognise me and the nearest they could get in identifying helpful people was 'a lady went round with the young doctor in open sandals.' Perhaps clients remember more easily the negative aspects and something reasonable passes unnoticed. Professionals have to try very hard and repeatedly to be clear and to make an impact, but they have also to accept that they may appear very shadowy and insignificant compared with the ghastliness of the events. But the effort should be put in and the apparent lack of impact is no reason for not trying.

I have suggested that the use of some of the traditional casework techniques may not be the most suitable social work method for irreversible conditions and there was some evidence from the Contrast Group to suggest that workers going in and talking about it were not being useful to the parents. It could be that some social workers professionally oversubscribe to the notion of the value of 'talking things through'. Some parents said categorically that they did not like talking about the situation.

"I don't like to talk about it."

"I put it to the back of my mind."

"Sometimes I wanted to talk and sometimes I didn't."

For some parents they can only continue to function by blocking off all thoughts and anxieties about the handicap now, and in the future. They develop these defenses because they need them and if they can only
continue to operate by putting the anxiety and fear "to the back of their mind" than these are very strong contra-indications to any method of working which approximates to the psycho-analytical model. Help for them needs to be external to their personality system and this in an Integrated Approach is a more realistic way of working. There is a place for one to one work. Some parents mentioned that the social worker was prepared to listen to "the same old thing over and over again." Mrs. Roberts said that the social worker let her talk about the things which made her cry but about which she wanted to talk about and was prevented from doing so by her family who were for ever trying to cheer her up. Mrs. Parker said she could cry with the social worker "but not with his mother." At the same time attention needs to be paid to the environment around because this is where the most significant change can occur.

4). Systems Thinking

There was good evidence from the saga of Stephen Archer's application for special education (see Chapter 5) to support social workers in being very actively engaged in working within the systems impinging upon the client with the problem. It meant uncovering the delaying mechanisms and revealed a special education procedure which would not operate smoothly, (in fact, in this case not at all) if it did not originate with a head teacher in the S.E.1 form. Obviously the system only worked for the over 5 year olds who were already in school. Following the trials and tribulations of this case a new procedure was established by which the consultant paediatrician could initiate the S.E. selection by writing to the Community Health Physician directly and thereby the head teacher's request was by-passed. This became standard procedure henceforth and resulted directly from social work intervention in the educational system.
Some of the comments made by the parents in the Experimental Group about the social work reflect something of the wider approach. They liked being told early and honestly. Nobody had found that the information was given too early or that the professionals had been too uncomfortably honest. They appreciated 'the knowledge', 'the advice', 'getting things for them', 'knowing the way round the system'. For many of them the social worker was perceived in the role of interpreter and go-between, especially with the medical profession and one consultant in particular:

"A very useful non medical back up." (Mr. Stephens).

"Explained the terms in layman's language." (Mrs. Richardson).

The social worker was also seen as having a special 'sharing' role:

"They have a special kind of listening ... they don't keep saying yes but ..." (Mrs. Stephens).

"The difference with social workers is that they get down to the heart of the matter." (Mrs. Stallman).

"They come straight out with it." (Mr. Harris).

These comments suggest that the social worker is somebody who is prepared to face the worst with them and the support is given by facing rather than by evading. Clearly it is a service which has to be experienced for people to really understand what it is. Mrs. Stallman spoke of it 'feeling good'; Mr. Cann explained that he used to think of social workers as 'well off ladies with nothing to do other than going round dishing out alms to the poor and needy.' Then he went on to say:

"But now we have met one and experienced the very specialised and professional work which goes on with the problems which can develop from illness, we have a very different impression. We've had advice, help, reassurance, moral support and perhaps most important we've had information. She was the only person who really gave us information, the only person who told us what it would be like."
There is no way of measuring or collecting evidence to link what had been considered 'good practice' with happy outcomes and 'bad practice' with poor outcomes. It would be expecting much more of a short term external influence than is possible or likely in a situation of such gravity and complexity. But there is some evidence that it felt good to clients just as it felt better to the professionals involved, and that surely is good in itself. It is humane and it accords the parents dignity and equal status. The expressing of compassionate and caring concern may be exceedingly difficult to measure but it is valued and appreciated and should be promoted for that reason alone.

THE PROJECT

This has been a study of the impact of having a handicapped child on the life of ninety-two families, and of the social work service which some of these families received. There is plenty of comment about the problems which can beset the handicapped child and his family but very little about "the families who meet the crisis of handicap as they meet other crises with resilience and common sense." (Hewett (1970)). It became apparent early in the survey of the Contrast Group that it does not necessarily follow that because a child is handicapped this is going to be more of a problem for the family than life would be without that handicapping condition. Some families seem able to adapt to and accommodate the demands of the handicapping condition, and rarely come in contact with the professional services which exist to assist them. Therefore an important aspect of this research study is that it has been of a sample of the total population of families with a handicapped child and not just an investigation of those who come to the notice of the caring professions by their frequent requests for help. (Kew (1975)).
It has been very much a consumer survey, something which the Court Report (1976) considered to be an area in need of much more research, and one which Lees (1975) claims to be particularly appropriate to the social work researcher. Throughout the assessment of needs and evaluation of services has been based upon major contribution from the parents and this was a much more successful component of the research than originally was envisaged.

The pilot survey done in the first instance with a group of parents at St. Nicholas nursery led to some minor modifications in the research schedule, and generally the questionnaire was quite appropriate to the data that needed to be elicited at the first stage of the enquiry. The questions asked seemed to trigger off interesting and relevant comments by the parents, and there seemed to be widespread enjoyment of taking part in the interview. The frequent use of the tape recorder, although making for a very time consuming second check on the interview, also enabled the data to be rich with quotation as well as much more accurate. The liberal use of these quotations throughout the thesis is a testimony to the value of such a method. The approach to the parents was fairly unpressurised in that the onus was upon them to post back the reply sheet with their decision about taking part in the survey. There was a 79% response and there was no way of knowing whether it was skewed towards including the 'cooperative' parents as opposed to the 'uncooperative' or whether it included a fair number with an axe to grind.

The Experimental Group on the other hand was a total population albeit a small one. It included all those children diagnosed as actually, or potentially handicapped who were referred to me in one year at the hospital. It was a smaller group than, from a research
point of view, had been hoped for, being about half the size of the Contrast Group. Of these 32 children only 12 met the criteria for being classified handicapped (see p. 22) so comparison between Contrast and Experimental Groups is numerically less balanced than was initially envisaged.

A more direct approach was made to these parents when the time came for the research interview, in that I wrote and asked if I might call at a certain time and suggested that they telephoned me if it was not convenient. The onus was therefore on them to 'opt out' rather than 'opt in'. It may well have been less onerous to take part in my research interview than to go down the road to telephone, but there was a 97% response from this Group. They were, of course, being invited by somebody they already knew to do something with which they were already familiar, i.e. be interviewed.

This very positive and cooperative response from the parents suggests that there could be even more ambitious research projects designed to gather consumer opinion. If the tape recorder was no inhibitor of speech, then audio-video equipment need not curb expressions and actions. Although the evaluative interviews were tape recorded none of the action research sessions was. It is now apparent that this was a great omission. Had this evidence been available it would have been possible to comment on the accuracy of the perceptions of client and worker as to what was actually said at various crucial times. It would have been even better if there had been a visual record of what had gone on.

Again it will be argued that to set up a television camera and to film a poignant interview is an intrusion upon people's privacy and at the outset of this project this would have been the view of
the researcher. However, by the end of it this personal attitude is changed considerably by these two factors. First, the parents apparent lack of inhibition of being tape recorded and second, the realisation that there is no other way of recording accurately what goes on in interviews.
The focus of this research has been upon the practice of social work and it set out to achieve three things. In the first place to consider the uses of an Integrated Approach in working with families having a handicapped child. Secondly, within that framework, attempts were made to improve upon existing casework techniques particularly by the incorporation of more recent knowledge of crisis theory, bereavement and loss, and planned short term treatment. Thirdly, there was an attempt to involve the parents more in the planning and evaluation of the work programmes and to acknowledge that they, too, were fast developing as experts in handicap who needed to be partners in the caring task.

The Uses of an Integrated Approach

Both the C.C.E.T.S.W. Discussion Document (No. 5) (1974) and the Court Report (1976) suggested that social workers need to be operating in the field of handicap. After completing the initial survey of the contrast group where parents' attitudes to social workers seemed to be so negative, it would be reasonable to think that perhaps the two working parties were incorrect in their assessments and recommendations. However, after gathering more data and experimenting with a wider range of interventive techniques, there were clear indications that a social worker has a role to play, but to be effective there has to be a recasting of some of the traditional ways of intervening.

Hitherto, social work practice has been in danger of being governed by the "law of the instrument". (Pincus and Minahan (1973)). If somebody has a hammer in his hand he will go along and bang all those things which he feels need hammering. If a social worker is trained to operate in only one method then, regardless of the nature of the problem, that will be the method used. The social worker may be extremely skilled in using that way of working but it could well blinker him into operating within a narrow way. It could be argued that a social worker operating
within the field of handicap needs to have considerable interest in and knowledge of the medical and educational components, as well as the social aspects of handicap, and also to be very well informed about the complex network of resources. As such that social worker would become extremely specialised in this area of work and, as a result, perhaps not be very competent in other fields.

It has been shown that an Integrated Approach is a way of analysing a situation, is a conceptual model which gives much greater flexibility in tackling the problems that exist. Its value is primarily that within a profession which includes so many areas of work, it is a way of thinking which can be transposed into a variety of situations. The interventive techniques which may be applied when working with families which have a handicapped child, might also be relevant in working with families which have an elderly dependent relative or a deviant youngster.

Much of current social work practice is casework, and this was true of the intervention with the Experimental group, but at the same time there was also being practised small group work, large group work and some community involvement. A variety of methods and ways of intervening were considered and, furthermore, the work was not just with the family but also with medical colleagues, educational psychologists, speech therapists and teachers. It included building up a network of effective communication between all the disciplines and developing an understanding of how that system could be mobilised for maximum efficiency. As such it met the two differences from current practice stated by Specht and Vickery (1977) in that there was a greatly increased range of choice made available and much greater communication. The one worker was doing all these things and where there were deficiencies in her knowledge about some aspect she made certain that she found out where to go for that information. The fact that many parents in the Experimental Group
commented in the final survey on the social worker's apparent knowledge of the resources, her skills in interpreting complex medical information and her ability to relate, would suggest that the liaising part of an Integrated Approach made a positive impact upon them.

Although the thinking of an Integrated Approach was evident in her practice, retrospectively it is now clear that the worker did not carry out fully the implications of the approach into her recording. Much work was done with the educational psychologists and special education department for example, to achieve change that was considered by her to be essential for the wellbeing of the families. A separate file of this work should have been kept. Where it related to a particular case there is a note of the interaction on the individual case record, but there were many more meetings and general discussions which were not centrally recorded. Likewise accounts of what occurred in interviews with colleagues were not recorded in the same detail as with clients and yet both were equally important.

