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"I THOUGHT THEY WERE SUPPOSED TO BE DOING THAT"

A Comparative
Study of Co-ordination of Services
for the Mentally Handicapped
in
Seven Local Authorities
June 1969 to September 1972

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PREFACE

The central theme of this book bears conscious affinity to Professor R W Revans' firm belief that the only people who could really understand and who could most help to put right the problems of health and social services are the providers of these services themselves. Representatives of seven local authorities, belonging to various disciplines, were given the responsibility of looking for definitive answers to the problems which in their view were relevant to the task of improving the services to the mentally handicapped. Although the providers of services were all trained people in their respective professions they had no particular skills in the techniques of examining the services they provided.

By working together on their common problems they acquired an improved understanding of their own roles and also of the structure and functioning of the system they help to run. They have learned much about themselves, about what their colleagues do, about the influence they have on each other, and more importantly about the needs of the handicapped and his family. This group of people were deeply responsive to Professor Revans' approach and showed steadily increasing appreciation of the value of their own involvement in a systematic examination of the services and helped each other to develop a method of participative research for this purpose.

An account of their experience is presented in this book. It is expressive of a great degree of cross-fertilisation that has taken place over the last three years. This account is fairly straightforward but the individual contributions of various participants have been so closely interwoven throughout the project that it will be confusing to draw attention to their origins. Because this book has been based on the writings and contributions of a number of participants, it should be seen as a collective effort. Just how collective an effort it was became apparent during the Hospital Centre Conference about the project. An account of this conference appears in Appendix G.

Ali Baquer

September, 1972.
The Hospital Centre,
London.

ACKNOWLEDGEMENTS

We are grateful to King Edward's Hospital Fund for London for a grant to enable us to undertake this research project. It attempted to give a detailed description of services for the mentally handicapped in seven local authorities, and to develop methods for improving those services through the active involvement of those who provide them.

We are indebted to the members of the original working party who encouraged the idea of this exploratory type of research.

We thank all the staff of the Hospital Centre (where the project was housed for over three years) for their help.

We owe immense gratitude to Janet Craig, assistant director, Hospital Centre, who in her capacities as secretary of the working party, representative of the King's Fund and active member of the Research Advisory Group, helped the research officer direct the project in a manner both pleasant and profitable. Without her constant encouragement, based on her belief in deeply involving the providers of services, the project could never have accomplished its fundamental aims.

We thank all those part-time research workers who have helped us at various stages of the project, and we are particularly grateful to Tim Eltham who, in addition to helping us with other aspects of the project, showed a deep interest in and a masterly command of the quantification of data and construction of indices. His ability to write enticingly about statistical facts helped us to prepare this book on time.

We are grateful to Diana Cortazzi who willingly invested all her leisure time in the activities of the Group and, more specifically, in assisting with the design of the research tools for our hospital pilot study; in developing the concept of critical incidents; and in identifying gaps in the services through scanning completed questionnaires.

We owe our thanks to the secretarial staff, who during their respective periods of work on this project, showed inexhaustible patience and skills in typing questionnaires and

reports. We thank Ann Chapman, Phillipa Bennett, Judy O'Connor, Stella Johnston, Sarah Stenning, Anne Woronow and Elizabeth Carnachan for their unfailing assistance.

We are also indebted to Mr W Abbotts, director, Computer Centre, the London Hospital, and a member of his Operational Research Department, Mr. Ray Banks, for their help and consideration in making the computer analysis possible, even at a time of power breakdown.

We are grateful to David Boorer, our editorial advisor who, at a time of immense pressure, read the final draft and made a valuable contribution in editing it.

Our greatest debt of gratitude is to the members of the Research Advisory Group, drawn from the seven areas, for their guidance in the design of the study, the collection of data, the analysis and interpretation of information, the diffusion of the methods, and, above all, in generation actions leading to better services for mentally handicapped people and their family.

CONTRIBUTORS

This book contains our impressions of a complex project which was designed and carried out with a large number of providers of services from seven areas of the county. They have all influenced the developments of this survey but the account presented in this volume is largely based on the contributions of the following:

- Sid Atkinson
- Ali Baquer
- Anne Blacklock
- David Boorer
- Diana Cortazzi
- Janet Craig
- Tim Eltham
- James Gardham
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- Shirley Hardy
- Graham Curtis Jenkins
- Richard Lloyd Jones
- Reginald Revans
- Paul Sommerfeld
- Michael Spark
- Joan Trigwell
- Denis Watkins
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FOREWORD

STUDIES OF COORDINATION

by

Reginald W, Revans

FOREWORD

STUDIES OF COORDINATION

This is a book about two themes. The first is the improvement of the coordination of services to the mentally handicapped. The second is a description of how the first theme was pursued, by methods of study and discussion characterised, as far as possible, by the direct, active and personal participation in that study and in that discussion of both the staff providing the services and the families for whom they are provided.

The pair of questions to which the book is broadly addressed are thus:

> What improvements in the coordination of services to the mentally handicapped are both desirable and possible ?
>
> What part - and how important a part - can those now providing or using these services play in pursuing and answering the first question ?

Involving the coordinators

Independent evidence is now emerging to suggest that our two questions must be asked together. For example, the most recent major study of social services, carried out in New York City, 'Analysis of Public Systems', (Drake, Keaney and Morse, MIT Press, Cambridge 1972) contains the following sentences:

> 'Crime, drug use, fire alarms, solid wastes, automobile traffic, underprivileged children in the schools, housing deterioration ... are all outrunning the programmes designed to deal with them. The continuing need to run twice as fast to stay in the same place buries the successes from changes in the system and often obscures their impact ... The ... research effort worked well in some city departments and abysmally in others. The sine qua non was an administrator both interested in programme analysis and able to attract the staff to do the job ... consultants ... in the main, ... were useful only in those agencies with staff sufficiently competent in analysis to manage the consultant efforts ...'

Thus to improve the services (that is, to answer our first question) we must develop the staff to carry out the analysis (that is, to answer our second question). It is idle to pursue the first and to overlook the second.

Involving the consumers

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Thus to improve the services (that is, to answer our first question) we must develop staff to carry out the analysis (that is, to answer our second question). It is idle to pursue the first and to overlook the second.

Involving the consumers

But our second question deserves double attention. Those who provide and use th services include not only the mental welfare officers and the nurses, the psychologists and the training centre staffs: they include the parents and the families of the disadvantaged, and our need is to involve these in the study, no less. Our American report has this to say:

> 'More and more clearly our society is coming to regard interest groups - ethnic and racial associations, labour organisations, and neighbourhood communities - as legitimate participants in local decision making ... Over the long run, ... policy research may well depend upon the ability of our society to provide these groups ... with the means of participating in public debate in a more informed and more rational way ... We will find that the quality and utility of the analyses performed for governments will improve ... towards a competence, relevance and comprehension in policy analysis rarely seen today ... '

Our studies in Britain amply confirm this opinion. Indeed, before the American report was published, we had already announced The Law of Involvement suggesting that the leading factor to determine the quality of service received by the handicapped person and his family was the extent to which the parent becomes involved in the treatment of his child. Indeed, we show that two measures of successful coordination (established and used here for the first time) - the activity of the mental welfare officer and the index of interservices coordination - are alike stimulated by the level of parental pressure. Our conclusion is therefore that, as a back reaction a major task of the mental welfare officer is to stimulate, rather than to sooth, the energies of the parent and of the family.

MEASURES OF PERCEPTION

The continuous involvement of the professional staffs in the design and conduct of this study has offered at least one advantage: the staffs have not been reluctant to disclose their feelings, their beliefs and their prejudices in front of each other. This has meant that we have been able to record not only what the various members of the various professions see themselves as doing, but also how they perceive the activities and shortcomings of their colleagues. An interesting result of this is that no profession seems to regard coordination as a major activity, in the sense that, in highly structured interviews designed by a research advisory group of those who work in the field, many members make little reference to the place of coordination in their daily work.

The impact of this result is not merely in its negative character. For we could only determine that coordination was indifferently carried out after we had constructed some reasonably clear ideas about its supposed nature. To exhort professional people to better coordination is to assume that coordination has been defined in the operational modes of daily practice. But this was not so, at least when our study was started, although there was then no lack of general judgments - misty and emotional - as to what sufficient coordination might be. Nevertheless, it was only in the collision between the opinions of different professions - especially in those analyses of failure first known as 'horror stories' but later as illuminative incidents - that we began to identify what was operationally important to ensure that the professions worked effectively together for the benefit of the patients. We have even been able to assess the quality of coordination by its two principal dimensions: perceptive and administrative. It is one thing to be administratively efficient, by knowing what other services there are and how to secure them; it is something quite different to perceive that the responsibility for so acting efficiently is one's own and not that of some colleague. For if two persons are to work with each other as members of a team, especially as professional colleagues concerned with the care of the helpless and the disadvantaged, it is important that each should have a reasonable perception of the powers and duties, or roles and responsibilities of the other. If, as in caring for the mentally handicapped, several colleagues from different professions are called upon to work together, the need among them for concordant role perceptions may be more than important. Our present project enables us to ask how far such concordances may be achieved, and we first present evidence that suggests no serious divergences of view.

How the general practitioner is perceived

We consider the responses of three important members of the service: the mental welfare officer, the general practitioner and the health visitor. These responses revealed not only what specific care and attention they saw themselves giving their clients, both families and patients, but also the care and attention, that should be given to the same clients by their colleagues. A glance at Table A reveals the factual details.

TABLE A

Role Item (or duty)	Percentages of respondents from three professions who perceive GP as needing to exhibit these role items		
GP should:	MWOs	GPs	HVs
i) advise parents on handicap, give general support and be kind and sympathetic	71	53	82
ii) be aware of services, refer child and family to their use	29	29	42
iii) identify the risk and refer the child to the specialist	27	23	31
iv) merely attend to general medical needs	27	5	23

TABLE A.: showing, for about four hundred members of three professions dealing with the mentally handicapped, percentages who perceive the general practitioner as needing to discharge any of four key duties.

The topics, that were brought before the respondents during the interviews at which the questionnaires were completed, were those agreed by the small working groups of professional staff as being highly relevant to the treatment of the patients. It was not as the final outcome of interprofessional controversy, for example, that one responsibility of the general practitioner was seen to be to 'identify the risk, arrange the assessment and refer the child to a specialist.' All engaged with the mentally handicapped were aware that general practitioners were well placed to offer these vital services. What was not known was how strongly general practitioners as a whole saw this as a major or inescapable concern. In Table A appear some measures of this strength, and for three other pre-occupations of the general practitioners in addition. The measures are not only of the perceptions of general practitioners themselves, but also of how their two professional colleagues, mental welfare officers and health visitors, see what they believe the general practitioner's responsibilities to be. The figures, or entries in Table A, are percentages of the total sample interviewed.*

We see that Table A reveals a very high concordance, even if the percentages of general practitioners responding to all or any items tend to be lower than the corresponding percentages of mental welfare officers and health visitors. This should not surprise us.

---

* The numbers of completed questionnaires were GPs (147), MWOs (169) and HVs (97) respectively. The responses are of percentages of doctors - or others - who mention the responsibility at their interview.

General practitioners do not overwhelm their interviewers with information; their response rate is low on all items. But when they are moved to respond we discover that their relative judgments of the importance of the four different items is the same as the relative judgments of their two colleague professions. Whether it is the general practitioners themselves who express their own views, or whether the two main professions with whom they share responsibility for the mentally handicapped who estimate the relative responsibilities of general practitioners as they know them, the four items are ranked in the same order of relative importance, namely:

1 advice and support to parents
2 awareness of services available and reference of family and child to appropriate agency
3 identification of risk and referral to specialist
4 concentration of GP on common medical advices and treatment

We may therefore conclude from Table A that the general practitioner is seen in much the same light by all three professions, although on some items the light is far from brilliant. Nearly half the doctors fail to give any evidence at all that they see themselves as called upon to advise the parents about their children's handicaps; indeed, although it cannot be read from Table A as it stands, six per cent of the general practitioners also declared during their interviews that subnormality is outside their professional range.

Homogeneity of GP image or profile

If we identify the relative orders of the four key items or duties of Table A as the profile of the general practitioner's task, we see that the three professions see him consistently. All expect him to behave in much the same way, although (in his responses) the general practitioner himself is significantly cooler than the health visitor who supports him. The main finding, however, merely confirms that, as a well established profession the social image of the general practitioner is significantly consistent. He is expected by others to follow a pattern of professional response very similar to that which he sees as his own.

Some significant contradictions

Consider now Table B. This describes the relative perceptions, by the same three professions, of the social image or profile of the mental welfare officer. The role

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Some significant contradictions

Consider now Table B. This describes the relative perceptions, by the same three professions, of the social image or profile of the mental welfare officer. The role items or duties are, of course, different.

TABLE B′

Role Item (or duty)	Percentage of respondents from three professions who perceive MWO as needing to exhibit these role items		
MWO should:	MWOs	GPs	HVs
i) visit, advise and supervise families, be kind and sympathetic	93	35	75
ii) be aware of other services, and refer to other helpful agencies	38	22	58
iii) arrange for care both long and short term	4	4	25
iv) arrange for entry to training centres	2	4	24

TABLE B′: showing, for about four hundred members of three professions dealing with the mentally handicapped, percentages who perceive the mental welfare officer as needing to discharge any of four key duties.

The striking conclusion of Table B′ is the insistence by the mental welfare officers themselves upon their direct role in the home (93 per cent) as contrasted to their coordinating role outside it (summing to 44 per cent on three items). How far advice and supervision, kindness and sympathy can be offered without coordination involves, of course, a definition of these ideas. But, on being specific, as in items (ii), (iii) and (iv), the mental welfare officers respond far less often than their health visitor colleagues would expect them to. If we may press the statistics, the health visitors have over twice the expectation of the mental welfare officers as coordinators (summing to 103 per cent over three items) as do the mental welfare officers themselves (44 per cent). On the specific items of care and training, the mental welfare officers hardly see this as their task at all, whereas there is a substantial opinion among the health visitors that this is a proper task for their colleagues. It is pretty clear that those out in the field should follow up results such as these, if only to discover why a minority of mental welfare officers report their need for contact with other agencies. It is also interesting to see how thin are the responses of the general practitioners;

only a third of them seem to have any view at all of the duties of mental welfare officers.

The role of the health visitor

We observed in Table B some mutual contradictions of views about the roles of mental welfare officers and of health visitors. The mental welfare officer did not see that his own coordinating role was particularly important. We observe further contradictions in Table C, where are set out the perceptions of the roles of the health visitors.

The mental welfare officer holds the same opinion of the health visitor's tasks, and sees the visitor mainly as a kind of professional mother's help, since the majority of mental welfare officers (60 per cent) see practical help with day to day problems as the main task of the health visitors; less than a quarter (23 per cent) of the visitors see themselves in this role. The general practitioners support their health visitors in this view of their duties; they also, more strongly than mental welfare officers, share the health visitors' perception of their main task as giving support and sympathy to the families and their handicapped members. The doctors, too, see more clearly than the mental welfare officers how important should be the coordinating functions of the health visitors, while the visitors themselves (at 65 per cent) rate their own coordinating role as most important. (For mental welfare officers the same index of self perception was only 38 per cent.) Health visitors thus see themselves as more concerned with coordination than do mental welfare officers see themselves; what is more, they believe that mental welfare officers themselves should carry coordinating duties more effectively than the mental welfare officers believe themselves.

General conclusion about coordination

We may draw one conclusion. All three professions see their own roles more concerned with direct action on behalf of the handicapped persons and their families than with ensuring that others are brought in to provide what help they might. It is true that this emphasis upon direct action rather than upon coordination varies from one profession to another. It is just noticeable among doctors but emphatic among mental welfare officers. However this may be, it is clear that we have material enough, both statistical and anecdotal, to introduce a permanent series of discussions among those who collaborated in the study, discussions to produce practical suggestions about the operational lacks only a third of them seem to have any view at all of the duties of mental welfare officers.

The role of the health visitor

We observed in Table B some mutual contradictions of views about the roles of mental welfare officers and of health visitors. The mental welfare officer did not see that his own coordinating role was particularly important. We observe further contradictions in Table C, where are set out the perceptions of the roles of the health visitors.

The mental welfare officer holds the same opinion of the health visitor's tasks, and sees the visitor mainly as a kind of professional mother's help, since the majority of mental welfare officers (60 per cent) see practical help with day to day problems as the main task of the health visitors; less than a quarter (23 per cent) of the visitors see themselves in this role. The general practitioners support their health visitors in this view of their duties; they also, more strongly than mental welfare officers, share the health visitors' perception of their main task as giving support and sympathy to the families and their handicapped members. The doctors, too, see more clearly than the mental welfare officers how important should be the coordinating functions of the health visitors, while the visitors themselves (at 65 per cent) rate their own coordinating role as most important. (For mental welfare officers the same index of self perception was only 38 per cent.) Health visitors thus see themselves as more concerned with coordination than do mental welfare officers see themselves; what is more, they believe that mental welfare officers themselves should carry coordinating duties more effectively than the mental welfare officers believe themselves.

General conclusion about coordination

We may draw one conclusion. All three professions see their own roles more concerned with direct action on behalf of the handicapped persons and their families than with ensuring that others are brought in to provide what help they might. It is true that the emphasis upon direct action rather than upon coordination varies from one profession to another. It is just noticeable among doctors but emphatic among mental welfare officers. However this may be, it is clear that we have material enough, both statistical and anecdotal, to introduce a permanent series of discussions among those who collaborated in the study, discussions to produce practical suggestions about the operational lacks in coordination at present and about action to restore such lacks in the future.

TABLE C.

Role Items (or duty)	Percentage of respondents from three professions who perceive HV as needing to exhibit these role items		
HV should:	MWO	GP	HV
i) support and advise parents on handicap, be kind and sympathetic	31	57	95
ii) be aware of other services, and refer child and family where appropriate	24	43	65
iii) attend to daily problems such as feeding; arrange practical help	60	14	23
iv) identify risk and arrange assessment	9	3	12

TABLE C.: showing, for about four hundred members of three professions dealing with the mentally handicapped, percentages who perceive the health visitor as needing to discharge any of four key duties.

COORDINATION IMPROVED

The learning processes set into motion by any critical evaluation of one's activities, particularly when that evaluation is supported and confirmed by others sharing both knowledge of and responsibility for those activities, should produce results from the very outset. Merely to ask oneself what one is trying to do - merely to identify what coordination may be - if critically attempted will lead at once to a clearer grasp of one's goals - or to a more realistic view of one's difficulties. To discuss these goals or these difficulties with others will speed such progress. And when these enquiries are adequately structured with relevant information and valid analysis, firm and continuous action can be taken long before any final report of the evaluation can be prepared. As evidence of this, we quote from a paper 'The Coordination of Services for the Mentally Handicapped: Initial steps to improve services in Kingstonupon Hull.' It is written by James Gardham and Roy Wardell, director and assistant director of social services at Hull, and the quotation follows their commentary upon the results

set out immediately above, namely that at the moment, no profession sees coordination as a major responsibility.

> 'A basic commitment which we made therefore was that each family which contained a mentally handicapped child should be visited by a social worker who would be in a position to assume caring responsibilities for the family from suspicion or diagnosis of the handicap onwards. A small number of mental welfare officers had previously been responsible for the supervision of such families and the total case load had to be more evenly distributed. The inadequacy of visiting in the early years had also been shown in the research results in that the peak of activity, including new referrals, visiting and coordinating activity was centred around the mentally handicapped child who had reached the age of five and fifteen years. If this inadequacy of activity in the early years of a child's life (which appears to have been common to all seven areas included in the research project), was to be remedied it was clear that we would be entering into a new era of operation and this raised training implications.
>
> There may well be several schools of thought on what training and specific areas of knowledge social workers need in order to equip them to deal with the family containing a mentally handicapped child. It could doubtless be said that a detailed knowledge of mental handicap is necessary, which in itself could occupy the larger part of any training programme. What the research project and our own investigations revealed, however, is that what is needed in the early years is support and practical information to overcome the family's initial feelings of despair and to begin constructive planning for the future. Such facilities for instance as baby sitters, playgroups, transport facilities, home helps and general reassurance in the form of some kind of plan for the child's education and adult life need to be discussed. Introduction to voluntary bodies, especially those which consist in the main of other parents with mentally handicapped children can often provide supplementary support as well as leading to introductions to further forms of voluntary activity and provision.
>
> The paediatrician, the psychiatrist, the general practitioner, the health visitor, the education services, all have important roles to play and the approach we have begun to pursue is that the real training need is for the social worker to see coordination as his vital role and to ensure that his clients are aware of his role on a continuing basis. He already has an array of departmental services, never before within one administrative framework, together with the ability to provide emotional support, and by the encouragement of communication and interaction between the wider range of services it should be possible for him to introduce his clients to agencies and services which can contribute to total family support.
>
> With the information which had been accumulated realistic plans had to be formulated and we felt that some immediate remedies had to be found if the newly formed social services department was to justify and encourage the referral of cases. Consultations were held with local agencies and we were fortunate in being able to establish links with the paediatricians and psychiatrists through which all newly diagnosed or suspected cases could be referred to the department.

> In this way we can hope for social work intervention at an early stage rather than the previous situation where such activity was largely centred upon the five year old and entry to the junior training centre.'

The report to which this is the introduction gives many other illustrations of what has been done and what can be done to improve coordination. But none who has been engaged on this study since it started four years ago could wish a better reward than the action described in this quotation. Not only has a particular set of problems been identified (delays until five or fifteen before detecting the handicap) and their causes assessed (poor perception of coordinative responsibilities), but a system has been set up to resolve them, and, perhaps even more important, staff training has been recognised as a major need for the department to tackle. Since what I believe we are all trying to do in this life is to use our limited abilities more effectively, these are gratifying results. Our only remaining wish is that others, profiting from our experiences, will discover ways of developing these resources more effectively still.

R W Revans
Fondation Industrie Universite
BRUSSELS

September 1972

INTRODUCTION

THEORY OF STAFF DEVELOPMENT

In the introduction the views on learning and communications, which have guided this project, have been discussed. The basis for learning is learning about oneself. It leads to improved communications and provides conditions for the development of staff.

Introduction

THEORY OF STAFF DEVELOPMENT

Improving communications

It was said of Napoleon that, every time he installed one of his brothers on the throne of some dispossessed monarch, he advised him to make many eloquent speeches about liberty-but also to ensure that no one got any. Today the subject in vogue is better communication. All senior managers talk about it, they hold conferences about it, and they commission experts to lecture about it. But, in general, like liberty, better communication can be a difficult concept to translate into practice. Insofar as communication determines knowledge and insofar as knowledge determines autonomy-or the opportunity for men to use their initiative-then those unsure of their authority will oppose improving it. They will, however, continue to speak glowingly of its need and advantages.

Not all persons in authority are, of course, as unsure of their positions as were the brothers of Napoleon, and most top managers could still do much to improve the quality of communication inside the organisation. It has, for instance, been known for over two thousand years that the man in charge largely settles what kind of following he will secure.

> If a ruler hearken to lies, all his servents are wicked(Proverbs Chapter 29, Verse 12). As the ruler of the city is, so are all they that inhabit therein (Ecclesiasticus, Chapter 10, Verse 2).

Thus the first condition for better communiation is that those in charge can convince others that they desire it.

To secure improvement in any complex human organisation, those who serve it must learn. Insofar as those within the system learn to communicate better, so will the system be improved. But in order to learn, whether leaders or not, men must wish to learn, for they learn only of their own volition and not at the will of others. Men learn when they perceive a reason for doing so, and, in everyday life, their best reason for so wishing is the need to solve a problem that continues to trouble them, or to disembarrass themselves of some intolerable inconvenience, perplexity or torment. Most organisations have problems enough, so that those in charge cannot claim lack of opportunities for all to learn how better to communicate.

Introduction

But there is an important respect in which learning to communicate better is different from learning to do many other things better. For communications being and end in the consciousnesses of human beings, and merely to minipulate better the external apparatus of communication - learning another language, understanding how to use the international telephone system, practising to programme a computer, installing a photocopier - merely to strengthen one's command of these codes or devices will not improve things if the real trouble lies in one's own internal being, as so often it does. It is not just a matter of, for example, taking elocution lessons so as to be more clearly heard: it depends upon who one believes oneself to be; or upon knowing why one says the things one says; or even upon being aware of what one does and of why one does it. Until any misunderstanding - or misperceptions - of this kind are first cleared up it is hard for any person to improve upon the quality of his exchanges with those around him.

The speed of change

These problems are exacerbated today by the increase in the rate at which society, in nearly all its aspects, is changing. No sooner has a new procedure, a new rule, a new code, been introduced than it is altered in some respect or another. It is not much good blaming whoever made the new order for what might go wrong because some later change was not foreseen; most consequential changes today are inevitably unforeseen. And on this account we must devise methods of management and administration specially to help staff at all levels adapt to change; they must be able to understand and guide the forces of innovation that forever press down upon them; they must grow increasingly able to deal with their local problems on their own initiative. This means that they must not only be able to pick up a new idea; they must be also to integrate it into the store of ideas that already crowds their consciousness. Much learning consists in the rearrangement of what is already known in changed perception rather than in the acquisition of the totally new. Thus any true learning - about those blockages within the mind which prevent better communication - must contain within it a constant challenge to what is already believed. It is one thing to have a head full of misperceptions, of unreal ideas as to what is one's place in the world, of one's true authority whether as the chief officer or as the filing clerk; all of us, to a greater or lesser degree, grope towards a continual misunderstanding of our roles and of our powers, much to our confusion.

But to have no means of finding out about ourselves and our misconceptions is a kind of living death, a constance imagining of ourselves to be persons other than the ones we are, giving to those around us a set of impressions quite different from those we imagine ourselves to be giving. Thus the organised challenge to our existing beliefs is a cardinal element in any effective learning about communications. Only after we have learned to ask ourselves why we imagine we are usually right can we start to say to others 'I may be wrong. Perhaps there is something after all, in what you are trying to tell me. I will go away and think about it'. Social reality is an excellent setting to try these approaches out.

For example, the health visitors who become involved in our project were astonished to learn that their colleagues did not see them as giving emotional support and helpful sympathy to the families of the handicapped persons; to the health visitor this was seen as their main function. Again, a mental welfare officer with a decade's experience, who had always seen himself as conscientiously doing all he could to support his families in their problems at home, was more than mortified to learn from colleagues that he was seen by the parents as the agent of authority trying his best to get their patients away into hospital. These, and many more examples, illustrate the need to reinterpret common experiences, and to learn from the everyday task.