The incorporation of recent knowledge into the casework.

The major concept that was experimented with was that of Wolkon (1971) who stated that the effect of intervention was the greater the nearer it occurred to the crisis. It was assumed that the majority of the parents would be put into a state of crisis when the information about their child's condition was given to them, and this generally was found to be so. For some (e.g. Mr. and Mrs. Harris) their behaviour prior to being given the medical details bore all the hallmarks of being in crisis, yet this was based only on their suspicions. Help was offered simultaneously with the information being given, and as the experimental year proceeded it became apparent that there was a greater willingness on the part of the medical profession to impart medical information to the parents at an earlier stage, even when
there was clinical uncertainty, than had been the practice in the past. The first hour after being put into a crisis state is a very sensitive period of time and the availability of informed, caring professional help at this point in time is crucial to the subsequent involvement with that family. The implementation of this sort of timetable required the social worker to be available outside normal office hours. It also called for medical consultants to be prepared to see parents at times which were less convenient to them. What did become apparent is that there may be some loose talk about crisis intervention within the social work profession and that some seemingly not particularly successful work is due more to the timing being at fault rather than the conceptualisation. It is likely that the workers are using crisis techniques in post crisis situations. People do begin to resolve their crises very quickly, and although their ways of doing so may at times be deemed to be pathological, the time of malleability and openness to offers of help has been missed. This part of the experimental work was perhaps the most successful because much progress was made in quantifying the time factors and in refining the techniques of intervening.

Involving parents in the work programme.

This was an aspect of the research which had mixed fortunes. As far as the social work was concerned the parents were involved in all the significant decisions. The social worker discussed with them the ways of intervening, the stages through which they were likely to pass in their crises, their grief work and their mourning. Parents seemed to be reassured by the accuracy of prediction. Doctors were amenable to being persuaded to explain to parents why the child was receiving the treatment he had, but there was still some evidence of medical authority, even arrogance in saying that this is the treatment that your child will have.
There was, however, less willingness from some of the other professionals to involve the parents. For example, both the educational psychologist and the administrators from the Education Department were reluctant to have Mr. and Mrs. Archer attend the case conference to discuss Stephen's schooling. The parents, unaware of the disquiet, did attend but only because the social worker insisted that they were invited and then got the paediatrician to back her in this stand. Generally there was an unwillingness on the part of other professionals to recognise that parents, and particularly parents of handicapped children, are experts within their area and do have something very valuable to contribute. Generally the notion of teamwork has yet to be extended to include the client within its working membership, but the indications from this research project of those instances where it did occur suggest that much of the hostility within stressful situations is removed by the ideal of a partnership.

**Implications of this research for practice.**

It augurs well for the social work profession, some of whose members are grappling with systemic concepts, that other disciplines are beginning to think in terms of multidisciplinary functioning. But the fact remains that the most enthusiastic profession for joint work seems to be the social work one, which may reflect a lack of professional self-confidence and a need to try to share an allied profession's rather more secure mantle. If social work is to be an equal partner with these other professions, rather than a poor relation, it will have to develop further and publicise, both its knowledge base and its professional skills. This project, and especially the work with the Experimental group, demonstrated that the social worker did have a unique contribution to make in the areas of relationship formation, grieving and loss and in establishing communication networks. Initially she had to seek out for
herself a place in the team, but latterly her position became established once it had been demonstrated that she had an important contribution to make. Since the completion of the research the inclusion of the social worker in the telling situation is now, wherever practicable, standard practice in that particular hospital. Furthermore, one of the paediatricians writing recently in a medical journal stated that now when he gave parents important information he included the social worker in the interview.

The only variation from the research practice is that the model of maximum availability calling for twenty-four-hour social work coverage is not operating. There was good evidence produced in the experimental year to indicate that if crisis work is going to be really effective social workers will have to be prepared to offer the same sort of duty rota coverage at the hospitals as do the doctors. Until this happens there will be missed opportunities of intervening in the crucial and short-lived period of maximum malleability. But this is an organisational issue which the profession may not be prepared to consider when the boundaries of its work area are so wide. It does involve long periods of being on stand-by for the possibility of a small number of situations and it could be argued that when there are currently so many pressures being put upon them this is wasteful of social work resource.

It has been stated earlier (p. 42) that the first major problem encountered in the research project was the location of the families where there was a handicapped child. There was no accurate up to date central register, and the lists in the various agencies did not always tally. Partly as a result of the deficiency being exposed by my research and partly as a result of internal developments in the hospital, an attempt was made to set up a system of notification whenever a child was diagnosed as having a handicapped condition. The register was to
be held and maintained by the health visitor for handicapped children.

Of more major importance were the problems of poor communication which existed between Education, Health and Social Services Departments in their joint care of handicapped children. If teamwork within one agency is recognised as being a more satisfactory way of working then it follows that an Inter-departmental team is needed. The value of this approach has been demonstrated, for example, in Exeter by the formation of a Youth Support Team. Police officers and social workers share an office and offer joint professional expertise in dealing with problems for teenagers and their families which stem principally from Care Orders being made. It would be equally valuable to establish a Handicap Support Team where Community Health Physicians, Social Workers, Educational Psychologists and relevant others worked together on the problems which handicapped children and their families face. In Plymouth the already established Child Development Centre and Beckley Unit, both on the same site, would provide a perfect geographical location for such an enterprise.

Although the implication of the C.C.E.T.S.W. Document was in specialised knowledge for social work in the field of handicap, this research has not substantially supported this. At the beginning the social worker knew virtually nothing about disability and the effects upon families of having a handicapped member, yet, apparently from the beginning was able to be effective. This was because she did know something about the effects of stress, about how people who were in crisis would behave, about loss and the need to mourn it, all of which are aspects of most social work training courses. If anything, this project has reinforced the need to have a set of basic skills and general social work knowledge, together with a great flexibility in style which enables the various models to be applied in different situations. To suggest
as does the C.C.E.T.S.W. Report, that each social work student needs to have experience of working with one handicapped client is, in the view of this researcher, to take a rather retrograde step to pre-Seebohm thinking. It is effectively to say that if a student has had one client who was handicapped then the work he has done with that person equips him to tackle all the problems of the handicapped which would be a nonsense when it has been shown by this study, and others, that the needs of these families are immensely different. Because the training period for social work is only two years this researcher would suggest that during it every student needs to work with some person who has experienced loss, for example, and then the student will have some knowledge of this area which may be applied in a range of situations, without undue regard for the labelling of the client group.

What is clear at the end of this research project is that the problems of having a handicapped child is something that is immeasurable in its effect upon each individual family. Not one of the parents with whom I spoke was happier with the child they had than the normal one they would so much have preferred. The advantages which accrue from being a family with a handicapped member are negligible; the disadvantages are enormous. So despite the ignorance, doubts and criticisms about social work that were voiced in the original survey, the experiment established something of the nature of the social work intervention and the variety of techniques employed which many, if not all, of the families appeared to find helpful in coping with the disadvantages. These parents were often able to say precisely what it was that had 'helped' or 'hindered' them and which supports they lacked. They provided a wealth of clues as to which services might be developed and how they might be more efficiently and sensitively provided.
Help which 'felt good' was valued, as well as more tangible goods and services. The fact that they were not unanimous on the helpfulness of social work, or on which of its components were of most use to them, is no argument for failing to experiment and expand. It merely underlines the need to provide the widest possible range of services offered with the maximum of flexibility. In this the social worker has an important role to play as a source of information, as a go-between and interpreter between systems, as a pressuriser and as a support and sharer in times of crisis.

This project has done something to increase the understanding of the range of problems created for families which have a handicapped child. The study does not - and could not - establish direct links between social work input and favourable (or unfavourable) outcomes for the families involved. What is does do is to provide us with a number of clear indications of where social work can be effective and how practice may be improved.
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Dear

I am writing to ask you if you would be willing to assist me with some research I am doing into the professional help needed by families who have a handicapped child.

Those parents who have a handicapped child can be of great help to future parents, to health visitors, to social workers and to all those concerned with the welfare of the child and his family because they have personal experience to pass on. I would like to come and speak with you both about your experiences of having a child who is handicapped, the professional help you may or may not have had, and the sort of help you think families need to have.

I do assure you that the information you give will be entirely confidential and that nothing about your family will be identifiable in the report I shall write. Would it be possible for me to call on if this time is not convenient, but you are willing to take part in an interview, perhaps you would very kindly indicate an alternative time on the form attached to this letter.

I enclose a stamped, addressed envelope for your reply and I should be most grateful to have this back as soon as possible.

Yours sincerely

Mrs. Gill Lonsdale
Senior Lecturer
Social Work
To Mrs. Gill Lonsdale, Senior Lecturer, Social Work

Please cross out which sections do not apply.

1. We are willing for you to call at the time you suggest

or

2. We are willing to be interviewed but would prefer you to call

on ...................... date .........................

at ...................... time

3. We do not wish to take part in the survey.

Signed ..........................

...........................

...........................

Telephone number if you have one ......................
This piece of research is concerned with knowledge for use in professional practice. The services which are available to families with a handicapped child are not always as good as they might be and in order to improve them, information about their functioning is needed. There is a great deal of logic in asking parents directly because they are the consumers of these services and it is they who directly experience the helping process and live daily with the results of that help. So the first part of the project was a consumer research study. I did not divide the children into mentally and physically handicapped but looked at the group as a whole and then wrote to a sample of the parents who were living in Plymouth. Some of the parents had met me in group sessions but the majority had never heard of me before they received my letter asking if I may come and speak with them. I am most grateful to them all for welcoming me into their homes and to their firesides on dark, cold and nearly always wet winter's evenings and for sharing their experiences and their precious time with me.
INTRODUCTION

I wrote to a total of 76 families of which 46 returned the answer sheet saying that they would be willing to participate. Three wrote back saying that they would prefer not to be involved. Eighteen did not return the reply sheet but when I made further contact with them were willing to take part. Four, when subsequently contacted said no, two had left the area and seven were not contacted further. This ended up with sixty families being willing to be interviewed, seven definitely saying no and a further seven probably also saying no.

The interviews were carried out between December 1976 and March 1977. Most were in the evenings and each took at least an hour. Although both parents were invited to participate this was not always possible mostly due to work commitments and especially the above average proportion of naval fathers away at sea. In fact only forty lots of parents were seen together. Eighteen mothers and two fathers were seen on their own. Most of the families agreed to the interview being tape recorded. As soon as possible after the interview I played through the tape and made further notes of important points that the parents made, and then I scrubbed the tapes and used them for the next lot of interviews.

Size of Family

<table>
<thead>
<tr>
<th>Size of Family</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>11</td>
<td>20</td>
<td>11</td>
<td>7</td>
<td>5</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>

Total number of children

| Total number of children | 11 | 40 | 33 | 28 | 25 | 12 | 14 | 8 | 0 | 10 |

Fig 1.