The learning process

There exist many theories of learning; we do not intend to review them here. There is learning by 'nature' learning by association; learning by mimesis; learning by insight; learning by trial and error; and various theories of particular people, like Comenius, Herbart, Montessori, Thorndike and Skinner. In our view, these are all variations of the same paradigm. This may be expressed in the five following steps

1. the assembly of information, impressions, data, opinions and other elements of awareness, including one's own recognition of the need to learn, or the curiosity to understand; this may be called the stage of 'survey' or input

2. the rearrangement of this input to suggest new ideas or new patterns or new relationships relevant to the curiosity or need to learn; this may be called the 'theory' stage, because the subject has now a new impression of his field of interest.

3. the try-out of this theory in the world of reality about the subject; he asks whether the 'theory' stands up to the test of practice (and such practice may be organised debate with equally well informed colleagues, themselves eager to learn); this we may call the stage of 'action' or trial

4 the review of the results of this trial action; did the 'theory' fit? Were the results obtained from the practical test (or informed debate with informed colleagues) what were expected from the rearrangement at stage 2) above? This comparison of results with expectation is known as feedback and the science of cybernetics is founded upon its immense range of application; we may call this fourth stage that of 'review'

5 the confirmation, modification or rejection of the 'theory' in the light of this 'review'. It is assumed that if the results are much what they were predicted to be the idea behind the results (or underlying the 'theory') is to be accepted; if the results are partly true then the theory is partly accepted; if the results are totally different from what were predicted then the 'theory' is rejected as false and nothing is remembered about it - other than its failure; this we may call the stage of 'consolidation'.

We must not assume that this five stage cycle is so obvious that any intelligent man always goes through it when perplexed by some intellectual problem. At most stages we often tend to close our minds against the evidence before our eyes and refuse to follow that evidence into the next stages of the learning process. But if the five stages above are lived through in a world of responsibility - wherein one is forced by the presence of others to recognise the final outcome of one's actual behaviour - then real learning becomes possible. And by real learning we mean 'that which affects and modifies the self, including those perceptions of the self that are cardinal to the improvement of one's ability to communicate with others'. For only here do we start to improve communicationas well as to talk about it; indeed, out behaviour in everyday matters my be quite visibly changed. Thus, in devising schemes that encourage people working within complex systems to develop their abilities to communicate better we need to observe all the following conditions

those in charge must be actively concerned to improve communications; they should not merely talk about the need for doing so

the desire to learn how better to communicate, among those where the work is done and where the quality of work depends upon the felicity of the communiciations, must be genuine; it must be felt as a professional responsibility, as a personal commitment, as something intimately emotional, and not merely as the exhortation of some official circular

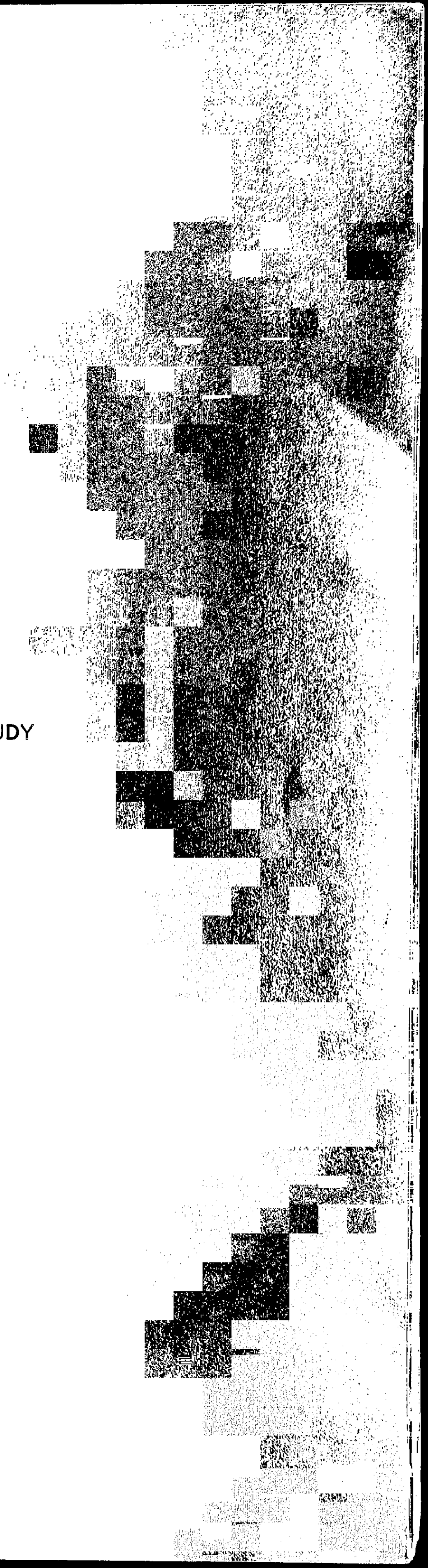
the subjects trying to improve their communications must be given the chance of trying out what they feel might be better methods; their exercises to improve their performance must be action-orientated and able therefore to give the subjects a convincing impression of the practical effects of their new metholds or new beliefs

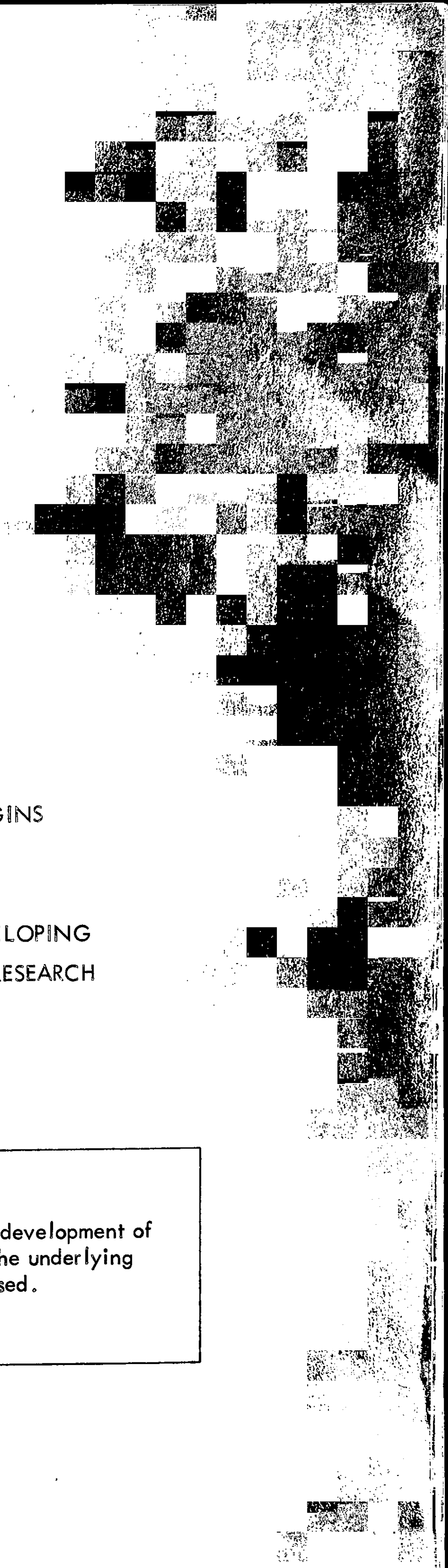
> these action-oriented exercises must be of a group or social character so that the individual members participating in them can get information from each other, not only about any objective aspects of the communication problem, but also about their own parts in creating or resolving it; participants must learn of the impressions they make on others and the support they need to draw from and to give to others

We feel that the subject presented in this book offers these opportunities of learning by listening, by enquiring and by doing. It offers a learning process for any who may be interested in the improvement of communications in modern society. We have not simply described a set of exercises specially staged for this particular set of workers in the field of mental handicap; the project is an experiment, using a national sample, to throw light upon the problems of institutional learning in general. As such, the four conditions above could be fulfilled within any organisation trying to help its members learn how to do their work more effectively. Since an increasing number of people are becoming obliged to pass their lives inside complex systems highly dependent upon good communication, there may be some virtue in making this study (although confined to the field of mental handicap) more widely known. It was launched and supported by the King's Fund and suggests how, in practice, to achieve genuine involvement between colleagues, alike satisfying and productive, by better communication, better understanding and better self expression. Learning by enquiring and learning by doing become collective learning by common action in resolving collective problems. It is a means of development that might in due course be indistinguishable from everyday management itself.

SECTION 1

WHY AND HOW THE STUDY WAS DESIGNED

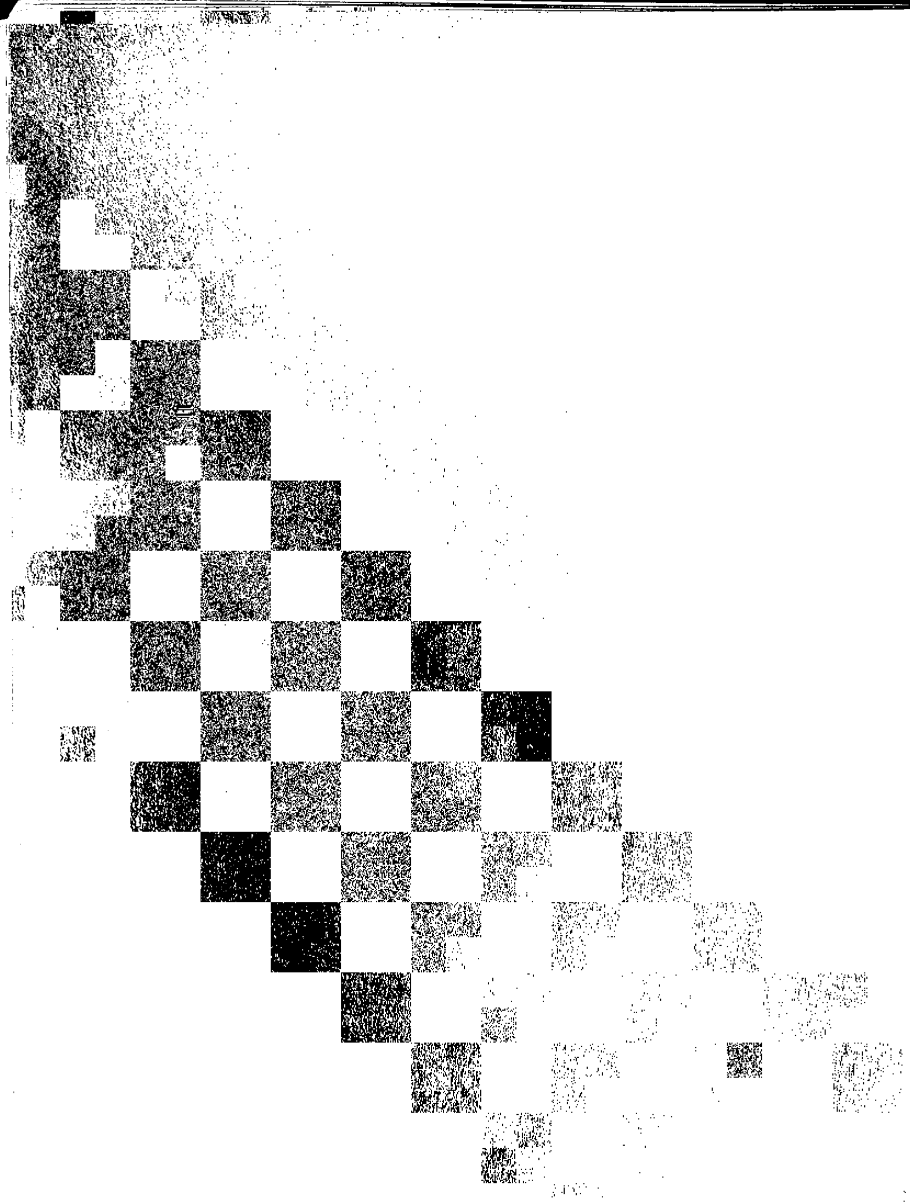




CHAPTER ONE

THE BACKGROUND AND ORIGINS OF THE PROJECT AND CONSIDERATIONS FOR DEVELOPING PARTICIPATIVE METHODS OF RESEARCH

In this Chapter the origins and development of the project are described and the underlying theory of involvement is discussed.



Chapter One

THE NEED TO UNDERTAKE RESEARCH ON COORDINATION

Background

Mental handicap, as a subject, has engaged increasing attention in recent years. The discussions have been as much influenced by reasons emotional and sentimental as by those scientific and administrative. Even a cursory review of the literature on the subject reveals how much interest the professionals and the scholars, the voluntary societies and the lay public, the government and the mass media have shown in the problems of the mentally handicapped. Since the passing of the Mental Health Act in 1959 there has been a growing concern for nearly all aspects of the life of the mentally handicapped, and also of his family. There is some truth in the statement that attitudes, both professional and lay, have been changing rapidly and in the ferment of ideas it seems that more has been written and proclaimed on this subject in the past ten years than in the whole of the previous two hundred years. But, apart from this impressive increase in the volume of literature, we are also struck by the absence of any consensus among those responsible for the mentally handicapped about a unified or integrated approach to the total delivery of services. Most proposals, significant and impressive as they undoubtedly are, tend to concentrate upon appently urgent and specific matters. The growth in the number and variety and professionalisation of people suggests that no single agency can any longer adequately meet all - or even a majority of - the needs of the handicapped. The need to shift attention from the viewpoints of professional specialists to more general and multi-disciplinary approaches becomes apparent.