The sample did pick up several large families by modern day standards (Fig. 1) and has resulted in the overall size of the family being three which is slightly above the national average. In eleven families the handicapped child was the only child and in a further thirty one he was the youngest child. Eighteen families had a further pregnancy after having a handicapped child. The average age of the handicapped child for the total sample was 6.9 years.

The parents in 55 families were living together, three mothers had remarried and two mothers were bringing up their children on their own. All sixty mothers are still actively caring for their handicapped child, although in some situations the handicap is so severe that the child has to be away from home for some of the time. In 11 families the parents were over 40 years but the rest were younger and most were in their twenties.
Rearing a handicapped child requires a great deal of time and makes tremendous demands emotionally and physically and inevitably the burden falls principally upon the mother. Parents need a break and school at the statutory age and optional playgroups earlier are seen as very important in meeting this need. However parents of the older children frequently spoke of the battle to get a place for the child in school. Several of them said that all the energy they had was needed to bring their child up and did not leave anything surplus to engage in external encounters with the Education Departments. The worst situations were concerned with children who had moved into the area and for whom the machinery of allocation to special schools seems to grind exceedingly slowly.

Playgroups are seen as being of great importance by many of the parents especially the specialised ones of Dr Barnardo's and Millford School. In response to this question concerning playgroups the figures were:

<table>
<thead>
<tr>
<th></th>
<th>Not Necessary</th>
<th>Important</th>
<th>Essential</th>
</tr>
</thead>
<tbody>
<tr>
<td>Playgroups</td>
<td>14.0%</td>
<td>31.0%</td>
<td>54.7%</td>
</tr>
</tbody>
</table>

Although the need for playgroups came out so strongly there was an interesting contrast occurring in the figures for short term hostel care:

<table>
<thead>
<tr>
<th></th>
<th>Not Necessary</th>
<th>Important</th>
<th>Essential</th>
</tr>
</thead>
<tbody>
<tr>
<td>Short term hostel care</td>
<td>45.3%</td>
<td>26.6%</td>
<td>28%</td>
</tr>
</tbody>
</table>

For the group who saw this as being essential it was to the extent that they thought their lives would become well nigh intolerable without it. For 26.6% of the parents it was important to have such a provision and in emergencies they would be glad to use it but for a much larger proportion hostel provision was unnecessary and they could not think of any emergency that would not be met within the family circle.

I asked parents about their use of parent support groups and of counselling and information giving:

<table>
<thead>
<tr>
<th></th>
<th>Not Necessary</th>
<th>Important</th>
<th>Essential</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent support groups</td>
<td>45.3%</td>
<td>53%</td>
<td>1.6%</td>
</tr>
<tr>
<td>Counselling and</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>information giving</td>
<td>4.7%</td>
<td>65.6%</td>
<td>29.7%</td>
</tr>
</tbody>
</table>

Many of the parents who said that they thought the groups were not necessary attributed this to the fact that they found it depressing to be with other parents who were in the same situation as themselves, whereas many of the 53% who found the groups to be important to them said that they found other parents helpful and learned about what resources were available to them from these parents.
At a time of spiralling inflation financial help may be regarded as being disproportionately essential, but no-one would deny that in rearing a handicapped child there is extra expense that would not occur with a normal child.

<table>
<thead>
<tr>
<th></th>
<th>Not Necessary</th>
<th>Important</th>
<th>Essential</th>
</tr>
</thead>
<tbody>
<tr>
<td>Financial help</td>
<td>6.3%</td>
<td>29.7%</td>
<td>64%</td>
</tr>
<tr>
<td>Help with aids and appliances</td>
<td>10%</td>
<td>45.3%</td>
<td>43.7%</td>
</tr>
</tbody>
</table>

Likewise with aids and appliances. In the south-west where the annual rainfall is more than double the national average, the mountain of nappies and bedding which continues to pile up from an incontinent child makes a washing machine and tumble dryer absolutely essential. The tumble drier was the most frequently mentioned piece of equipment to make life bearable, to be closely followed by the telephone.

Although various resources are available to help families with a handicapped child some parents feel that they have even had to fight for these. At the time I was doing the interviews the first children to be allocated the Attendance Allowance were coming up for review and several had had their full rate reduced to the lower one. Parents were justifiably angry because, if anything the child was more difficult to handle. Many parents had missed out completely on resources that were theirs by right because nobody had told them that they existed. Although 71.7% of the parents recorded their financial situation as being adequate many added that they would not have been in this category had they not had the Attendance Allowance and grants from the Joseph Rowntree Trust towards essential equipment.

Parents were asked about illnesses which had a direct cause and effect link with having a handicapped child and illnesses other than these were not included. Of the mothers 33% had suffered with an illness which resulted from having to look after a handicapped child and without exception this was either a chronic back or nervous troubles. 10% of the fathers spoke of similar illnesses which they felt were caused by the stress of having to look after a handicapped child.

Of the total of mothers who were not working 51% felt that they were prevented from doing so because they had a handicapped child. Of those who were working (and in most cases it had to be part-time) 26.6% thought their work performance was affected by having a handicapped child. Factors like lack of concentration, needing to take a lot of time off work, having to take less well paid jobs because the hours fitted in with meeting the school bus were all mentioned. 85% of the fathers were working at the time of the survey and another 10%, although not working at that time had until fairly recently had a job. Overall 20% thought their work performance was affected by having a handicapped child. Likewise a higher proportion of mothers (50%) felt that their social life was affected compared with 41% of the fathers.

The group as a whole tended to be a fairly static population and only two of the families had lived in Plymouth for less than two years. Of the total 48 had lived in the area for more than five years, and of these 26 had been there for more than ten years. This could suggest that having a handicapped child tends to make a family put down roots. Life does have to become very geared to the needs of the child, as one father
put it, "It's been one long concentrated round of hospitals, doctors, appliance fittings and physiotherapy." It would be a gigantic upheaval to re-establish this process in another environment. Certainly the families who have moved to Plymouth since having a handicapped child spoke well of the services compared to some of those that they had experienced elsewhere.

TELLING PARENTS

As perhaps is to be expected the parents remembered very clearly who it was who told them about their child being handicapped. 68% of the mothers and 37% of the fathers were told by the doctor at the hospital. A further 6% of the mothers and much higher percentage of the fathers - 44% - were told by their spouses. 56.25% of the mothers and 40.6% of the fathers were told on their own, whereas only 28.1% of the mothers and 32.8% of the fathers were told with their spouse. Overall 10.9% felt that they had never been told, and the remaining few learned of their child's condition from the midwife, educational psychologist or the physiotherapist. When asked if they had been told at the right time 53% of the mothers and 45% of the fathers thought they had, but 35.9% of the mothers and 28.1% of the fathers thought they had not. All said one of two things. They should have been told earlier (nobody said that they had been told too soon) and they should have been told with their spouse.

FAMILY STRESS

Of the total 28% of the parents felt that their marriage had not been affected by having a handicapped child and 17% recorded an improvement in their relationship. The remaining 58% felt that their relationship had been strained by having a handicapped child and for 8% this was extreme leading to desertion. These are high figures and reflect the tremendous amount of stress that can be created by having a severely handicapped child to look after. It is to the credit of these parents that despite all the problems which handicap has made for them they are still together and both sharing the enormous task of bringing up this child. Other research studies done elsewhere in the country have suggested that the brothers and sisters of handicapped children may feel neglected and have behaviour disorders because of this. I asked parents with other children what their experience had been. The overall sibling total was 121 and of this total there was evidence of:

(i) behaviour disorders in 9% of the siblings;
(ii) disturbed relationships with the peer group in 13% of the siblings;
(iii) disturbed relationships with the handicapped child in 13% of the siblings.

These figures are much lower than in any of the other studies and are very near to those of the National Child Development Study of normal family situations where there is not a handicapped child.
SOCIAL WORK

Amongst all the professional services that were available to parents and their handicapped child I was particularly interested in their experience, if any, of social work. I had contact with 118 parents, although for a few it was the secondhand contact with their spouse. Of these:

70 had never had any contact with a social worker;
48 had some contact of which - 12 were one-off situations
   36 more than once
   26 currently in contact.

Out of the 26 currently in contact 19 were seeing the social worker from Dr Barnardo's who visits families of the handicapped children who are attending the special playgroup.

I asked parents what was their impression of what a social worker did and the replies included:

<table>
<thead>
<tr>
<th>Task</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don't know</td>
<td>25</td>
</tr>
<tr>
<td>Resources</td>
<td>13</td>
</tr>
<tr>
<td>Do nothing</td>
<td>8</td>
</tr>
<tr>
<td>Help</td>
<td>6</td>
</tr>
<tr>
<td>Deal with problems</td>
<td>5</td>
</tr>
<tr>
<td>Liaise</td>
<td>5</td>
</tr>
<tr>
<td>Visit people</td>
<td>4</td>
</tr>
<tr>
<td>Listen</td>
<td>3</td>
</tr>
<tr>
<td>Do a good job but don't</td>
<td></td>
</tr>
<tr>
<td>know what it is</td>
<td>3</td>
</tr>
<tr>
<td>Advise</td>
<td>2</td>
</tr>
<tr>
<td>Support</td>
<td>1</td>
</tr>
<tr>
<td>Change jobs a lot</td>
<td>1</td>
</tr>
</tbody>
</table>

There was quite a wide ranging view of the social work task but by far the larger proportion of the comments were negative, although many parents said that they had not had any personal contact with a social worker so were speaking of other people's experiences of what they had read in the newspapers. The preference for an older social worker came out many times in this survey and I believe this is an important point. So, too, did the fact that several families said they would very much like to have had social work help and had never seen one, whereas other families felt that they did not really need a social worker and yet one was still calling.
Dear Mr & Mrs

Some little time ago you very kindly agreed to help me with some research I am doing on the services available to the families of a handicapped child. Several of the parents asked if they would be told of any of the findings of the interviews I did with the sixty families and I promised to let them have some of the information as soon as I had analysed the questionnaires. I am enclosing a brief breakdown of the most relevant facts and figures which you may be interested to have. Obviously because of the need for confidentiality I have only given the barest facts and no details which can be identifiable. If you have any comments or would like to discuss any parts of this further I should be only too glad to hear from you.

I was very glad to come and meet you and would like to thank you again for all the helpful information which you gave me. I hope as a result of all this the next generation of parents of handicapped children will have a more efficient and smooth running system of professional help.

With all good wishes,

Yours sincerely

MRS GILL LONSDALE
SENIOR LECTURER IN SOCIAL WORK
Dear

In the autumn term you very kindly spent some time showing me round your school and telling me about educational provision for handicapped children. I thought you might be interested in some of the facts and figures which emerged from the interviews which I did with sixty families, some of whom would be parents in your school. For reasons of confidentiality these are the barest of facts, but several of the parents I spoke with asked for some information when I analysed the questionnaires, and because they were so interested and generous of their time I thought it was important that they had some feedback so I have sent a copy of this to each of the parents who took part.

If you have any comments or would like to discuss any parts of this further I should be only too pleased to hear from you.