Alongside such broadening developments in the field of mental handicap there have been emerging new attitudes and motivations of work people all over the world. Even to a casual observer of the human condition, there appears to be a revolution in the way the authority is perceived by those who traditionally submit or have in the past submitted to it. This questioning of authority, which reflects the dynamic nature of progress itself, is universal, in Church, university, school, armed services, sport, politics and public administration, no less than family, office, workshop, factory and coal mine. It is generally agreed that, across the world there is needed new thinking about the nature and exercise of power. Consultation by officials and representative bodies, although welcome, is not enough. It now appears necessary, more than ever before, to develop methods by which individual work people, however modest their station is in the hierarchy,

can be brought, not only to feel that they are sharing in the design and control of their daily work, but also in the design and control in truth and in reality. As our work developed, we began to ask the same questions about the participation of the clients.

Origins of the project

The origins of this project have an important bearing upon such considerations as are discussed above. In 1964 and 1965 the Ministry of Health, as it was known then, issued two very significant circulars[1] on improving the effectiveness of services for the mentally ill and mentally handicapped. The Royal College of Nursing held a three day conference in December 1965, at Church House, London, under the chairmanship of Professor R W Revans, to exchange ideas on these two important documents. A number of participants described what they were already doing about such ideas. The meeting ended with suggestions for still further gatherings of this nature, and Janet Craig, assistant director of the Hospital Centre, took the initiative in organising a series of meeting among interested parties to develop mutual support and make better use of their existing resources. Different hospital staff discussed with each other the patterns of services they had envolved in their own hospitals to improve the care of the mentally handicapped. The proceedings of these meetings were published by the King's Fund[2] and were widely distributed and read; as a result a national conference of interested organisations and individulas was held at the Hospital Centre, London, in March 1968. Approximately 60 participants, representing some 30 organisations involved in the provision of services for the mentally handicapped in the country, felt that the series of meetings organised by the King's Fund had revealed at least two things; that many serious problems of coordination existed, and that those working within the services could examine these problems using their own personal and professional judgement. What was needed was the 'organised opportunity' for the professional workers to carry out a study of their own problems of coordination, supplementing their ingenuity, goodwill and other hidden resources with the help and advice of those skilled in operational research and similar modes of systems analysis.

Working party

A small group of participants of the national conference volunteered to discuss the problems relating to coordination of services and recommended some suitable topics to study in depth. This working party* met for the first time in June 1968, and then spent a year in reviewing the needs for better coordination. It discussed for example, the desirability of studying assessment of the handicap as a means to bring the many interests

together in fruitful enquiry and debate. In the end this working party look a wider view of the needs of the services, and resolved to examine, in a sample of areas across the country, what were and had been the experiences of those who receive and those who provide services for the mentally handicapped. It was agreed that the project would be called 'Coordination of Services for the Mentally Handicapped'. The King Edward's Hospital Fund for London kindly accepted the responsibility of financing the project, of housing its workers and of providing other facilities at the Hospital Centre in London until further funds were available. The working party appointed a full-time research officer ** who supervised the project from June 1969, until its conclusion in September 1972.

Broadly the intention of the working party was, first, to collect evidence of various forms of practice for the provision and utilisation of services in diverse local authorities in the country, and second, to help the providers and consumers of services to play an active, developmental role in the conduct of the research at all of its stages.

The two significant outcomes of the series of meetings held at the Hospital Centre during 1968 were, first, the gaps between the progressive views expressed about the services for the mentally handicapped and the reports of actual practice in care and treatment; second that the staff in direct contact with such problems were keen to understand better the strengths and weaknesses of the services which they helped to provide and run. The working party, influenced by the thinking and the concern of such people, maintained that the plans to build new services should draw more fully upon the experience of those working in the field. It was agreed that existing patterns of coordination of services in different parts of the country offer many degrees of fusion of traditional and modern attitudes and codes of practice.

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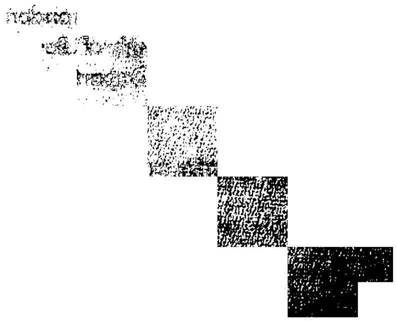
* Members of the original working party set up by the King's Fund
Professor R W Revans, (Chairman)
Dr R Fidler, Principal Medical Officer for Mental Health, London Borough of Harrow
Dr J Gillet, Medical Officer of Health, London Borough of Barking
Miss F M Hodge, Administrative Assistant, Education Department, Hertford
Dr A Sippert, Regional Psychiatrist, Leeds RHB
Dr R Wilkins, Principal Medical Officer, DHSS
Miss J B Craig, Assistant Director, Hospital Centre (secretary)

** Ali Baquer



This blend of dynamic components, had both disintegrative and reintegrative potential. The working party, therefore, decided that the contemporary needs and responses of administrative, therapeutic, voluntary and kinship groups must be studied in an empirical and factual way. Any attempts to reform existing services and to plan for future needs should be based on a realistic measurement of present realities. The success of any administrative improvement largely depends upon how efficiently the authorities and the individuals concerned can work together constructively to build and run a comprehensive service for the mentally handicapped.

The working party felt that all individuals and authorities, whether in their private capacity or exercising their statutory responsibilities, need to examine in a clear and operational way how to make 'best' use of services available (or likely to become available if a good case can be made for them). The concept of 'best' was, however, considered misleading as what is best in one area is not judged so in another, or what was considered best ten or twenty years ago may or may not be regarded as such now. Such a discussion of best often implied a central judgment on all. The working party, consequently, agreed that the project should not concern itself with such judgment. At the time the project was initiated, the entire service was passing through a major change and new demands were being made on people providing the service. The research was proposed as a modest attempt to measure the impact of these demands and to examine the responses of the selected areas to meet the growing challenge. The working party hoped to discover objectively what type of services were operating at local level. Another purpose of the research was personally to involve in the study as many of those who actually wished to see improved coordination. If social research had to be related to achieving social action, then it was felt to be imperative that those responsible for the treatment and care of the mentally handicapped should coordinate their own efforts to carry out this enquiry; to achieve cooperation of individuals and organisations in the study would, in itself, advance our understanding on how to improve coordination. A combined effort to undertake the research would advance it from an exercise of scholars to an instrument of social action.

Before a detailed account of the actual research project is presented it is important to state the assumptions which have guided and characterised this project. This would help the reader to understand the development of the 'participative method of research' evolved during the project, and to appreciate more fully why the working party and the research officer took certain actions and avoided others.

Chapter One

PARTICIPATIVE RESEARCH AS A METHOD OF STIMULATING ACTION AND LEARNING

Satisfying basic objectives

This project began, as has been described in Chapter 1, after general agreement among those caring for the mentally handicapped in this country that there should be an assessment of the different ways the services are being utilised and developed. Very few people these days openly disagree with the need for research, although some may suspect its usefulness and relevance. There are, of course, differences of opinion about the strategies of research, and not less importantly, about who should do it and how. The style and outcome of research are controlled, if not wholly dictated, by the general political climate and expectations of those who support the research. The King's Fund provided the opportunity by financing this exploratory type of study under the supervision of a working party.

The working party had declared at the outset that the evaluation of the coordination of the services should be based on the judgment of those who actually provide the services. There is a need to stress this point because it, alone, characterises the development of the project. The working party maintained that, if such an appraoch could be attempted, it would produce knowledge and expertise necessary for improved management of services. The entire project activity, from start to finish, was guided by the thesis that management is best learned by managers themselves acquiring knowledge to solve their problems, to take decisions and to evaluate the results of their actions. To put it simply improvement in management depends on learning by doing. The managers in this instance were-and remain-the providers of the services . Before there can be any policy for improving any service, it is necessary to know at least two things:

what are the services already doing?

how far do those who now run these services feel able to change whatever may be in need of change?

Even after these two very general questions have been answered there will still be further conditions to be met before the services can, in fact, be improved. To know what the strengths and weaknesses of the services are at present and planning to build on those strengths and to eliminate those weaknesses are not, in themselves, enough. The need is then to develop viable methods of action and amelioration, and this may not be easy. It is one thing to resolve to change a system; it is something quite different to change it as resolved. If the system is, and has long been, under stress, to change if for the better may be a task as uncertain as it is immense.

Chapter One

The primary aim of the project was always an essentially practical one, namely, of improving the coordination of services by first improving the insight of those who provide them into the nature, organisation and distribution of their own services. It was hoped that such improvement would also stimulate learning, leading to action, at the levels of both the individual professionals and their organisations.

This concept of learning implies:

> a wider understanding by the individual of the needs of the handicapped, of his own role and of the roles of others in fulfilling those needs and, above all, of his responsible involvement with others in the provision of services;
>
> increased awareness leading to adaptations in the formal and informal structures or procedures within and between organisations likely to facilitate better communication and understanding.

The project was therefore planned to incorporate two strategies for achieving these objectives:

> Research: the collection, analysis, and feeding back of information which the providers of services could use as a basis for identifying and describing problems
>
> Involvement: the provision of opportunities for self-learning by involving providers and consumers of services in action at all stages of the research itself. It was expected that if those who are the normal participants in the services should discover the problem areas for themselves they would be more likely to be committed to consequent changes than if the issues were identified and possible solutions suggested by outsiders. Thus, involvement was seen as a method of developing in members of the organisations studied, both a desire and a capacity for assessing and improving their services.

It is the degree and extent of involvement of providers and consumers of service in a thorough and systematic examination of nearly all aspects of it which distinguishes this project from other researches. It does not imply that the approaches of other researches are not of value. Indeed, our own studies are supported throughout by knowledge of other researches in fields far removed from the provision of social welfare.

Alternative methods

While discussing the choices for setting up a participative method of research we need to consider the other options which were open to us to achieve the broad aims of the working party, namely the collection of evidence on various existing patterns of services, and in so doing involving those running the services.

It was felt that no particular model existed at the time at local or national levels whereby such concepts could have been translated into practice. Furthermore, a case has to be made for the practicability, feasibility and acceptability of such intentions.

Objective research

Research has long been accepted as a tool of social change. Traditionally, it is undertaken by an independent person who, because of his training in behavioural sciences, tries to minimise his influence on the system under study so that he is able to present a detached analysis of the data he has collected. The arrangements in favour of an objective, scientific and pure research are well known. The research methods and techniques employed are widely used and have been standardised to a great extent. The credibility of such investigations is acknowledged and the expectations from such researches are clearly defined. This type of research normally proves or disproves a clearly drawn hypothesis. Very often the validity and reliability of the methods used are more important than any actual impact of the research. The very insistence on observing total objectivity tends to remove from the researchers any responsibility for the use that may be made of their findings. Researchers from outside the system, moreover, tend to offer solutions to the problems they are trained to see. They tend, in the first place, to turn up only those problems to which they command the technical solutions, and not seldom, even to manipulate quite different problems until they appear ready for the appropriate technical solution. Furthermore, scientific methods, to maintain 'objectivity', may often reject that very emotional involvement of the personnel without which the significance of the data and the force of the findings may be radically impaired. This project, consequently, was undertaken on the understanding that the methods of scientific research, although desirable for offering findings with a certain degree of confidence, should be adapted, where necessary, to obtaining the involvement and participatio of providers of services, many of whom claimed no command of traditional research technology. This study was not meant to be a research project of an academic type; we are, however, willing to discuss the validity of our methods and our results with any other research workers of practical experience in the field of social or institutional change.

Change projects

This project was not, however, designed primarily as a change strategy. It had been hoped that the involvement of the providers of the services in their systematic and purposeful examination would eventually lead to an overall improvement.

Such research activity could, of course, hardly fail to produce some change in the structure and functioning of the system, or in the attitudes of the people running the system, or in the inter-relationships of all components of the system, or in other ways unforseeable at the start.

To change a complex human system, like the services for the handicapped, demands different types of inputs, more than a single research officer, even supported by a small part-time team, can provide. In order to change an organisation of any complexity one needs to have a strategy which commands skills and resources to directly or indirectly change technology or structure or people. A change project, thus, has different types of controls, inputs, facilities and supports than were available for this study. The goals of a change project are defined well in advance. The kind, degree and extent of change desired are determined beforehand. The means of achieving and maintaining such change are secured, in adequate supply. To measure such change a 'control group' is selected for comparison and any change, thus observed, may then be confidently attributed to the project activities. In this project no such arrangements for the measurements of the impact of the study were made. There is an absence of all the prerequisites of change strategies from this project. We did not deliberately start out to initiate change as such. But the use of this method implied clear possibilities of changes occurring.

The underlying goal of this study was to provide opportunities for development and learning, because when a wide variety of providers of services show willingness to participate in a project, such as this one, they do so with an eye on improvement of services.

Participative research

The method of research evolved during the project has made good use of standard techniques of data collection, through the use of questionnaires, analysis and data processing. The major departure from the scientific method has been in placing responsibility of research decisions on the providers of the service. The considerations in attempting to develop a new method and adapting the available research procedures have been dictated by a firm belief that improvement in a system is most effectively produced when all those with responsibility for taking action in the system are involved in an examination of it. This project, was, therefore, undertaken with a sincere and honest appreciation of the value of the judgment of those with first-hand knowledge of the handicapped and the services.

Throughout the survey the providers' judgement has been recognised as superior and more valid than that of the scholar. Our experience has convinced us, and most of those who have been actively involved in this project, that all programmes directed towards the social, administrative, organisational problems of our changing society must be based on this recognition. We realise that we are not the only people to appreciate the value of participation of those at the 'cutting edge' of the service. We are aware of the use of this concept in management and other fields of human activity. We have merely attempted to increase its depth and to extend it to research.