With all good wishes,

Yours sincerely

GILL LONSDALE (MRS)
SENIOR LECTURER IN SOCIAL WORK
EVALUATION OF SOCIAL WORK INTERVENTION WITH FAMILIES HAVING A
HANDICAPPED CHILD

Time

Section A       The Family

(1) Name

Father

Date of Birth  Occupation

Mother

Date of Birth  Occupation

Now

In Past

Home address

How long has the family lived there?

(2) Children by age on the date of the interview, birth order, and sex, ringing the handicapped child. Mark deceased children in correct birth order and include date of death.
(3) Are these the natural parents of the handicapped child?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Father</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Section B Practical and Financial

(4) a) Poor, low or irregular income, would benefit from financial assistance, aids, holidays, rehousing

b) Adequate means. Just comfortable, able to cope. No serious housing problem

c) Affluent. High standard of living. Good housing and facilities.
### SECTION C  
**Nature of disability of handicapped child**

(5) **Medical diagnosis**

<table>
<thead>
<tr>
<th>None</th>
<th>Slight</th>
<th>Marked</th>
<th>V. Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Degree of mental handicap

Visible deformity

Functional deformity (e.g. need for aid in climbing stairs, eating)

Other handicaps

---

### Section D  
**The effects of the handicap**

(6) What has been the direct effect of having a handicapped child on:-

(i) **Siblings**

<table>
<thead>
<tr>
<th>Child</th>
<th>None</th>
<th>Slight</th>
<th>Marked</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

a) Behaviour disorders

b) Relationship with peer group outside home

c) Relationship with handicap child
(ii) Other significant relatives

<table>
<thead>
<tr>
<th>Relative</th>
<th>None</th>
<th>Slight</th>
<th>Marked</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) ability to offer help</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) ability to accept handicap and its implications</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c) avoidance of situation and family</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d) overt disruption in family ties</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(iii) Marriage

<table>
<thead>
<tr>
<th>Slight</th>
<th>Marked</th>
<th>Extreme</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) marital tension</td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) development of deeper understanding and support of each other</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
IV) Family Health

Have there been any illnesses in the parents which have a direct cause and effect link with the handicap?

<table>
<thead>
<tr>
<th></th>
<th>Mother</th>
<th></th>
<th>Father</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td></td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
<td></td>
<td></td>
<td>No</td>
</tr>
</tbody>
</table>

If YES specify

<p>| |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td></td>
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<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

V) Family Functioning

<table>
<thead>
<tr>
<th></th>
<th>Mother</th>
<th>Father</th>
<th>Siblings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Who has gone out to work?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Who has been prevented who may have wished to?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has anyone felt that having a handicapped child affected their work performance?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has social life been curtailed?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
(7) Has there been any change in the family's attitudes and values since having a handicapped child? (e.g. religious beliefs)

SECTION E  Professional Help

(8) When the diagnosis of long term handicap was first made who gave the information to you?

<table>
<thead>
<tr>
<th></th>
<th>Mother</th>
<th>Father</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor at the hospital</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Midwife</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health Visitor</td>
<td></td>
<td></td>
</tr>
<tr>
<td>General Practioner</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other Person (state whom)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
(9) Were you told

<table>
<thead>
<tr>
<th></th>
<th>Mother</th>
<th>Father</th>
</tr>
</thead>
<tbody>
<tr>
<td>On your own</td>
<td></td>
<td></td>
</tr>
<tr>
<td>With your spouse</td>
<td></td>
<td></td>
</tr>
<tr>
<td>With social worker</td>
<td></td>
<td></td>
</tr>
<tr>
<td>present</td>
<td></td>
<td></td>
</tr>
<tr>
<td>With another person</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(state whom)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(10) Were you only told once or more than once

<table>
<thead>
<tr>
<th></th>
<th>Mother</th>
<th>Father</th>
</tr>
</thead>
<tbody>
<tr>
<td>Once</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More than once</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(11) Did you feel you were told at the right time?

<table>
<thead>
<tr>
<th></th>
<th>Mother</th>
<th>Father</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
(12) What additional help do you think should be available to families with a handicapped child?

<table>
<thead>
<tr>
<th></th>
<th>Not necessary</th>
<th>Important</th>
<th>Essential</th>
</tr>
</thead>
<tbody>
<tr>
<td>Financial</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aids and appliances</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurseries and playgroups</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hostel care for short stay e.g. holidays, family emergencies</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent support groups</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Counselling and information giving</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (state)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
(13) (i) Have there been times since you had a handicapped child when you felt you needed help?

<table>
<thead>
<tr>
<th></th>
<th>Mother</th>
<th>Father</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(ii) If Yes have these been

<table>
<thead>
<tr>
<th></th>
<th>Mother</th>
<th>Father</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very rarely</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occasionally</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Often</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very frequently</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(iii) To whom  
a) have you turned for help  
b) would have liked to turn for help

<p>| | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>a</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relatives</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doctor</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Priest</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health Visitor</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Worker</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other person (state whom)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
(14) (i) Have you had any contact with a social worker?

Mother

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

Father

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

(ii) If Yes

a) When was this

b) How often did you see your social worker

c) What sort of service did you feel you got

d) Was this adequate

e) What more could have been done
(iii) If No
Would you have liked to see a social worker?

.................................................................

.................................................................

.................................................................

.................................................................

.................................................................

(15) What is your impression of what a social worker does?

.................................................................

.................................................................

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(16) SECTION F Personal comments

State any personal comments about the problems facing a family with a handicapped child. Is the family situation similar to what it was before the child's handicap was diagnosed or are things very different now?

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Time ..................  Interviewer's Name ...................................................
Date of Interview  ..................................................
EVALUATION OF SOCIAL WORK INTERVENTION WITH FAMILIES WHERE
A CHILD HAS DIED

Time

The Family

(1) Name

Father

Date of birth

Occupation

Mother

Date of birth

Occupation

Now

In past

Home address

How long has the family lived there?

(2) Children by age on the date of the interview, birth order, and sex, ringing the handicapped child. Mark deceased children in correct birth order and include date of death.

<table>
<thead>
<tr>
<th></th>
<th>M</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1st</td>
<td>2nd</td>
</tr>
</tbody>
</table>
(3) Medical Diagnosis

What was the cause of the child's death?

(4) Professional Help

When you were told that your child was unlikely to live can you remember who it was who told you?

<table>
<thead>
<tr>
<th></th>
<th>Mother</th>
<th>Father</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor at the hospital</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sister at the hospital</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Worker</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other person (state)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(5) Were you told

<table>
<thead>
<tr>
<th></th>
<th>Mother</th>
<th>Father</th>
</tr>
</thead>
<tbody>
<tr>
<td>On your own</td>
<td></td>
<td></td>
</tr>
<tr>
<td>With your spouse</td>
<td></td>
<td></td>
</tr>
<tr>
<td>With another person (state)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
(6) Were you told

<table>
<thead>
<tr>
<th></th>
<th>Mother</th>
<th>Father</th>
</tr>
</thead>
<tbody>
<tr>
<td>Once</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More than once</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(7) Did you feel that you were told at the right time?

<table>
<thead>
<tr>
<th></th>
<th>Mother</th>
<th>Father</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If no when would have been better? ........................................
........................................................................
........................................................................

(8) Can you remember exactly what you were told? ..................
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........................................................................
(9) How much help did you have from the hospital staff?

<table>
<thead>
<tr>
<th></th>
<th>Mother</th>
<th>Father</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not very much</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sufficient</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Too much</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(10) What sort of things did you find

a) helpful

.................................................................

.................................................................

.................................................................

b) unhelpful

.................................................................

.................................................................

.................................................................

(11) Mother When you left hospital how did you feel?

<table>
<thead>
<tr>
<th>In need of further help</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Just coping</td>
<td></td>
</tr>
<tr>
<td>Well</td>
<td></td>
</tr>
</tbody>
</table>
(12) Father  You were not a patient at the hospital. Did you feel that the attention was focussed

<table>
<thead>
<tr>
<th>On your wife</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>On you both</td>
<td></td>
</tr>
</tbody>
</table>

Did you receive as much help as you felt you needed?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

(13) Were any of your near relatives involved at the hospital?

<table>
<thead>
<tr>
<th>Mother</th>
<th>Father</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>

If yes how did they feel that they were treated? ........................

...............................................................

.............................................................
(14) i) Have you had any contact with a social worker?

<table>
<thead>
<tr>
<th>Mother</th>
<th>Father</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>

ii) If Yes

a) When was this..............................................................

b) 'How often did you see the social worker................................

c) What sort of service did you feel you got................................

d) Was it adequate............................................................

e) What more could have been done........................................

iii) If No

Would you have liked to see a social worker? ......................

(15) What is your impression of what a social worker does?........

.........................................................................................

.........................................................................................
(16) How long do you think it was before you began to get back to normal?

Mother.................................  Father.................................

................................. .................................

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................................. .................................

(17) How did you know that you were getting over it?

Mother.................................  Father.................................

................................. .................................

................................. .................................

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(18) Has it had any long term effects?

<table>
<thead>
<tr>
<th>Mother</th>
<th>Father</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>

If Yes what have these been?

Mother.................................  Father.................................

................................. .................................

................................. .................................

................................. .................................

(19) Has the event affected the siblings in any way?

.................................................................
(20) Marriage

<table>
<thead>
<tr>
<th>Slight</th>
<th>Marked</th>
<th>Extreme</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) marital tension</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) development of a deeper understanding and support of each other</td>
<td></td>
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</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(21) How do you feel now?

Mother........................................ Father........................................
...........................................................................................
...........................................................................................
...........................................................................................

(22) Personal comments

State any personal comments about the differences which losing a child has made to your life. Is the situation now similar to what it was before the child's medical condition was diagnosed or are things very different?

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Time........................................ Interviewer's Name........................................
Date of interview........................................
EVALUATION OF SOCIAL WORK INTERVENTION WITH FAMILIES WHERE
A CHILD MIGHT HAVE A POTENTIAL DISABILITY

Time..............................

The Family

(1) Name.........................

Father.........................

Date of birth............... Occupation.........................

Mother.........................

Date of birth............... Occupation

Now.........................

In past.........................

Home address ..................

................................

................................

................................

How long has the family lived there?..........................

(2) Children by age on the date of the interview, birth order and sex, ring the child who was investigated. Mark deceased children in correct birth order and include date of death.

<table>
<thead>
<tr>
<th>M</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>F</td>
<td>1st</td>
<td>2nd</td>
<td>3rd</td>
<td>4th</td>
<td>5th</td>
<td>6th</td>
</tr>
<tr>
<td></td>
<td></td>
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<td></td>
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<td></td>
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</tbody>
</table>
(3) Medical Diagnosis

Why was the child referred to the Paediatric Department?...........................
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When was this?...........................................................................................................
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What was the outcome of the investigations?......................................................
..........................................................................................................................
..........................................................................................................................
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Was the final diagnosis as serious  [ ]
less serious  [x] than the provisional one?

How did you feel about this?................................................................................
..........................................................................................................................
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Can you remember exactly what you were told?...............................................
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..........................................................................................................................
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..........................................................................................................................
..........................................................................................................................
..........................................................................................................................
(4) **Professional Help**

When medical information was given to you at the hospital can you remember who gave it to you?

<table>
<thead>
<tr>
<th>Mother</th>
<th>Father</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor at the hospital</td>
<td></td>
</tr>
<tr>
<td>Sister at the hospital</td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td></td>
</tr>
<tr>
<td>Social Worker</td>
<td></td>
</tr>
<tr>
<td>Other person (state)</td>
<td></td>
</tr>
</tbody>
</table>

(5) **Were you told**

<table>
<thead>
<tr>
<th>Mother</th>
<th>Father</th>
</tr>
</thead>
<tbody>
<tr>
<td>On your own</td>
<td></td>
</tr>
<tr>
<td>With your spouse</td>
<td></td>
</tr>
<tr>
<td>With another person (state)</td>
<td></td>
</tr>
</tbody>
</table>
(6) Were you told

<table>
<thead>
<tr>
<th></th>
<th>Mother</th>
<th>Father</th>
</tr>
</thead>
<tbody>
<tr>
<td>Once</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More than once</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(7) Did you feel that you were told at the right time?

<table>
<thead>
<tr>
<th></th>
<th>Mother</th>
<th>Father</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If no when and how would have been better?

(8) How much help did you have from the hospital staff?

<table>
<thead>
<tr>
<th></th>
<th>Mother</th>
<th>Father</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not very much</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sufficient</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Too much</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
(9) What sort of things did you find
   a) helpful...........................................
   b) unhelpful...........................................

(10) Were any of your near relatives involved at the hospital?

<table>
<thead>
<tr>
<th>Mother</th>
<th>Father</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>

If yes how did they feel that they were treated?..........................
........................................................................
........................................................................
........................................................................
If no why did they not come?.................................................
........................................................................
........................................................................
(11) i) Have you had any contact with a social worker?

Mother

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

Father

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

ii) If Yes

a) When was this...

b) How often did you see the social worker...

c) What sort of service did you feel you got...

d) Was it adequate...

e) What more could have been done...

iii) If No

Would you have liked to see a social worker?

(12) What is your impression of what a social worker does?
(13) For how long did your child receive treatment?

<table>
<thead>
<tr>
<th>Mother</th>
<th>Father</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>

Is your child still receiving treatment?

(14) Has it had any long term effects on the parents?

<table>
<thead>
<tr>
<th>Mother</th>
<th>Father</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>

(15) Has it had any long term effects on the child?

<table>
<thead>
<tr>
<th>Mother</th>
<th>Father</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>

If yes what have these been?

a) On the parents.

b) On the child.

(16) Has the medical situation affected the siblings in any way?
(17) Was your marriage affected in any way by the events?

<table>
<thead>
<tr>
<th>Slight</th>
<th>Marked</th>
<th>Extreme</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td></td>
</tr>
<tr>
<td>a) marital tension</td>
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</tr>
<tr>
<td>development of a</td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) deeper understanding</td>
<td></td>
<td></td>
</tr>
<tr>
<td>and support of each other</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(18) How do you feel now?

Mother:........................................... Father:...........................................

........................................... ...........................................

........................................... ...........................................

(19) Personal comments

State any personal comments about the differences which going through this experience has made to your life. Is the situation now similar to what it was before the child's medical situation was investigated or are things very different?

........................................... ...........................................

........................................... ...........................................

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........................................... ...........................................

........................................... ...........................................

Time:.......................... Interviewer's Name:..........................

Date of interview:.........................
APPENDIX E

An example of case recording from Group A - handicapped and lived.

This case was of a baby boy whose condition was not clinically obvious and whose parents did not suspect that anything was amiss. He was slightly premature and was in the Special Care Baby Unit so there was some separation from mother. However, she was keen to breast feed and was expressing milk and being as involved as she could at this stage. There was very much a planned team involvement in the telling of the parents and the subsequent care of this family and I believe we got the process as near to right as we ever did. I quote in detail this as an example, perhaps even a model of how to handle telling parents of their child’s handicap when some little time has elapsed between birth and the telling.

STEPHENS FAMILY

Dr. Brown came to see me about 4 p.m. Baby Stephens was born two days ago about three and a half weeks premature. The houseman had thought that there was some indication of Down’s syndrome but Dr. Brown when he saw the baby was not sure and had asked the registrar who had specialised knowledge in this area also to examine him. The registrar had just done this and they were almost certain that the baby was a Down’s syndrome and had sent blood off to Bristol for confirmation. The question was when to tell the parents. Should we tell them now while there was some doubt or should we wait until the results came back from Bristol. I had no doubts about this and possibly pressed for telling as soon as we could organise a joint meeting with the parents. After checking with the ward that Mr. Stephens would be visiting his wife that evening we arranged to see the parents together at 8 p.m.

Day 3. Mr. and Mrs. Stephens came up to the Special Care Baby Unit a little before the time arranged and immediately said that they were very
worried about having to see the paediatric consultant. Unfortunately, Dr. Brown was delayed and all I could do was to recognise the anxiety with them and say that any medical information had to come from the consultant. (In a perfect situation it might have been preferable for the parents not to have any prior warning that the consultant wished to see them and somehow he should be passing — with the social worker — when the father just happened to be visiting his wife. This is not to deny the functional value of anxiety but we gave them absolutely nothing on which to focus their anxiety. Perhaps at 4 p.m. we could have told Sister in arranging the meeting to say that although Peter was very well there were one or two features which might make for problems in the future and that we would like to discuss these with them.)

Dr. Brown and the houseman joined us. Dr. Brown told them simply and straightforwardly and repeated several times the medical details and said that there had been some doubt about the diagnosis which was the reason for the slight delay in telling them. Mrs. Stephens sat with fists clenched and both parents were visibly shaken, but initially extremely calm. They asked a few questions but it was obvious that they wanted to be alone and when I suggested that they had some time together and that we saw them later they gratefully accepted. The tears were coming and Mrs. Stephens said that her mother was on the ward and she did not think she could tell her. I offered to go and see her.

While Mr. and Mrs. Stephens had time alone I went to see the Grandmother in one of the side-wards downstairs. I repeated the main facts as Dr. Brown had given them to her daughter. She was stunned and took hold of my hand as I told her. She and her daughter are very close; her second baby — a son — had died soon after birth and she could not have any more children, so there had been tremendous rejoicing when a baby grandson had been born. She asked a few questions and then said that she
would like to sit in silence for a while. I offered to make her a cup of tea which she accepted. As I returned with the tea, her son-in-law came in and said that her daughter would like her to go up. She sipped some of her tea because she was shaking and then she took my arm and I walked up with her.

Later Dr. Brown, the houseman and I were asked to go back and speak with them all again. Mrs. Stephens had cried a lot but was more relaxed now. They both asked many questions about the condition and how it would affect their baby and their own future life. After the doctors left, I stayed and we discussed feelings and reactions. Both acknowledged that they felt numb and we talked about the phases of disbelief, depression and anger which accompanied crisis. Mr. Stephens said that he could not go back to sea because he was needed at home, but I encouraged him to think about compassionate leave for the moment and then to look at the implications for the future when they had had time to think round the problem. Mrs. Stephens had some milk to express but was fearful of going back to the ward and having to face the other mothers. She wanted to go home with her husband but also wished to breast feed Peter. We talked about this and I said that the other mothers would find her return difficult because by now they would realise that something was wrong and would not know what to say to her. Mrs. Stephens went back to the ward while the other mothers were out feeding their babies and when they returned she was able to tell them and this was the first hurdle successfully over.

Day 4. I arrived at the same time as Mr. Stephens who had brought some freesias in for his wife. Both were feeling much better, but if anything were a little too euphoric. Mrs. Stephens had been given sleeping tablets last night and as she said "had gone out like a light". Mr. Stephens had gone home with his mother-in-law and they had had some
brandy and then he had been able to ring close friends and relatives
and give them the information. We talked over the queries of last night
and established that Mrs. Stephens was more resigned to staying in
hospital until Peter had got his feeding routine established. They were
more receptive to taking each day as it came for a while and not rushing
into taking any firm decisions. I arranged to see them on Monday morning.

Day 6. Mr. Stephens had been given compassionate leave, the length of
which was to depend upon Dr. Brown's recommendation. Mrs. Stephens
spoke about the stages she had gone through over the week-end, including
disbelief and we discussed the mourning process. She mentioned a friend
who had had a miscarriage recently and who was so depressed that they
had taken her to the doctor. We looked at the links between mourning
the loss through abortion and her needing to mourn the loss of the normal
baby which she first thought that she had, and that a reactive depression
could be a common factor in these situations. She said that her husband
was feeling very low yesterday but his parents had come down and she
thought this had helped him to get things more in perspective. Sunday
had also been the day that her own mother had been able to break down and
really weep for the first time since knowing of Peter's condition.

I talked with her about how the professional helping services could
be used to assist a family with a handicapped child to live a life as
near to that which they had mapped out for themselves had they had a
normal child. Mr. Stephens loves life at sea and was planning to take his
Master's ticket. They knew that he would not get such a well paid job
ashore but Mr. Stephens did think that Peter would need his ongoing
rather than his intermittent care. We looked at the fact that most
children needed to have a father around and how this could be a problem
for the families of sea-going fathers, but there had to be a balance
between children's needs and father's careers and somewhere also some
consideration of mother's happiness. I said again that I thought they should continue to live from day to day for a while and then begin to look forward and see if their plans had to be modified to fit in with the new situation created by having a child with Down's syndrome.

Day 7. The results from Bristol were positive. Dr. Brown and I saw the parents together for nearly an hour. There could be no more doubts and no more flights into the world of it may not be true and from that time we were able to really look at the true implications of it all. Perhaps more important was the fact that they were well prepared to do this and it was a most constructive interview. Mrs. Stephens was to be discharged later that day but Peter had to stay in for a while until his weight increased and his feeding was established.

Week 2. Mr. and Mrs. Stephens came in regularly, did much for Peter and when he was ready to go home his mother came into the flat for 24 hours to take over his complete care.

Month later. I visited the family at home. All was going very well and the grandparents were staying. Mr. Stephens' compassionate leave seems to be never ending, but now it is because a ship is not available. It has really given this couple the opportunity of making an excellent start with the daily management of their son. They had asked for something to read about Down's syndrome so I took them a copy of 'Bernard' by John and Eileen Wilkes. I told them that I thought it was an honest, well written account of their experience of bringing up a son with Down's syndrome but I did not know when parents should read it and would be glad to have their comments on this in due course.

We talked about the future social work contact. They understood that I had been actively involved at the beginning to help them adjust to the birth of a handicapped child. They knew I was the social worker for handicapped children and that I would see them when they came up to
the hospital for the out-patient appointments. We were agreed that for the first year at least the problems with Peter would not be all that different from those of the normal child and likely to be for the Health Visitor, but that when he got towards his third year and educational assessment began there might be more social work to be done.