CHAPTER TWO

APPLICATION OF THE THEORY OF INVOLVEMENT AND ACTION

How the theory of involvement of the providers in a systematic examination of the service they offer has influenced the development of this project is discussed in this Chapter.

Chapter Two

OPERATIONAL ASPECTS OF INVOLVEMENT

We now describe how we tried to convert our vision of involvement into actions. To accept the principles of involving the many providers, drawn from different areas and within each area from various professions and within each profession from different levels is one thing; but to translate these principles into operational terms is another. Most of our difficulties arose out of our insistence that the providers should, in fact, help each other and us, both in defining the aims of the study and in discovering how to examine the demand for and the delivery of service. They themselves were particularly expected to assess the effectiveness of the services they provided; this is a matter of professional judgement, the fruits of conscience and experience that they alone could gather. We insisted that they should collect the essential facts of the systems they were responsible for running, so that their faith in their own values and actions was tested and confirmed. These attempts to put the responsibility for designing and executing the research on the shoulders of the providers of the services reversed the traditional role of client and expert. There was, in consequence, uncertainty surrounding our early attempts and both parties were required to provide mutual support before our plans were working smoothly. Much of our energy and resources were spent in making the participants aware of the usefulness, indeed, of the critical necessity, of their own contributions at all stages. There was no one method to follow this objective. There were few known precedents,at the time, to be followed. It was also difficult to forecast the full range of supporting activities needed for initiating and sustaining a participative method of research; at the start we offered suggestions on questionnaires design and population sampling; at the end suggestions upon the significance of date for practical action.

The particular ways in which the providers without any training in research methods, could be involved in this project were not completely known. Operational interpretation of the concept of involvement only developed gradually as the project progressed.

We had committed ourselves to do research in a highly complex field. The services for the mentally handicapped are made up of many intricate components. These components interact with each other, in a wide variety of ways and form changing patterns of arrangements. These arrangements are determined by the law of demand and supply. Care of the handicapped is the responsibility, in the first instance, of the parents, but a network of

statutory and voluntary organisations have been built up with supportive services. The handicapped person either remains with the parents or elsewhere in the community, or if the social and/or medical reasons mean that community care is not possible he is offered the substitute services of the subnormality hospitals.

The construction of a research design to study the totality of this complex system had to be based on practical considerations. Even before the start of the project we had agreed not to impose a preconceived design on the providers because we thought that such an attempt would make us rather rigid in our approach. Rigidity, even in a subtle form, would have defeated the very principle of involvement. The notion of 'directing ' research was considered redundant by us in this project because it implies an autocratic principle. To direct a project by selecting research strategies for scientific or other valid reasons, means overlooking, if not completely undermining, the contributions that people for whom the research is undertaken in the first place can make. We made consistent efforts to discover ways and means for the participants to become self aware through a process of collective and individual learning. Our intentions were:

> to help participants in the project become aware of, and consequently, more able to utilise their resources, so that they were prepared to take the initiative and to question the purpose or method of their actions;
>
> to help organisations increase their sensitivity to the needs of their clients, and to remind them of the pressures which continuously keep changing, and to help them to examine the influence these pressures make on the purpose and operations of the system, and also to increase their awareness of the contributions the individuals within the system are potentially capable of making.

Chapter Two

ASSEMBLING A TEAM TO DESIGN THE STUDY

Selection of research areas

It would have been unrealistically ambitious to attempt to examine all that was going on throughout the length and breadth of the country. We decided to sample the overall situation. If a comparison could be made of what was actually happening to the mentally handicapped in half a dozen or so local authorities and their appropriate hospitals we could be well placed to identify where the strong and weak points of the services were. The project was not undertaken to seek generalisation at either local or national levels, but if, despite the diversity of localities selected, certain common features and similarities emerged they would indicate general trends. A comparative study would have discovered variations and differences in the forms of treatment and care offered to the mentally handicapped. We had decided, however, not to address ourselves to such differences as it would have hindered the execution of the project within our terms of reference. The project was designed simply to allow the exploration of the many different methods, both formal and informal, by which the services were coordinated.

Seven reasonably representative local authorities of the country from north, midlands and south, were selected to make a comparative study of services, and these were:

a regional capital
a large industrial borough
a traditional city, with university and cathedral
a rural county
an affluent and developing county
a 'mirror city' - dominated by the influence of a world of famous neighbour city
a local check area, a London borough chosen to try out our research methods.*

The consent of all those with responibility of providing services to the mentally handicapped in the selected seven areas was obtained. The support was, thus, enlisted from, among others, the appropriate:

Regional Hospital Boards
Hospital Management Committees
Executive Councils.

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* Our first choice of 'minor city' declined the invitation to join the project lest any findings might prejudice its case before a tribunal on the reorganisation of local government. All other authorities quickly agreed to join.

Chapter Two

Local medical committees, and
Local Health Authorities

Getting providers together

Representatives from the areas selected for the project were invited to join the research that had been considered necessary by a national conference of authorities engaged in providing services to the mentally handicapped. We asked them collectively to examine their real problems, as they saw them. If the services failed, why, or if they succeeded, why? How did the performances of one area compare with those of others?

We felt that the framework for conducting such complex research, involving a full range of services in seven diverse local authorities, had to be wide enough to promote mutual understanding and create a sense of 'we' feeling and comradeship amonst the participants. The range of topics to be studied had to be broad enough to include the specific interests of different providers of services willing to participate in the study. The scope of the project had to be comprehensive enough to cover at least all major activities in the field of mental handicap. The timetable of the project had to be flexible enough to allow participation without hindering the day to day running of the services. We were not surprised, when subsequently, some of the less committed participants, and others interested in the project but critical of the usefulness of the concept of participation of 'non experts' in research, regarded our activities with suspicion. There are no shortcuts to building a team. There are no known mechanics of involvement. Commitment to involvement gradually emerges as a result of a slow process of changing and learning together. The only guidance one can offer is to be patient and non directive. It takes a long time for involvement ot become internalised.

The research advisory group

The absence of any canonical model of research and our choice of non directive methods gave the participants full freedom to develop whatever suggestions they thought might be relevant to the study. The so-called 'obscurities' in not presenting the participants with a a neat research design proved to be a real strength and an important characteristic of the project. We thus succeeded in recruiting the representatives of the seven areas to plan the direction of a major research, and in releasing the priceless enthusiasms of those who had previously thought of such activity only as the exclusive preserve of full-time professional social scientists.

Chapter Two

The participants represented all seven local authorities and came from many different levels of bureaucracy, from junior front line workers to senior administrators. They belonged to nearly all the professions involved in the care and treatment of the mentally handicapped. We were aware that if all ranks and grades of providers of services gave us their full support our success might well be impressive. But, since enlisting the support of the entire organisation for this exploratory work was not easy, we thought it wise to be satisfied with any representation from the seven areas, however meagre.

The participants met for the first time in London in October, 1969, and formed themselves into a research advisory group. They elected a general practitioner* as their chairman. Subsequently, in July 1970, a second group consisting of representatives in the hospital service, was formed from those hospital staff who had shown an interest in the project. This group elected a consultant psychologist** as its chairman. Finally, the two groups merged when, to their members, it became obvious that stronger links between hospital and local authority services must be forged for the benefit of the mentally handicapped and their families. The enlarged research advisory group included a wide variety of staff at all levels. Members of the group numbered over a hundred and included a fringe of providers of services unable, for various reasons, to be quite actively involved. Nevertheless, they still attended occasional meetings and advised on particular aspects of the research. Active members held meetings from time to time either at the Hospital Centre, London or in one of the seven areas, to discuss the research, to review its progress and to take decisions on its next stages. Approximately 25 to 35 participants from the areas attended each of the meetings. The representation varied according to the importance given to this project by individual areas. The research officer acted on the advice of the group, and coordinated the research activity. Often helped by a part-time research staff he maintained continuity to the project by circulating reports of the meetings and of any progress of the project.

The opportunities for learning

Most of the participants had experience of social research in some form or other. They had either helped in supplying information to investigators or they had been consulted on such subjects by those who do research. In both these situations the investigators themselves

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* Dr. M Spark
** Dr. R Mein

clearly define the purpose of their research. At the first meeting with the group, instead of offering any hypotheses for this project, the research team asked the providers themselves to suggest questions which they would like to answer, in order to understand better the coordination of their own services. The members of the group were first surprised at this request; some even felt that it showed lack of both clarity and structure of objectives, and even of competence, by the team. We repeatedly reminded the participants that the concept of involvement demanded that such questions must necessarily be raised and, if possible, also answered by people within the service. We had thus created an unusual situation for the participants. They had been requested to ask questions rather than merely to answer the questions formulated by others. This was the beginning of a new learning process for most of them. Some, however, long continued to look upon us for the sort of guidance researchers normally are expected to provide; their expectations for a structured research design had an inhibiting influence on their own learning in the beginning.

CHAPTER THREE

THE SURVEY:
DECISIONS ON TECHNICAL ASPECTS

This Chapter deals with the sequence in which the method of participative research evolved. It describes the research model on which the project has been based.

Chapter Three

RESEARCH DESIGN

Listing research topics

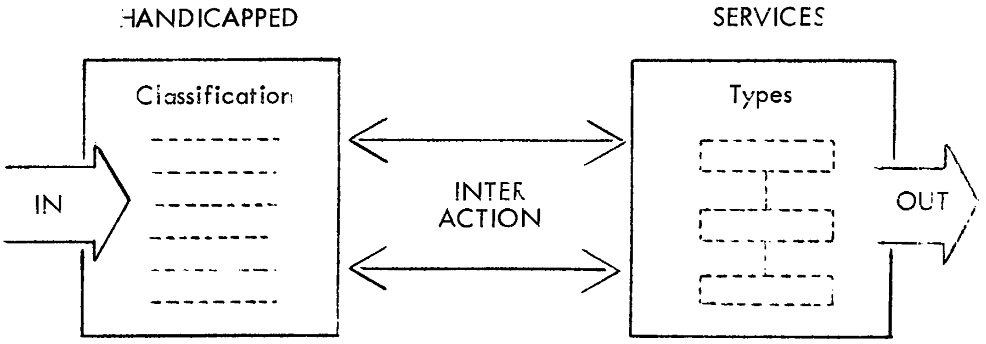
The majority of participants accepted responsibility for deciding what information ought to be collected, the manner of its collection, and how it should be analysed. They started suggesting questions, identifying areas of concern, pointing out sources of information. We soon become aware that such a large interdisciplinary group would propose too many questions to make use of in one limited project, but none was dissuaded, since each was defending - and thus clarifying - his or her own professional concern. Each individual had to personally discover the concepts of economy and discrimination. The research team, purely to create a learning situation, actively encouraged them to go through with these exercises.

The research model

In order to clarify the purpose of the research the participants agreed to use a simple input/output model. On one hand, there is a whole set of handicapped people who fall into various classifications . On the other hand, there is a variety of services with specific functions. The group decided to examine the interactions between the two systems, and the interactions within the service.

DIAGRAM I

RESEARCH MODEL



The participants discussed the need to find more information about the mechanisms which get the handicapped into administrative, social and medical classifications. How do the handicapped change their classification, if ever? Once a child, or an adult, is thought to have some kind of handicap, what interactions occur between parents and providers?

Chapter Three

What does the handicapped, in fact, receive as a result of this administrative activity? Since the performance of a system is judged by the outcome, the group agreed to seek answers to some of the following questions:

how and when did parents of the mentally handicapped, or those providing the services, first suspect subnormality?
what actions followed the suspicion?
how did those involved perceive the needs of the handicapped, and how much - if at all - did they differ from each other in their respective perceptions?
how did those involved see their own roles towards the handicapped and towards other providers of the services?

In addition to a list of the questions the participants also drew up a list of agents who provide the services to the handicapped. They agreed that, to get a comprehensive picture of the experiences, both of the handicapped and of the services, the providing agents must be asked questions corresponding to those addressed to the families being provided for.

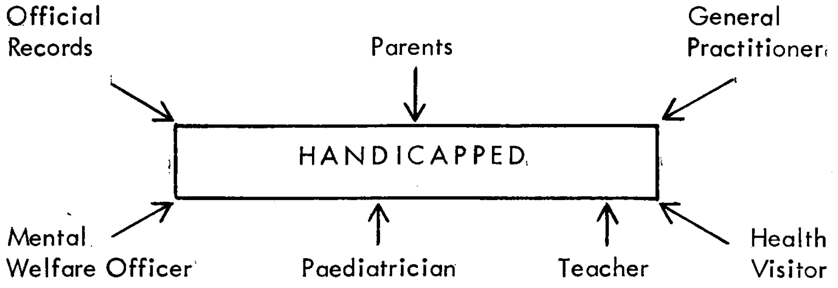
The research strategy

The group decided to sample five percent of the mentally handicapped, whether still living in the community or taken into hospital. It was agreed to draw the samples, first at random from those under the age of thirty known to be living in the community, and then from an equal number of patients from the same local authorities with matching dates of birth, and known to be inpatients in hospital.

The group agreed to use questionnaires to obtain information. The participants were not expected to justify the shortcomings of the service nor to defend the performance of the staff engaged in providing the services. The task they had was simply to examine the various practices of coordination. They were concerned with the here-and-now situation and were not burdened with a long-term, sophisticated and somewhat abstract theoretical and conceptual model. The conditions of pure academic research which demand an absolute degree of accuracy were sacrificed primarily to promote a sense of togetherness among the members of the group. An approximate and subjective assessment of the strengths and weaknesses of the services as described by those providing it was considered acceptable, questions were admitted as opinions and answers accepted on impressions. Overlooking the rigours of scientific research became a sort of safety valve and controlled the risk of

producing anxiety which could generate when members of a system evaluate their own performance. For example, if a mental welfare officer said that he had visited such and such a family X times in the past Y months, he was not asked to produce his diary to confirm his statements. In such studies rigorous evidence is impossible to gather in abundance enough for statistical analysis; one must fall back on the treatment of belief, rumour, misunderstanding and subjective impression. An interdisciplinary group, committed to a common task, created a climate of increased understanding of each others' roles. An awareness of new aspects of the needs of handicapped soon became felt by members of the group, and they jointly searched for useful areas where solutions to problems of poor coordination could be found. Individual participants began to see how they were part of the whole structure. The preparation of survey instruments was a group exercise of great value, because it brought the handicapped person to the centre of inquiry.

DIAGRAM II



Encouraging those at the 'cutting edges' of the service to build their own model of research soon brought out those problems and needs of the client that demanded attention. This was acknowledged as an important outcome of our participative methods. The questionnaires were then tested, modified and improved by the participants. They became increasingly conscious of their own professional roles and subsequently admitted greater appreciation of the importance of other professions in their own routine work.

Administration of questionnaires

Once the questionnaires had been agreed upon we encouraged the participants, and through them their colleagues in the field, to use these questionnaires themselves. We offered no specific training in research methods, or guidelines for interviewing, probing and recording as such.

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Through meetings, personal contacts and the circulation of research documents and reports of the meetings, we seemed to convince many, who had been directly involved in the group's activities, that their participation in the project was a worthwhile exercise. We had either directly, or through other active members of the group, assured them that the project was not aimed to evaluating or critising the professional efficiency of their service. This assurance weakened, it not altogether eliminated, any feeling of a need by qualified staff to defend themselves.

We hoped that the use of questionnaires in the field would, in itself, offer some opportunity to the providers to gain new insights into the systems for which they were responsible. They, as a result of this study of coordination, would together learn more about the needs of their clients, the roles of their colleagues, and their own roles. Through the reconstruction of their own 'public' knowledge each would be motivated to provide an improved service. Public knowledge and personal action are closely related. We were, in other words, hopeful that increased insight shared by those in contact with the family, would lead to more purposeful action by all.

The conduct of our fieldwork on the project, unfortunately, coincided in time with the reorganisation of local authority services inaugurated by Seebohm. Research assistance thus had to be provided to complete the work in areas where the pressure on officials of reorganisation could have driven them to abandon the project altogether. The researchers we had used were all part-time workers. Each one of them was specifically requested by us to concentrate on completing the work through the active participation of the staff of the local authority. This practice somewhat delayed the fieldwork. But the presence of a member of the research team in an area invariably increased the interest and activity among those local staff who had, hitherto, remained unaware of, or unimpressed by our participative method.

Absence of definitions

After some considerable discussion on how to define mental handicap, the term as used by professions working for local authorities and hospitals was accepted by the group. We neither challenged nor attempted to explain it. Mental handicap was purposely taken in the broadest sense. We expected that the finding of the research would show specific variations between professions or areas. We anticipated discovering differences in the

Chapter Three

Knowledge of the handicap and varying degrees of confidence with which the term was being applied in the seven differing areas of the country. We were thus concerned in our samples with all those cases which had passed for mental handicap, regardless of the ultimate 'validity or invalidity' of their classification .

Involvement at the stage of analysis

The object of using a set of six questionnaires on each selected case was not just to collect, profession by profession, information in the form of a clinical catalogue; it was to see how far, through the multiplicity of providers in one common study, the records of the mentally handicapped could suggest where coordination between the efforts of these many specialists might be improved.

We were aware at the start of this project that the involvement of a number of different professional interests in an examination of their mutual problems would lead to the collection of a vast amount of data. But in order to bring together different professional approaches we allowed the participants to identify whatever information each one of them thought was vital for discharging their duties effectively. Once the statistics from the community study in the pilot area became available we requested the participants to identify the information from their local situations which they required to collect and to control, and to select the data which, in their view, was relevant to the theme of coordination. We were not surprised when, after a day long meeting of various providers of services working in small multi-disciplinary groups, we were expected to analyse and quantify a vast amount of information. Any experienced researcher would have considered the gathering of such statistics as not only useless in outcome but impossible in practice. Since, however, we believed that this work of supererogation would help to build a better climat for participants to work together, we willingly analysed all the information requested by the group and processed it on a computer. The information, duly analysed, has now been presented to all the appropriate representatives in the seven areas. They are currently examining the data and drawing conclusions relevant to their own local services.

Stastical data, from six fairly independent sources, has been collected on the problems and characteristics of each individual in a randomly selected sample of mentally handicapped. We have information on most of the services which are being provided to those in the sample

and their families, a catalogue of the consumers' perception of their needs, and of their expectations of the services provided for them. We also have the views of the providers on what they thought they were doing, and what they had expected their co-workers to be doing in the common task. From a fast feedback of this information to the seven areas, we have succeeded in obtaining some reactions from the participants which are presented in this book. It is probable that the major impact of the feedback of the data, and indeed of the method of study, is still to come.

Pilot hospital study

Although the original suggestion for undertaking this whole project had originally come from those working in subnormality hospitals, a combination of circumstances resulted in our starting this community study first. The intentions of the members of the research advisory group were to follow on with the experiences of another sample of handicapped, belonging to the areas under study, after admission to hospitals. The group had hoped that such a follow-up would not only be complementary to the community study but would also throw light on the hospital community links.

The Pilot study in the two hospitals was carried out largely with the help of a clinical psychologist* from an area other than those included in this project. Her growing appreciation of participative research, through her involvement in the seven local authorities, made it possible to develop and test further research tools. A health visitor** was subsequently seconded by the London borough in the survey to assist with the fieldwork in the hospitals. This secondment helped to link the hospital and community on a close person to person basis.

Within the limits of time and resources, it has not been possible to develop the hospital study beyond the pilot stage, although a description of the experience of initiating a research project of this type in hospitals has been prepared separately. Among other topics it describes how research tools were developed, used and analysed; what lessons can be drawn from the information collected; what participative research can contribute to the assessment of the needs of the patients, of the current organisations of resources; what it can contribute to the study or organisational structure and communications in hospitals, and

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* Diana Cortazzi

** Joan Trigwell

how the attitudes of the staff affect their performances; and finally what the hospitals need to do if they wish to involve their staffs in the identification, description and evaluation of the cooperation between their services.*

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* A complete description of the pilot hospital study is available in lithograph form. D Cortazzi and A Baquer 'Action Learning', the Hospital Centre (multilith THC 72/736).

CHAPTER FOUR

DIFFICULTIES IN DEVELOPING PARTICIPATIVE METHODS

In this Chapter some of the difficulties faced in evolving a method of participative research are discussed.

Chapter Four

PROBLEMS IN ADMINISTRATION

ACCEPTABILITY OF RESEARCH

Our society for some time has sought possible relationships between the social sciences and social policy; between management sciences and organisational development. Social scientists have had some success in establishing the importance of social research in identifying social pathology, in offering solutions and in planning reforms. The administrators and the top managers, who had been approached to co-operate in this project in the first place, must have done so expecting that the skills and expertise of social scientists, responsible for the study, would make little or no demand on the time of their already overworked staff. The fact that we started our activities by presenting this project as a tool for gathering information on existing services probably helped us gain the consent of the various bodies appropriate to participate in this study. Senior levels of social and health service organisations are accustomed to giving formal permission for a research project to occur in their areas, expressing some interest in the work, but then leaving the detailed field work and the treatment of its data to the researchers. Research, normally, is not an activity in which the executives themselves are expected to be directly involved. The project we intended to conduct did not start with any neat design, and its very development depended on the active participation of not only the top management, but, through them, of the rest of their organisations. The value of such such staff participation could not be fully understood at that stage, and was not seldom stubbornly resisted. The notion of it was more than once derided.

Chapter Four

PROBLEMS ARISING FROM MIXING RESEARCH AND LEARNING STRATEGIES

Research as an activity is frequently justified as being 'useful' and to most people it is not directly related to change and learning. A fact finding exercise is, on the whole accepted as non-threatening and provides an easy and legitimate entry into a system. The importance of this concept of changing through learning, and learning by trying to change a system is relatively new. Some of the participants, not surprisingly, showed a tendency to perceive this project essentially as a traditional research operation. They appeared somewhat confused when we presented them with the concept of learning by getting involved in the research process itself. The initial communication to potential participants of the idea remained extremely ambiguous no matter how simple our own explanations were. The involvement concept conjured up incomplete or incorrect images because the idea of learning by doing did not relate to their past experience. On the other hand, at that time, we had no knowledge how to present it in a way that it could be understood and responded to. Since we were also inviting them to participate in a research programme they reacted to this familiar phenomenon and consequently research images, and expectations from such an activity, played a dominant role. The full understanding of the basic aims of the project, namely, increasing their awareness of the system through acquiring greater knowledge of their problems remained dependent on their actual learning process emerging from subsequent development of the project.
We had, in the first instance, to be content with the interest they were showing in only the research aspects of the project.

THE CHANGE IN ROLES

A traditional type of research activity is characterised by certain expectations both on the part of the researcher and those on whom this research is done. In this project we had dramatically modified and changed our own roles and that of the participants. This created confusion in the minds of those who did not appreciate the value of our method of research, or who were sympathetic with the concept but did not understand our difficulties in actually obtaining participation. Some had joined the Research Advisory Group suspecting our motives and their negative attitude caused our work to be undermined. But misunderstandings were never irreparable. Although a number of participants had started playing active parts in the construction and administration of questionnaires they

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LEARNING BY DOING

We are, however, convinced that learning occurs through doing and not solely by reading books, or attending lectures. People cannot be ordered to learn, they learn because they want to. Our endeavours in the administration of this project were largely focussed upon providing the opportunities for the participants to act, since we believed that it is through action that they will learn about their services, and having gone through the exercise of learning they will commit themselves to improve the services.

We all found ourselves in the new learning situation: the participants were learning how to design, control and direct the study; we, on our part, were learning how to place our research skills at the disposal of the participants and how to provide continuity and momentum without interfering with the decisions taken by the participants. Both parties experienced some natural anxiety as in any unorthodox situation: but both also developed a counter balancing enthusiasm. There was some overlap in our respective roles but we mainly succeeded in getting a firm agreement on our mutual objectives. We had access to obtaining funds; were able to call meetings, possessed skills of supervising operational aspects of designing questionnaires, undertook the responsibility of organising the administration of research; the participants had the goodwill to get together, the enthusiasm to support us and each other, and above all the practical wisdom and insight in the problems of the services, without which our project could have turned into another academic type of research programme.

COMPLEXITY OF THE SUBJECT MATTER

To add to our difficulties of exploration of new methods was the complexity of the subject matter itself. Anyone attempting to measure as complex a subject as co-ordination of services will be overwhelmed with a desire to examine all its facets. We have attempted to continued to regard these activities as not only unusual but also totally unrelated to their normal professional tasks. We discovered that there was often a time lag between engaging in actually doing something related to the examination of the system and the appreciation of the value of such tasks in terms of personal learning and organisational development. It varies so much between one individual and the other that any generalisation in this respect could be misleading.

LEARNING BY DOING

We are, however, convinced that learning occurs through doing and not solely by reading books, or attending lectures. People cannot be ordered to learn, they learn because they want to. Our endeavours in the administration of this project were largely focussed upon providing the opportunities for the participants to act, since we believe that it is through action that they will learn about their services, and having gone through the exercise of learning they will commit themselves to improve the services.

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INFORMAL CONTACTS

The traditional researcher, often, attempts to maintain a social distance from members of the system being studied. We, on the other hand, tried to develop and maintain informal links between us and the participants, and among participants directly. Such contacts would, we had hoped, help the participants appreciate that we were not using any highly complex and almost mystical techniques of research but were, in fact, dependent on their contributions and participation. By exchanging views with each other we had anticipated that the participants would attempt to understand the problems they faced in a new learning situation on their own.

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Chapter Four

COMPLEXITY OF THE SYSTEM

We had undertaken a research project of an unusual kind in seven highly complex human systems, separated from each other not only by physical distance but also by their own particular historical development of services, their own programmes of change and improvement. The diffuseness of the system acted both in favour and against our method.

Since our project was a comparative study of seven areas it gave us an opportunity to avoid any open hostility against our concept of learning hindering the progress of our work. If one top official in an area seemed rather unco-operative we consoled ourselves when his counterpart from another area showed some understanding and facilitated our research activities, hoping perhaps that some learning by example would take place.

In the first phase of the project, the designing of a research model, we held central meetings in London. Here, we consulted representatives of the areas and of the hospitals, and assumed that they would return to their base and discuss details with their colleagues. We left the initiative of spreading the main method of work with the participants.
But in practice this was not always as neat an arrangement as we had hoped. There were areas who gave, quite reasonably, low priority to our research, thus, some participants were rather poorly placed to stimulate project activities, or even discuss its value, in their own areas. To be able to involve people from various departments within an area requires approval from a high level in the hierarchy. Among those tho had volunteered to co-ordinate the research activities at the area level the intellectual and emotional commitment to the idea of involvement varied greatly and it reflected in their giving time and energy to the organisation of activities. Others again could not relate the immediate objective of the project (collection of data) to the promised final outcome (improvement in services).