An example of a case record from Group B - Handicapped and Died.

The example in this section is concerned with the death of a little boy aged two. He had never been ill in his life and then quite suddenly he was struck down with a particularly nasty type of viral meningitis from which he did not recover consciousness. He was the much adored younger son of a couple who lived for and enjoyed every minute they had with their children. He had grown up in a small community surrounded by numerous great aunts and uncles and his grandparents and was known to nearly everybody who lived locally. The loss for these parents was harder than in any of the examples, where a child had died shortly after birth, because they were losing so much more; not a brief relationship which had hardly had a chance to get going, but a much cherished one of two years standing. On the positive side these parents had two years of memories which other parents lacked. It was a harrowing experience for the parents and their family and also for the staff who were involved in caring during the crisis. It was very much a team involvement and the team needed the support of each other to give the maximum service to the whole family.

RICHARD THORPE

Day 1. About 5.30 a.m. Richard woke up and was sick and went back to sleep. His father gave him a drink before he went to work and his mother went in soon after 8 a.m. and gave him another. At 8.30 a.m. she found him unconscious, rang her husband at work and the family
The doctor, himself, drove Richard and his mother straight into the hospital followed by Mr. Thorpe in his own car. As soon as they reached the ward a lumbar puncture was done which confirmed the diagnosis. At 2 p.m. Richard stopped breathing and was moved from the children's ward into the Intensive Care Unit and put on a ventilator. The houseman rang me in my office and I went straight over and was introduced to the parents by the registrar. They were in the little sitting-room on the Unit which had been made available exclusively for their own use.

Both parents were prostrate with grief and could give very little support to each other. I began by asking them what the doctor had told them and they kept repeating that it was very serious and they did not want him to be a cabbage. Very gently I led them back over what had happened and they were able to keep going through the events of the morning and say how well he had been yesterday and described how he had sat on his father's knee to watch the European Cup Final last night. Midst all their tears Mrs. Thorpe kept saying that she would never be able to watch football again and that he had lovely clothes and that she dressed him up every day. They talked about all the things he did and what he said. As their confidence in me seemed to grow they were able to ask about the outcome and acknowledge that the chances of him living were remote.

Although the nursing staff were actively treating Richard I thought that it was important for these parents to have access as and when they needed. They found it difficult to go into the treatment room and at the beginning Mr. Thorpe could do this only very briefly. We gave them a chair on each side of the bed and encouraged them to hold Richard's hands. Mrs. Thorpe was able to do this but her husband could not stay near his son. An aunt and uncle who are very close to the family came...
in and stayed for a while in the sitting-room. They had organised the picking-up of the elder brother from school and one of the grannies was going to have him to stay for the night. They said that Mrs. Thorpe's mother had had hysterics when she had been told about Richard.

Dr. Fergus came in to examine Richard and did not exclude the parents while he did so. Earlier the staff nurse had thought that she had got a slight response from the pupil, and the primitive response of the foot had been seen, but there was no evidence of this when Dr. Fergus made his examination. He spoke with the parents and told them that there would be no change for 24 hours but the situation remained very serious. We encouraged them in their wish to go home briefly. They were a bit worried about being in their working clothes and wanted to have a wash and change. We said that they could stay the night in hospital or come and go, whichever arrangement suited them best. As they left I suggested that they brought back Richard's teddy or the toy that he took to bed with him each night. The aunt and uncle briefly saw Richard but were too distressed to remain in the room with him. They were very supportive to the young couple.

I returned to the hospital just before 9 p.m. Mr. and Mrs. Thorpe were back and had brought a few things in for the night and also Richard's goollies which were tucked up in bed with him. There was no change at all in his condition but unfortunately the alarm bell on the ventilator was faulty and kept ringing which caused the parents a lot of unnecessary anxiety. The Anaesthesia came and checked it and sent the parents out. After he had fixed it I asked him if he would have a brief word with the parents and explain what had been wrong. He seemed surprised but did so, and they felt reassured that it had been a faulty connection. The night staff came in and introduced themselves to Mr.
and Mrs. Thorpe who generally speaking were fairly calm by now and much reassured that some of the doctors slept in the hospital and were readily accessible. I told them if there was any deterioration in Richard's condition during the night I would come in, otherwise I would see them first thing in the morning.

Day 2. I went to the Intensive Care Unit soon after 8 a.m. to be greeted by another Sister with, "If you're the social worker thank goodness you've come; they're in a terrible state." Although there was no change in Richard's condition there had been no improvement in the reflex patterns and the parents knew that he was not going to survive. There had been a gap between them being told that he was unlikely to live and accepting this of about 18 hours. They were very distressed again, going through another periodic weeping stage and saying that they would have to move away from their present home because they would not be able to tolerate seeing the other children who lived near them growing up. Mrs. Thorpe could sit by Richard but Mr. Thorpe was hyperactive and could not settle anywhere. The nursing staff suggested that he went out of the hospital for a walk or that he sat down on a chair, but when I explained to them that he could not do either, they let him pace up and down the corridor and in and out of the room as he wished. It made the nursing less organised but it helped a grieving father and the nurses when they understood this could not have been more co-operative.

Dr. Fergus came and after examining Richard told the parents that he planned to keep him on the ventilator for the time being and perhaps over the weekend. He was going to arrange for an Electro-encephalogram to be done which would show if there was any brain activity. Mr. Thorpe pleaded with Dr. Fergus not to let Richard live if he was going to be a cabbage and not to use him as a guinea pig. Dr. Fergus listened sympathetically to him but said that he would make the
medical decisions and his decision at this stage was to continue treat-
ment. We then talked about how we could help Mr. and Mrs. Thorpe with
their personal agony. The houseman had given them some valium and had
telephoned their family doctor whom they knew well to ensure that the
medical care continued. We would give what emotional support we could
at the hospital.

The aunt and uncle, two grannies and a grandad came in. Mrs.
Thorpe wept loud and long on her mother-in-law's shoulder. There is a
good family network here because two brothers married two sisters and
they are all very close. Mrs. Thorpe's father died of cancer so she has
had some experience of losing a close relative and it may explain why
apparently she is coping better than her husband who, as yet, has never
lost anyone whom he loved dearly. I made tea for the family and served
it to them. Then, with the exception of the maternal grandmother who
is inclined to faint and have hysterics, each one went in to see Richard.
They were all very upset but were glad that they had been able to bring
themselves to do this. It was agreed the best thing would be for the
parents to go home for a break. They understood that life was being
maintained artificially and that there could be no change while this
was being done. We encouraged them to telephone in as many times as they
wished.

Soon after 2 p.m. Dr. Fergus had the results of the Electro-
enccephalogram which showed that there was no brain activity at all and
he decided that it was futile to proceed with treatment. The parents
had not returned, or telephoned, but rather than send the police to
find them and by so doing alarm them, we agreed to wait until they came
back in. I thought they would probably meet their other son from
school and then return, and this in fact was what they did.
Dr. Fergus and I saw them together. He told them that there was no brain activity and no hope for Richard and asked them if they would wish the ventilator to be turned off. Mr. Thorpe became very calm at this stage and persuaded his wife to agree. Dr. Fergus went out for a while and we spoke about the situation. Mrs. Thorpe asked if she could hold Richard and I went to ask Dr. Fergus who agreed. I took her back into the treatment room and helped her sit down by the bed. Richard, still with numerous tubes attached to him was lifted on to her knee and as she hugged him to her the ventilator was switched off and he died in her arms. Both parents kissed him good-bye and when they were ready we took them out of the room. Mrs. Thorpe went to her uncle and Mr. Thorpe had a long talk with Dr. Fergus. Somebody gave him a drink which was not a good thing probably, because he did not usually drink. A calmness began to descend and we made arrangements for the immediate issue of the death certificate so that they did not have to come back into the hospital again. Mr. Thorpe did not seem to want to be with his wife and appeared to need the routine administrative tasks as an outlet for his hyperactivity. Mrs. Thorpe desperately wanted to get away and I suggested that her uncle took her home and that I brought her husband when everything was tied up, but she insisted on waiting for him. He seemed to be reluctant to leave the place. Finally, I had to say to him that his wife really did need to go, so he drank the brandy straight back, collected Richard’s clothes and gollies and the death certificate and went to her. Through their tears they said good-bye to the registrar and me and said that they knew everything that could have been done had been done. Slowly, with tears streaming down their faces, they walked out into the hot sunshine and to pick up the threads of their shattered life. We, who were left, blinked away our own tears, talked about the tragedy and watched a shrouded bundle leave the
Month later. This was a long interview but it was perhaps the first time since Richard had died that Mr. and Mrs. Thorpe had talked at length about it. Their other son was still up when I got there but after a little chat with me he went off to bed. He is waking up in the night and complains of aches in the throat, arm, teeth and tummy much more than he ever did before. I explained to his parents why this might be and how children of his age (nearly 6) had little understanding of death and the finality of it, but that going to sleep sometimes brought with it separation anxieties and he may have fears that this might be what happened to Richard.

Mr. and Mrs. Thorpe had a very real need to talk and at times could hardly wait for the other to finish before adding something. They went through the events leading up to Richard's death, the days that followed, the funeral, the cremation and the problems with people being uncomfortable and not knowing what to say. The families had rallied round them; Mrs. Thorpe's mother had come to stay for a while and done all the cooking because all they felt like doing was to sit in a chair. They soon stopped taking the tablets because they had made them feel drowsy and they thought that they began to feel better after that. Last week they had been to Cornwall for the holiday which they had already booked and paid for. They went without enthusiasm and mostly for their son's sake and did not particularly enjoy it, but it had been a change and an attempt to keep going.

Early in the interview Mrs. Thorpe cried a little and her husband looked anxiously at her, but let her be, presumably because there is still a need to cry and that it was part of the process of mourning in which they were both engaged. She also smiled during the interview and was able to look forwards as well as backwards. Originally, Mr.
Thorpe had thought two children was enough, although his wife had wanted a third and had hoped for a girl. Now they were beginning to talk about having two more babies because their son would be so much older than any subsequent children they might have. Mrs. Thorpe is 31 and it took a year to conceive Richard so she is a little worried about managing to start a pregnancy but knows that there is plenty of time. At the time of closing this case my assessment states:

This couple have moved a long way in a month and are realistically facing up to a new and at the moment much more empty life. All of Richard's toys and clothes have been put away and his photograph removed from the sideboard. We talked about this and the necessity of having done it now, but that in the future it should go back in its place. Richard was part of their family and his memory needed to be preserved and his former presence acknowledged. They will be able to do this in time. They know that part of them died with him, but they also grew together as a couple and developed strengths within themselves which have enabled them to stay in their present house, to mix with the other families again and even to go to the street Jubilee party a few days after the funeral. Life will not be the same for them but they are taking a positive look to the future and all augurs well for them. I offered to sort out some minor problems about the death certificate which I did next day. They were appreciative of the help and care which they had had from the hospital and Mrs. Thorpe said that she would be able to face going back there to have any other babies. At this stage, I realised the point of not being able to replace but only add to a family's membership. Another baby would not take Richard's place; it would be a baby in his own right as he had been. I believe they were already understanding this because Mrs. Thorpe said that perhaps it would be better if a girl arrived next although it was a boy.
we agreed that if there were times in the future when they felt the hospital might be able to help them they would make contact with us, but at the moment they were making a good recovery and the case should be closed. Two months later I received a letter to let me know that Mrs. Thorpe was pregnant and they were all absolutely delighted. She would be having her baby in the hospital and did not mind coming back at all now.