The limitations of available resources, in terms of personnel and time, made us ecomonise in giving support to areas when asked. Consequently we missed opportunities in other areas of overcoming resistance, indifference and misunderstandings. Equally, we could not follow up many requests for help with tangental projects shown by any one local authority, although we did request the participants to make a list of such opportunities, for future development.

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We had realised that, in a project like ours, there would be people who would show interest at different stages of the research, and their enthusiasm and skills should be used according to the needs at each stage. Not all those who have been active in this project have in fact participated in all aspects of the research activity. But we have made systematic and deliberate attempts that decisions taken at any stage of the project should reflect the views of the representatives of all areas and disciplines. The orientation acquired through developing a common outlook, by such multiple participation, in itself eliminates the risk of a narrow outlook.

Our experience has shown that in areas where the senior levels of power structure showed sympathy and understanding of our method there were greater facilities available for learning. Greater learning led to a more effective self-diagnosis and consequently to greater procedural and organisational improvements. On the whole we found that those who started with a clear understanding of our approach showed a higher degree of involvement than others. Our recognition of the value of the operational mechanics of involvement increased as the project progressed.

SOME OTHER BARRIERS

Any project concerned with the improvement of the existing situation is likely to encounter forces tending to maintain the status quo and it is worth pointing to such forces which appeared as barriers to the development of this project.

Myth of excellence

Social administration is largely composed of activities which maintain a certain degree of stability in the system by resisting attempts at altering it. A myth of excellence of the system prevails and most people are more or less satisfied with the way a system is structured or is functioning. If those providing the services for the mentally handicapped had been in some way personally dissatisfied with the system then the involvement in our work would have been higher. Our task was to dispel this myth to some extent and prepare the participants to acquire a questioning attitude.

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Chapter Four

Attitude of complacency

At the time of starting this project the complacency and affability which we generally found amongst those who did not appreciate the need for an evaluation of their services was sometimes stong enough to counteract the social conscience which provokes corrective actions. Not many people willingly agree to an examination of their activities. They take the usefulness of their actions for granted. Many suspect any type of research activity as a waste of time and effort. They explain that it takes all their time to give the services of today rather than talk about the needs of tomorrow.

Preconceived remedies

We came across providers of services who had already decided upon a diagnosis of the system, 'we need more money', 'We need more staff' and so on. Research activity of any kind is likely to come up with information disagreeing with their own diagnosis. The best way to protect one's image of an all-knowing, efficient provider of services is to resist research and thereby eliminate the risk of confronting a threatening situation.

Weakening of authority

To some of the participants our method of consultation with the staff, especially those with first hand knowledge of the client and his family, implied a certain need for change in the administration procedures. It appeared to such people that our approach was going to weaken authority by questioning its procedures, practices and decision making. They, too, tended to oppose to research activity.

Timing of the fieldwork

The fieldwork, (unfortunately for us), coincided with the reorganisation of the local authority services as recommended by Seebohm. These large scale changes in the structure and functioning of the services demanded a great deal of time of the staff. We did not expect the participants to let our research activities interfere with their normal duties. It was difficult for some of them to give their minds to the activities of the project and at the same time to be involved with the Seebohm changes.
We depended, almost entirely, on the voluntary co-operation of the providers.
Our fieldwork consequently suffered serious setbacks.

Chapter Four

Lack of time

Apart from the reorganisation of services, time was a real constraint for many participants. Thus in one area when a senior official, on grounds of scarcity of time, felt bound to refuse permission for his staff to interview parents, we had to use outside researchers, although several of his staff had expressed their willingness to do one or two interviews. The excuse of lack of time is particularly powerful because it cannot be disproved. To have challenged it would have caused damage to our relationship with those holding senior posts in the system. We were, however, encouraged by the statements of some of the participants to assure their colleagues and counterparts that this type of involvement did not add any serious burden on their time. They declared that the participative method of research meant that they had to perform their day to day tasks somewhat differently.

Availability of funds

A major constraint on us was to obtain adequate funds from the start. It costs money to do research, since research, no matter how modest in its scope, requires funds, facilities, time and personnel. Normally the researchers have a very clear idea of the design, scope and duration of the project at the time of applying for funds. Our approach, because it was experimental, was not very systematic and all we could show at the start was a desire on our part to explore the possibility of involving providers in an examination of the service. Throughout the project we had to look for justifications to continue this research, and to avoid the risk of withdrawal of financial support. We are grateful to the King's Fund for their act of faith in our approach and financing this project as far as they did.

CHAPTER FIVE

ASSESSMENT OF THE BENEFITS OF PARTICIPATIVE RESEARCH

An attempt has been made in this Chapter to assess the benefits and advantages of involvement of staff in the evaluation of services they provide.

Chapter Five

THE EXPECTATIONS FROM RESEARCH RESULTS

Any researcher can succeed, to a greater or lesser degree, in recognising some of the problems in a system, but not every researcher commands enough knowledge of the total system to offer solutions. In order to make his findings effective he largely depends on the support of those responsible for running that particular system. In this project we attempted to combine the processes necessary for making a diagnosis and also for arriving at solutions by involving the providers of the services in the exercise of identifying problems as well as in applying the research findings, which they had helped us to obtain, to their real life situations. This way we have made involvement positive and constructive. The providers were helped to realize, collectively, that it was within their competence to put their finger on the weakness of the system, and to suggest pertinent solutions to rectify those weaknesses. They were encouraged to work together to use their education, training, experience and insight in working out a programme of evaluation of their services.

If, in any situation, people feel they have no control over their destinies they become uneasy and apprehensive. Our method attempts to dispel such fears.

In this project, by giving the responsibility of conducting the research and making the recommendations on the basis of the findings, we eliminated the risk of resistance to solutions imposed from outside.

In attempting to understand, with their colleagues and counterparts, what services they were providing to the mentally handicapped, the providers were surprised to discover that they were not dealing with the problems they thought they were. Organisations frequently continue to function in a somewhat different way from when they were first structured. This change occurs so gradually that no one can register it. Our study, based on participation, facilitated the perception of change by those who would have denied its existence. At the same time it offered skills to identify the need for change and examine its effect and value.

The success of a research programme, especially if its objectives were change and improvement in the system, should be judged by its benefits as seen by those for whom the research was undertaken. Such an assessment will help the reader to appreciate on the one hand

the steps taken to develop a participative method of research, drawing its strength from the involvement of a cross-section of providers of services, and the validity of the outcome of such an approach on the other.

METHOD OF ASSESSMENT

No systematic procedure or evaluation was built into the project. Such a scheme would have demanded a comparison of 'before' and 'after' measurements of the impact of this project, which, in itself, would have constituted a major research programme. The resources allocated to this project were too modest for this. Secondly, in order to allow a scientific evaluation of an activity of this type we had to offer some lucid explanation of the strategy we intended to use. But the operational aspects of involvement developed only gradually and haphazardly as the research progressed. It was not clear to us at the start how the providers of services, without any formal training or orientation in research methods, could become actively involved in a project which relied heavily on standard survey techniques.

Every human system, depending on its size and complexity, has procedures, elaborate or superficial, to deal with the problems which present themselves from time to time. Most of those running the system often have no real opportunity to examine the origins of the problems as was demanded by the nature of our project. We attempted to increase the awareness of the members of the system about their problems which emerge either owing to malfunctioning of the system or because of external pressures on the system. We also wanted to increase the awareness of the participants to problems within the system which exist but are not dramatic enough to demand urgent solutions. We did not want to solve problems ourselves but to develop mechanisms which would facilitate the conditions for self diagnosis and self treatment. This we had hoped to achieve by providing greater understanding of the system by the participants through participative research.

THE EXTENT OF LEARNING

Given that for many of the providers, care of the handicapped was only one of their responsibilities, and also that not many could be exposed to research activities for long periods, they attest in varying degrees to increased appreciation either of needs and

feelings of the parents of the handicapped and/or of the work and problems of some of the other providers of services. Thus, one experienced health visitor, as evidence of how she had learned a great deal from applying the questionnaires to parents, said she had found that 'parents don't like the term "subnormal" and prefer to talk of "mental handicap";' and another learned of the resentment felt by some parents towards medical consultants and general practitioners.

As one health visitor expressed it 'the mother said things to me because of the questionnaire which she would not have said to me simply as Miss X, the health visitor.' Mental welfare officers referred to similar learning experiences. One for example, was specially struck by the discrepancies between his own and parents perceptions as to the frequency of his visits to them. Others realised that parents have little awareness of differences between the many varieties of health and social workers and, consequently, understood the need to explain to parents who they were and what their role was. Some saw more clearly than before the need for counselling to help parents come to terms with the fact that their child was handicapped.

The providers found they had been offered an opportunity to learn about all the services concerned with the handicapped as well as to learn about the needs of the parents. One group of health visitors who interviewed general practitioners came to understand more about the limitations of general practitioners in caring for handicapped children. To see that general practitioners often have little training or experience of mental handicap and that because of pressure of time they are unable to do more than deal with routine medical problems they realised the need for greater support from health visitors to the family and the general practitioner alike. Similarly, social workers involved in designing the questionnaire for teachers began to see gaps in coordination between parents, training centres and mental welfare officers.

The particular learning was unique to each participant but each gained some further comprehension of his or her own role, the role of others in providing services, and the problems of relationships between various parts of the system. It is difficult to assess, with any scientific accuracy, how deep or long lasting this learning is and how much it has actually improved the quality of care provided by the individual concerned. If we had had the opportunity of repeating our entire programme we would have succeeded in making the initial learning phase powerful enough to have an effective impact on the whole system.

Chapter Five

The experience of the project has shown that by offering to the providers an organised opportunity to examine the services a significant development has been an increased concern for mentally handicapped people and their problems. Thus the participants saw the project as 'creating a climate of increased liveliness in the concern of some mental welfare officers of the mentally handicapped. It revived questions and interests which had been allowed to slide, through the pressure of day-to-day work'. A deputy medical officer of health claimed that in his area 'the whole department has become much more conscious of mental handicap as an issue'. Increased concern is important because it raises the priority accorded to mental handicap by officials. Mentally handicapped people have traditionally been a low priority or 'forgotten' issue so that, for example, mental welfare officers would deal with mental illness more readily than with mental handicap. The question of priority accorded consciously or otherwise to a particular type of problem, becomes even more serious for the new breed of generic social workers whose time has to be shared between all types of social work problems.

A significant development through the project is the personal growth exhibited by at least those who had been actively participating. An increased self confidence and use of initiative has been experienced by those who had learned the value of involvement rather rapidly after their initial contact with the project and had then sought for and taken further opportunities to continue their involvement. Thus, two trainee mental welfare officers gained some insight from interviewing parents and then went on to suggest to the Research Advisory Group the need for the questionnaire for the staff of training centres. They devised such an instrument by involving quite a few providers of services within their area. A senior social worker after seeing the discrepancies occuring between his perceptions of cases and the parents responses to questionnaires, helped actively to promote the project in other areas. A medical officer who did not strictly need to be constantly involved became very active in discussing and planning improvements to research methods as the project progressed. A consultant paediatrician played a very active part in helping to design a questionnaire for his own profession, as well as in improving the quality of other research tools. The increased self confidence of such individuals is demonstrated by their greater willingness to take initiatives and responsibility and, more importantly, to question the provision of services in their own areas.

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The participants have also learned that they are capable of making use of their past experience in developing research design, in constructing questionnaires, in the collection and analysis of data. They have discovered, much to their surprise, that they possess the potential and resources to undertake a thorough evaluation of their system if opportunities could be provided for them. They have learned the mechanics of involvement of people like themselves in participative research and have accepted its value. They now know that such an activity provides them with opportunities to look at their own predicament. Research activity of this kind offers a framework within which they can learn to question their own actions and environment, and can also discover remedies for any problems they might find.

RECOGNITION OF THE VALUE OF THIS APPROACH

The assessment of the impact of a participative method of research on individual participants, and through them on the services they represented, is made on subjective statements. We have been asking the participants, irrespective of their degree of involvement in the project, to describe in their own words, the benefits of their experiences. Some quotations and statements are from people firmly committed to this project, others from those personally interested but less deeply involved, and others again from senior administrators whose juniors have been active in this research. Sometimes they had expressed these views in articles written for the professional press [3] ; but most often in meetings held either in London or in the research areas, or in the seminars and conferences held elsewhere where they had represented the project. The assessment is also based on the statements made in the letters of the participants to the research officer, interviews held with them, and their contributions to the various progress reports prepared at various stages of the project. At the time the comments were made none of the participants were aware of their present use. The subjective accounts of the participants, on different aspects of this project, have been considered sufficient to indicate the value of our <u>approach</u> in participative research. The reaction to the <u>data</u> collected has been discussed separately in Chapter Eleven. We believe that once the data is carefully examined by the participants it will provide clarification for them of the real issues requiring action. The providers of services would, however, need a longer period than our rather hurried attempts to feed back the vast amount of analysed information allowed. The participants, through their involvement in designing research and the collection and analysis of data, have gradually acknowledged and accepted the implication of the statistical research findings. They need now to be encouraged to

develop their own solutions and action plans to deal with the problems which they have identified.