An example of a case record from Group C - Impaired but not permanently handicapped.

I have followed the medical classification and have placed SHARON KENDALL in the impaired group because although theoretically the treatment will cure the illness and she should be well, the side effects of the treatment are likely to cause permanent damage and in consequence impairments. Sharon has an elder brother and a younger sister. At the age of four she developed leukaemia and her parents were told she would live for about two years. She was on treatment for five years during which time she had one major relapse when it was discovered that her spinal fluid was affected and radiotherapy had to be given. She was expected to need treatment for another three years following the relapse, her gut began to deteriorate with the harsh treatment programme necessary and it just had to be stopped. "To the best of our knowledge she is cured" her parents were told. Her mother lived in ecstasy; her father lived in doubt. Eighteen months later there was a further relapse, when Sharon was 13 years old.

Sharon had not been feeling well so was sent into hospital to have a blood marrow test done. The results confirmed that the leukaemia was active again and Dr. Jones asked me to join him when he told Mr. and Mrs. Kendall, and when later he told Sharon.
Day 1. Dr. Jones outlined the clinical situation and discussed the possible treatment plan. All Mrs. Kendall could say was that "it was back to square one." They knew the side effects of the drug therapy and all the problems which Sharon would have to face. For a while they held hands and talked about their marriage. In the past Mr. Kendall had withdrawn into himself and would not discuss Sharon's illness, but now they were able to talk together about the horror of it all. Both Dr. Jones and I talked about the importance of involving Sharon in any decisions that had to be made and that it was important for her to be accepting of any treatment plan. Mrs. Kendall spoke of not allowing a child to refuse treatment and surely while she was still not adult her parents had the final say. She went to get Sharon who came in crying and flung herself on her father's knee. They both tried to cheer her up but we said that it was important to let her cry and then we would talk. Dr. Jones told her very simply what the situation was but she could not absorb; later when he had left we went through all he had said again but very little was retained. Sharon fears needles being put into her and knew only too well that for a blood transfusion she would have to face this. She said that she did not want Dr. Jones to do it because he used scissors. I said that was fine because she had made a decision and it could be arranged that one of the other doctors did it. (I told Dr. Jones later and he laughed. Apparently he uses forceps to assist getting into poor veins.) Mrs. Kendall said that she would have to go out for five minutes and Sharon asked her if she was going out to cry. Mrs. Kendall said that she might, so I asked Sharon if she wanted her mother to stay and cry with her which was what she did want. I offered to make them a cup of coffee which was one of Mrs. Kendall's reasons for wishing to go out of the room.
Mr. Kendall went home to get Sharon's nightdress and Mrs. Kendall and I spent some time talking about the treatment and how it would affect the whole family. Sharon was understandably low but her mother said that she had been depressed recently and very withdrawn. Her mother kept insisting that she must talk and tell them everything but all Sharon would say was that she did not want "to be a bother to anyone". Sharon cried about the likelihood of putting on weight again and all the children at school laughing at her. We talked about her being very anaemic and that when she had had four pints of blood she would feel better in herself and that would make it a little easier to face the treatment.

Later in the afternoon, Sharon was in the side ward doing a jigsaw and eating jelly sweets. Her brother and sister had been in to see her and her grandmother was due soon. She was still anxiously waiting for the drip to be put up. I explained to the ward staff about the anxiety and asked if the process could be expedited. Phone calls produced the blood and the registrar who was going to put up the drip. I called back just before I left at 6 p.m. They had just finished putting up the drip and a very pale and tearful Sharon told me that it had hurt her very much. I said that I was sorry which sounded banal. Mr. and Mrs. Kendall were fairly calm but Mrs. Kendall said she just felt numb. Tomorrow will probably be a more difficult day when nature lets the impact of the shock be felt. I told Sharon that I would come and see her in the morning.

Day 2. Sharon was having the last pint of blood when I went in about 9 a.m. She was looking much better with some colour in her cheeks. Both parents were in and we sorted out when Sharon would be ready to go home and who would be able to take her. Mrs. Kendall works in the afternoons but her husband is able to organise his work so that he can
come up to the hospital when he needs to. They had been able to sleep last night and were surprised that they felt more on top of the situation this morning. I spoke about social work involvement and they said that they had never been offered anything like this before. Afterwards I spoke with Sharon and told her that sometimes when things were worrying one it helped to talk to somebody. Because one loved one’s parents, it was not always easy to share painful things with them, nor did parents always share their worries with children. Yesterday and today we had all talked together and there had been more sharing. There may be times when this was not always possible or the right thing and it may be easier for her to talk with somebody outside the family like Dr. Jones or me. Sharon does not say very much but she smiles her understanding. She was very much the privileged patient this morning with her father delighting in waiting on her hand and foot. She had kept me a toffee.

Later in the day I saw them briefly when the drip was down and they were waiting for the medicines to take home. I arranged to see them the following Wednesday when they came up for treatment.

Week 2. The weekly treatment session. While Sharon was having her blood test done Mr. Kendall asked if he could see me. He said that his wife did not want him to ask but he was very worried about their financial state knowing that Sharon would need new clothes as she put on weight. I took details of their finances and said that I would contact the Malcolm Sargent Fund. We had a long talk about the strain of Sharon’s illness, family relationships and his wife’s migrain and menstrual problems. I spoke with Mrs. Kendall during the morning. She looked poorly and very strained. Sharon was quiet and sad; I think her parents may be too claustrophobic with her and she needs a breathing space.
Rang the Malcolm Sargent Fund. The secretary promised £25 for clothing and £13 car tax allowance which she would send by first-class post that day. I telephoned Mrs. Kendall to let her know.

**Week 3.** Shardon had to be admitted to the ward. Her white blood cell count was very low and she was running a temperature. A large encrustation on her lip was getting worse and because there might have been a fungal infection underneath she would have to go to theatre and have it removed. Because of the high risk of infection I only put my head round the door and said hello to Sharon. Dr. Jones and I spoke with the parents and they asked about the risks involved. He told them that there were risks with any surgery and in her condition they were somewhat higher. She would be given platelets before the operation and blood would be available during the operation. Tears were near the surface for both parents and they dare not ask any more questions; they said that they would not tell Sharon until the morning of the operation. They went away to have a cup of coffee and to talk together.

The scabs were removed under a local anaesthetic because there were problems with the platelets. Mr. Kendall took three days leave and spent the time with Sharon in hospital. She was drowsy for most of the time and fairly demanding of attention when she was wide awake. Her parents looked strained and although they kept a cheerful facade up in front of Sharon they were very worried.

**Week 3.** Clinically there was progress this week and Mr. and Mrs. Kendall continued to try to jolly Sharon along but she remained low and despondent. Towards the end of the week I raised this with Mrs. Kendall and suggested that maybe I could help Sharon. We both agreed that Sharon may not be able to face her worst fears with those nearest to her. During the following week Mr. Kendall would be back at work and Mrs. Kendall had to work full time so it might be an opportune
moment for me to spend more time with Sharon.

**Week 4.** Monday morning. Sharon was alone, lying on her bed fully
dressed but with her head turned to the wall. I sat down in the visitor's
chair and we had a few brief exchanges of words but there was obviously
something wrong and I waited quietly until Sharon felt like talking.
After a little while she rolled over with tears in her eyes and told me
that her hair had begun to fall out. We talked about how she had first
realised this and what the implications would be. At last Sharon was able
to cry about everything and spoke about whether or not the treatment was
worth it. She would be bald, other children would laugh at her, she would
not be able to go swimming and she would not be able to go to her uncle's
wedding. I raised the possibility of her wearing a wig and that if she
would like me to I would ask Dr. Jones to sign the form that day. She
feared that it might blow off in the wind so it was important to have
one that fitted. Although her nose and upper lip were better than they
had been they still looked rather unsightly. We talked about whether she
might wear a hat which had a little veil so that nobody at the wedding
would notice, but we decided that that would be "too old fashioned" and
that there was still time for it to heal. Later that day I made arrange­
ments for the wig to be ordered and the hairdresser promised to take
samples round for Sharon to try on.

**Tuesday.** A much happier girl this morning and for the first time during
this admission she was asking when she could go home. She decided to
tape record her chat with Dr. Jones when he did his round and then her
parents would know exactly what he said about her discharge. When I
passed by during the afternoon she told me that the houseman had said
that she should not use her tape recorder when Dr. Jones was in her
cubicle so she 'had told him where he got off' which showed that there
was some fight coming back.
Wednesday. Mrs. Kendall was sitting with Sharon but they were not speaking because Sharon had nothing to say. There was a twinkle in her eye which was another sign of emotional progress. Later that day she went home.

Weeks 5-8. A month at home with weekly visits for blood tests and intravenous treatment. Previously Sharon had had tablets and because of her horror of needles (made worse by the fact that she has poor veins so it is very difficult for the doctors to get into one) she became gradually more opposed to having treatment. Her parents became more strained and were frequently in touch with the ward, querying what was being done. It was obviously time to take stock of the situation.

Dr. Jones and I saw the parents together and we spent more than an hour reviewing the problems. He explained why it was necessary to have such a rigorous treatment plan but said that if after a sensible trial period it was felt that the treatment was worse than the disease then there may come a point when a decision has to be made not to continue. Mr. Kendall asked how long Sharon would live and was told weeks but just how many could not be predicted. Dr. Jones said that if this decision has to be taken he would be the one who made it but it would only be with their agreement. We then talked about Sharon's depression and how we might be able to help with that. It would be possible to give her anti-depressants but since we believed this to be a normal reactive depression I was more in favour of trying some intensive casework with her. I felt that any more pills were going to add to the hostility to being treated and that these should be deferred at least for the time being. The parents were agreeable to me seeing Sharon frequently over a short period of time and said that they would like to ask Sharon if she wanted to take part. Sharon said that she would and I arranged to go round the next day.
weeks 9-10. The contract that Sharon and I made was that we should have six sessions on a daily basis where possible, and that the content of our discussions was confidential to us but that she could share with her parents or anyone else any matter which she felt that she would like to. The only person that I would speak with would be Dr. Jones because he and I were part of a team but if there was any matter which she did not want to be mentioned to him she would say so.

**Session 1.** Sharon looked ill and did not say very much. We spent some time talking about leukaemia and what it was (not mentioning the word cancer) and how it affected the blood cells. This led us on to talk about treatment and what the various drugs were doing. Although she hates the treatment and especially having a drip put up she would never refuse to have it done. She cried when she was saying this and said that she never wanted to leave mummy and daddy. Very gently I pressed her on why she thought that she may have to leave mummy and daddy but she said that she did not know and we left the subject there. I mentioned the possibility of having a home teacher and she was very keen for me to find out if she could.

**Session 2.** Tomorrow is Uncle Jimmy's wedding day so we spent much of our time today planning what she would wear and what she would eat. She did not have a lot of information about the event itself either because she is not given it or because she does not retain very much of what is said to her. We used this situation as an example of having things in life to look forward to and how much this helped one along when things were not going too well. We arranged not to meet tomorrow because of the wedding but that I would come the following day at 2 p.m.

**Session 3.** All the children were at home recovering from the day before! Sharon had enjoyed the day but had been sick in the evening.
which had rather spoilt things. The teacher had been round that morning and had arranged to start working with Sharon next week. In many respects this was giving Sharon a very optimistic message of not wishing her to fall behind with her school work while she had this illness. I used it as a way in to talk about her future education and to say that this was only a temporary measure and that we should think sometime about a special school if she did not like her recent one very much. Sharon told me that she had thought of another thing to look forward to and that was Daddy's birthday in ten days time. I spoke with Jenny and Paul before I left. Jenny said with considerable feeling that she was being sent away for the weekend. Paul and Jenny may need some help too.

Session 4. I had telephoned between sessions and spoken to Jenny who had said that Sharon was being sick and that she felt sick too. The outcome was that she wanted to have a talk with me like Sharon did. I cleared this with the parents and told her that I would see her after I had spoken with Sharon. When I went round I was greeted with a beaming smile from Sharon and a caustic remark about Jenny "being on about seeing me all morning". It gave me an opportunity to ask if it was helpful for me to come and talk with her. She thought about it for a little while and shrugged her shoulders and said that she did not know and within minutes we were engaged in a very earnest discussion about death. Sharon spoke of feeling very frightened of dying and when would she know if she were going to live or die. I spoke generally about everyone dying and that it was the only sure thing in life and then linked this in with the uncertainties which went with leukaemia, especially when she had known other children die of it and here she was several years later still alive. This linked in with looking forward, fighting and willing oneself to
keep going. Sharon spoke about how much she hated her hair coming out and having to wear "that thing" (she cannot bear to call it a wig), of being sick so often and having diarrhoea after the treatment and whether any of it was worth it. She is very impressed at the moment by the local Faith Healer who does not believe in doctors or medicines or injections. She said that her father had said that he would never let the treatment stop but Uncle Frank (the Faith Healer) said that it was not necessary. She asked me what I thought about it so I said that I would not be working at the hospital if I did not believe in that way of treating illness but that I did also believe that sometimes one had to put one's hands in God's and trust in Him. Today was the break through. There was a new Sharon - cheeky, smiling and fighting and we had talked about some very painful and frightening areas.

Session 5. I wondered as I walked up the garden path if there would be a withdrawal today. I rang the bell and opened the door to go up as usual and there was Sharon dressed and coming down to meet me. We had a cup of tea; we discussed this and that and then I reviewed with Sharon what we had set out to do and how much of it would she be able to share with her parents with whom she is so very close. Jenny had told her that her mother said she would be told what we had talked about. I said that I could not tell her because that had been part of our bargain but I would be very happy about her telling them. We had one more session so I asked Sharon how she would like to use it. She said that she would like to come and see me in my office and that her father said he would bring her down. I got out my diary and suggested a time and asked her if it would be convenient.

Session 6. Sharon came wearing the new clothes which the Malcom Sargent Fund had sent money for and "the thing" which she said was the wrong colour and would have to be changed. She told her father to wait in
the waiting room and with a wink he meekly did as he was told. Once inside Sharon told me that she was going to actually speak to David Soul and we both agreed that that really was something super to look forward to.

Weeks 11-14. The weekly treatment continued but it began to get increasingly difficult to find a usable vein and in the last week they failed to do so and it was agreed that it would have to be done under a general anaesthetic. Sharon was very upset by the trauma of this and was refusing to speak to the family again. Mrs. Kendall was having bad migraines and there was marital stress. I offered to go and see them at home. In spite of what her parents had said Sharon was in good spirit and although she was fed up 'with always being mucked around' as she called it and said that the doctors should have been able to do it she dismissed the event quite casually and then went into raptures about how marvellous was David Soul and how he had sat next to her and asked her about her treatment and when he went he kissed her good-bye and said 'God bless'. She was going round next door for tea with the elderly couple who looked after her while her parents were at work. By this time, Mr. and Mrs. Kendall had returned from work. The stress of the last few weeks had really built up and the relationship between the two of them was very strained. My presence seemed to act as a catalyst and they really let fly at each other which perhaps needed to happen. It focussed on small things like use of the car, who slept with who and that he never took her out without the kids or the dog. It also tended to be predominantly one way but Mr. Kendall did come back at his wife more than he is usually supposed to do.

we looked at the stress, the constant fear of death with which they lived and their own guilt feelings about being angry with Sharon when she will not smile at them or even speak at times. At the moment,
moment she is very much a mummy's girl and Mrs. Kendall finds this
difficult and wishes she would become a daddy's girl which is what he
wants. They know that their marriage will survive; it is long estab-
lished and they feel the basis is still sound, but they both confess
to it going through the roughest patch they have ever known. They said
that it helped to talk and I thought it was no bad thing to have a con-
frontation to clear the air and help communication. Mrs. Kendall was
tense, vulnerable and tearful. She fears that all the anxiety may make
her a psychiatric case like her father. Mr. Kendall is silent and very
withdrawn and this, in fact, may be even more concerning.

Week 15. Sharon came in to have her bone marrow test done under an
anaesthetic and while she was under the influence of it a drip was going
to be set up for her injections. I went into the cubicle just as the
houseman was about to start the injections; Sharon was very upset and
protesting fairly strongly about having it done. She said that she had
a pain in her arm but, in fact, he had not done anything.

Mrs. Kendall was holding Sharon's hand and Mr. Kendall was stand-
ing on the other side of the bed. It all became too much for Mrs
Kendall who began to cry. We took her from the bedside and sat her in
an easy chair on the other side of the cubicle and let her weep. She
was at the end of her tether and she just lent against me and cried.
Mr. Kendall wanted her to brace herself but I persuaded him that she
needed to cry so reluctantly he let her be. He stood by Sharon and
kept glancing at his wife. When she had stopped crying I went over to
him and very quietly suggested that he gave her a hug. It was the most
therapeutic thing that he could have done and was perhaps the first
time he had demonstrated any affection for his wife for quite some time.
Later they told me that during that afternoon they had gone to bed
together for a little while. Meantime I held Sharon's hand, the nurse
held her arm and the houseman got on with the injections. I told Sharon that she could grumble at him, even put her tongue out at him and he would not mind. In fact, she rallied considerably and began to make jokes as well. Mrs. Kendall had stopped crying and was quite composed again so I asked her if she was ready to come back. She took Sharon's hand and I withdrew. Mr. Kendall followed me out of the cubicle and spoke again about it all getting them down and the stress makes him withdraw into himself so that he cannot give much much support to his wife. I said that they both very much needed each other's support and affection and if that could be kept alive then they might be able to find enough strength to struggle on, but we did all realise how great a burden they were being asked to carry. At the end of the day Sharon went home. I telephoned next morning and she was still in the throes of the post treatment sickness and diarrhoea and feeling wretched.

Week 16. The cancer specialist came for his regular six weekly clinic and he, Dr. Jones and I had a discussion about the situation. The prognosis is less good, there is the ongoing difficulty caused by Sharon's poor veins, the drugs are giving some very unpleasant side effects and the family stress is considerable. We were doing all we could to minimise this but knew that this could be only marginal and that to a family already worn by years of coping with this illness, their emotional strength is ebbing. When we raised these points with the parents, Mrs. Kendall said, "What you are saying is making me panic inside." Both parents were still inclined towards treatment at whatever price. A compromise situation was suggested that an artery would be attached to a vein to blow it up for the injections and that a monthly regime of increased dosage should be tried. We were getting regular grants from the Malcolm Sargent Fund to help with the financial burden and were in the process of negotiating special educational facilities for Sharon.
In the case of the education we had seemed to be getting nowhere in trying to meet Sharon's unusual and quite considerable needs, when out of the blue one day I had had a 'phone call from the teacher who ran the special teaching unit housed in one of the local schools. Sharon's home teacher worked there for the other half of the day and had spoken to him about Sharon's fears of mixing with other children and he thought that this unit could help.

**Week 17.** I visited the Unit and spoke with the teacher psychotherapist. Neither Dr. Jones nor I knew of the Unit's existence but we thought it would help Sharon and so did the parents when they visited. The administrative procedures were initiated but Sharon started attending the Unit long before they were completed because the teacher did not mind ducking under the red tape when it got in the way of meeting needs. It was planned that this would be a transitional stage in the move into special schooling and that it was likely that Sharon would start at the school for physically handicapped children in the following term.

**Week 18.** The plans to link an artery with a vein ran into problems of blockage and after the second attempt it was decided that it was futile to persevere and that the treatment would have to be given under anaesthetic which pleased Sharon. Both she and her parents were feeling much more on top of the situation. During this week I told them that although they may see me around next year I would be very much a part-time social worker and they really did need to have access to somebody who was around all the time. They asked a little bit about what I specifically did and expressed the normal reluctance to having a change. Mrs. Kendall, in particular, said how helpful it had been to have had somebody who had a family herself and who was older and to whom she had been able to pour out her woes. We looked generally at Johnson's quotation "no change is made without inconvenience even from worse to
better" and I spoke of the advantages which my colleague had in that she was more familiar with acute conditions and being younger than me would probably be a more appropriate worker for Sharon. I arranged the transfer interview for the following week and also wrote to a local fund to try to get some more money towards keeping their car on the road.

Week 19. Joint transfer interview in which I outlined the work we had attempted, the matters that were outstanding and what problems seemed to be on the horizon. Mr. and Mrs. Kendall were able to raise their apprehensions to changing worker but now having met my successor were able to appreciate some of what she could offer to the situation. Mrs. Kendall told her that she had been able to relate to me because I was older and perhaps also because I was the first social worker who had done anything to help them. However, they were very glad to continue having social work assistance and recognised that during the possibly short-lived time of things going relatively well, it was the right time to make the change-over.

(While I was writing the final chapter and nearly two years after I had worked with the family and nearly a year since I had done the research interview, Mrs. Kendall telephoned me at college. She wanted to be the one to tell me that Sharon had died, and that although they felt very sad she thought that they had been able to face the end calmly because they had been given so much support when they had most needed it. She explained that although there had been two social workers since it was the work done before that which was so important to them now. I asked her if she could explain that. She said she could not really except that I had been there when they needed it and gave them strength to look at what they had not dare face. It was this which had kept her going and she knew she could still keep going.)