The following quotations are by no means exhaustive. They have been selected as indicative of a more general response. We have also attempted to relate them to the following four conditions which, in our view, illustrate optimum development:

a active concern of those in charge
b responsibility or commitment of those at the 'grass roots'
c the chance to try out new methods
d methods of participation in a group

The comments of the participants have been arranged in an order which characterises the learning processes discussed in our introduction:

recognition of the need to learn
rearrangement of present knowledge to suggest new ideas or perceptions
try-out in an operational setting
feedback

RECOGNITION OF A NEED TO LEARN

a Active concern of those in charge:

> '........... these senior staff members ceased to feel so anxious and threatened and were prepared to admit to themselves and to us, that the files were poorly organised.' (Trainee social worker).
>
> 'The health department representatives, the deputy medical officer of health and the two nursing officers were interested in the project both in concept and in application .... to them an important realisation was of the project as a form of training.' (Student)
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> 'The children's department asked for a talk about the research, and the senior staff, impressed by the methodology, encouraged their department to participate.' (Mental welfare officer)

REARRANGEMENT OF PRESENT KNOWLEDGE

a Active concern of those in charge:

> 'We are encouraging the use of the questionnaires as a systematic examination and as a teaching and learning situation, to encourage awareness of individual misperceptions and misperceptions of the roles of various professionals:

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i) training individuals to be more aware of themselves
ii) training of professions to be more aware of their roles
iii) in doing this, discovering the gaps in the services.'
(Deputy medical officer of health)

'This project has resulted in identifying the need of a training programme for the providers of services, ie general practitioner, health visitor, social worker etc, relevant to the needs of the mentally handicapped.'
(General practitioner)

b Responsibility or commitment of those at 'grass roots':

'Staff involved in this part of the country have experienced an enrichment of their insight and knowledge of the needs of the mentally handicapped and their families, that no lecture or text-book could ever hope to provide.'
(Mental welfare officer)

'One experience in particular that occurred during the project convinced both of us of the implications of this type of research for future training purposes ..... workers in the field and those at administration levels could be stimulated by the philosophy of involvement .... ' (Social worker)

'The research provided the necessary impetus for change to be brought about.'
(Senior mental welfare officer)

'We in the local authority services are becoming more aware of what hospitals want from us.' (Area team leader)

'The term "communication" has now become lack of awareness of the true roles and functions of the individual.' (Psychologist)

'........ it is sad to see how isolated some people appear to be. Because their attitudes had become very narrow, they either had no cooperation from others or "as much as one can expect".' (Health visitor)

'We thought that if someone organised us into communicating, we would do a better job. The point we now realise is that we can't wait for someone else to do it for us.' (Consultant psychologist)

TRY-OUT IN AN OPERATIONAL SETTING

b Commitment of those at 'grass roots':

'I knew something now of what was behind his attitude: how he saw my job as office-bound and out of touch with reality, whilst I had seen his role as a bored messenger delivering someone to my office for interview, always in a hurry. When he next called, he was invited to participate in the session - the first time he had evern done so.' (Senior psychologist)

c Change to try out new methods:

> 'They perceived the gap between the JTC and the ATC and the tensions between the two, and found that their seniors were reluctant to discuss this. They decided to try to bridge the gap by involving the training centre staff in designing their own questionnaires for the project, as this had not been done. They finally produced the questionnaires, which were completed in five of the research areas and are now awaiting analysis.' (Comment on two junior social workers)
>
> 'Eventually all the social workers in one area undertook to complete questionnaires, taking one family each ... the welfare department asked to be included in the project and two more social workers and some health visitors followed. This was important, because there was a need to establish a relationship between health visitors and social workers on a firm basis.' (Social worker)
>
> 'I have been able to establish a weekly clinic with an attachment of a health visitor to look at the growth and development of children. To equip myself better I am attending a course in developmental paediatrics at the local university.' (General practitioner)

d Participation in a group:

> 'Being engaged with others from different areas in a common task has made the idea of a critical analysis of one's own services less threatening.' (Mental welfare officer)
>
> 'One gets, from the group, some astonishing impressions of how one's role is seen, learning at the same time how totally wrong one was about that of other professions. It makes one very much aware of how people in one's own area may be seeing one's role.' (Psychologist)

FEEDBACK

b Commitment of those at 'grass roots':

> 'Communication has been isolated as the major problem. It has been very revealing to the communicators to see what impression has been made on parents by their efforts at communication and procedures are being studied to improve matters.' (Senior mental welfare officer)
>
> 'Training courses and conferences were considered a waste of time ..... through this involvement of actually having to search out exceptional cases, this person was encouraged to consider them in depth and their ramifications became clear perhaps for the first time.' (Social worker)

c Chance to try out new methods:

> 'One benefit can already be seen: there is little or no resistance to taking on work with the mentally handicapped and their families. The opportunity given by the use of the questionnaires for a survey of the area has helped those new to the field to enter into the case work situation in possession of some knowledge they would not have had without the research.' (Mental welfare officer)
>
> 'The process of developing questionnaires has helped me to stop and think about the validity of present practice. It has also been a valuable means of creating staff involvement in the project.' (Area team leader)

d Participation in a group:

> 'Through the group discussions I am less inclined to see deficiencies in the services entirely in terms of lack of resources, although this is undoubtedly a difficulty. Inability to use resources effectively is also a major problem. This new perspective is more encouraging because I feel I can do more about utilising present resources than I can to increase them.' (Social worker)
>
> 'I used to rely on parents to keep me informed or had to telephone the mental health department to find out about decisions taken. However, since this project, people in the department and health visitors in our area have become more aware of each other's role, and now have an excellent rapport, finding it easier to approach each other over difficulties arising in a particular family and to offer support between them. This is important to the clients and much more satisfying to the field workers who have in the past tended to work in their own isolated spheres.' (Health visitor)

CONFIRMATION, MODIFICATION OR REJECTION OF THE THEORY

This was considered to be the final stage of the learning process in our introduction. We had committed ourselves to feedback the data to the research areas for their reaction, comment and action. The feedback is the logical outcome of the discussions the providers have had concerning the design of the research over a period of three years. The motivations of the participants have been raised and real possibilities exist of obtaining grass-roots interpretation of data.

SECTION 2

WHAT WAS DISCOVERED

CHAPTER SIX

DESCRIPTION OF THE SURVEY

The technical aspects of sample size and response to questionnaires are outlined in this chapter and ten characteristics of the sample population are discussed.

Chapter Six

DESCRIPTION OF THE SURVEY

THE SAMPLE

The sample for our study was drawn from six local authorities across the country and a London borough which was used as a pilot area for testing the questionnaires. The six areas and the pilot area were deliberately chosen for their different settings in an attempt to cover a wide range of problems and situations. It was felt that not only would the results of such a comparative study be of relevance to local authorities but the interaction of participants from different areas might also stimulate fresh approaches to overcoming shared problems. The seven areas involved in the project were as follows:

The pilot area - London Borough of Hounslow
(population: 206,870)*

A 'mirror city' - County Borough of Gateshead
(population: 100,780)

An industrial county borough - City and County of Kingston upon Hull
(population: 294,720)

A regional 'capital' - City of Nottingham
(population: 305,050)

A 'traditional' city - City of Oxford
(population: 110,050)

An expanding area - County of East Sussex
(population: 428,250)

A rural county - County of West Suffolk
(population: 155,240)

It was decided that a 5 per cent random sample of mentally handicapped people living in the community would be the minimum necessary to identify the factors affecting coordination. In Gateshead, the 5 per cent sample yielded only 14 cases which the participants from that area thought was insufficient to provide useful information about their problems and therefore the local staff conducted a follow-up survey of all mentally handicapped children under the age of ten.**

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* Population figures are from the 1966 census.

** We have not been able to integrate this larger survey with the results from the other areas and so, for the purpose of this study, we have confined ourselves to the smaller sample from Gateshead.

Chapter Six

The population from which this 5 per cent sample was drawn had the following characteristics:

> The handicap of the population was subnormality as defined by the 1959 Mental Health Act. It included people with a wide range of mental and associated physical handicaps, from those who were previously classified as idiots to those who are educationally subnormal (ESN). It does not include people who suffer from physical handicaps only.
>
> The population was living within the defined geographical area of the selected local authorities.
>
> The population was living in the community. By living in the community we mean all those who spend most of their time outside the subnormality hospitals. They could be living at home with parents, or with relatives, or foster parents, or in local authority hostels and so forth. All those who normally stay in the community and have been admitted to a hospital for short term care are also included in this population.
>
> The population had not only to be known to the local authority mental health department but also to be on their active supervision list. Although most cases known to the mental health department are on the active supervision list, some cases, for a variety of reasons, are no longer supervised and are not in receipt of any local authority services. Since our concern was with the coordination of services we were not interested in these 'closed' cases. Handicapped people whose files were still active but who were not having regular contact with the mental health department were still included in this population.

In addition to these four population characteristics, the sample was confined to mentally handicapped under the age of thirty. This was done for two reasons. First, by the time a handicapped person is thirty years old, it is possible for him to have received the gamut of services available and consideration of the period beyond thirty would not add appreciably to our understanding of coordination. Second, if we had included the older group of subnormals, there would have been a danger that the sample would have been weighted towards those people who received the majority of their services before the 1959 Mental Health Act. It has been argued that our sample is already biassed in this way, and that a study of the pre-1959 situation is pointless because the provision of services has changed out of all sight since 1959. However, to anticipate one of our major findings, this argument is only partly valid because the improvement in services has been confined to a few sectors. This finding would not have been possible had we not included the older age groups in our sample. To achieve uniformity in the sampling of each area, we stipulated that the sample had to be drawn

from mentally handicapped people whose birth dates fell between January 1940 and December 1969.*

MULTIPLE SOURCES OF INFORMATION

This 5 per cent random sample yielded a total of 212 mentally handicapped people (the numbers for each area are given in Table 1-A). The actual method of drawing the sample is described fully in Appendix A.

One of the strengths of this study is the diversity of sources of information. The research programme involved all the providers concerned with the mentally handicapped collectively in constructing survey instruments suitable for identifying what had happened to each mentally handicapped person up to the time of the enquiry. The object was not just to collect, profession by profession, information in the form of a clinical catalogue; it was to see how far the examination of different records of the same case could suggest where coordination between the efforts of these many specialists might be improved. In the event, six questionnaires were prepared and administered, one for each of the following sources of information.

The parents
The general practitioner
The health visitor
The mental welfare officer
The staff of the training centre
The official files of the local authority mental health department

RESPONSE TO QUESTIONNAIRES

The questionnaires to the case files and the parents were administered first. As far as possible, they were administered by participants from each of the areas, although in a few instances, research assistants from outside the areas were used to support the local professionals. The general practitioners were interviewed by mental welfare officers, health visitors and part-time researchers. The questionnaires to the other professionals were self administered. The parents' questionnaire is provided in Appendix B.

It was hoped at first to gain a 100 per cent response to all the questionnaires but this was not possible for a number of reasons. The best result was from the case files where only

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* Note that because the 5 per cent sample was drawn from the total population of mentally handicapped in an area, which of course included adults of 30 years or older, we in fact sampled something like 10 per cent or more of the under 30 age group

one file was missing, thus giving a response of 211 to this questionnaire. All 212 parents were contacted: randomly selected substitutes were used where the parents in the original sample either refused to cooperate or were unable to do so. However six questionnaires were not returned in time to be included in the computer analysis and a further two were excluded because they did not contain sufficient information to be of any meaningful use. This left a sample of 204 parents.

Details about who the respondents' present general practitioner was had to be gained from the parents because this information was lacking on approximately two thirds of the case files. Although all general practitioners were contacted, replies were received from only 147 doctors. Most of the non-respondents claimed pressure of work, lack of interest, or in a few cases, the ethics of revealing confidential information.

The questionnaires for the other professionals were divided into two parts. The first part dealt with factual information about the handicapped person and the professional's experience of the case. The second part called for the respondents' opinions and perceptions of the roles of various agencies. For mental welfare officers and training centre staffs, Part One was completed in more cases than Part Two. This apparent discrepancy is because many of the mental welfare officers and school staff are responsible for more than one handicapped person in the sample and having completed Part Two on one questionnaire, it was not necessary to repeat it on subsequent questionnaires. With the health visitors, the situation was reversed. Because supervision by the health visitor ceases at age five in most areas, those with personal knowledge of the case could be contacted in only a few instances, mostly for children in the younger age groups. Thus we had only 33 responses for Part One. However, 97 of the present health visitors were sufficiently interested in the project to complete the second part on general opinions and role perceptions. The full details of the responses are given in Table 1-B.

Chapter Six

TABLE 1-A

Number in the sample

Hounslow	19
Gateshead	14
Hull	45
Nottingham	46
Oxford	23
East Sussex	45
West Suffolk	20
TOTAL	212

TABLE 1-A: showing, the number of mentally handicapped in the sample for each of the seven areas.

TABLE 1-B

Response to questionnaires

	Part One	Part Two (where applicable)	
Case files			211
Parents			204
General practitioners			147
Mental welfare officers	169	44	
Health visitors	33	97	
Training school staff	94	61	

TABLE 1-B: showing, the number of respondents to each of the six questionnaires.

Because we are in effect dealing with nine sub-samples of differing sizes, it would be misleading in many instances to refer to the results in absolute terms. The procedure we will adopt therefore whenever comparisons are made between different questionnaires will be to refer to the result as a proportion or in percentage terms.

Chapter Six

PRELIMINARY ANALYSIS

The questionnaires were designed with the assistance of a largernumber of participants from the areas, and were first tested in the pilot area. When the results became available from the pilot study, the participants in the project were asked to reject information which, in their view, was not highly relevant to the theme of coordination. Not surprisingly, very few items were rejected; it was felt that since it was becoming apparent how complex and inter-related a subject coordination was, as much information as possible was needed to evaluate the existing services. The subsequent analysis of the results from the other six areas confirmed the correctness of this judgment. The pilot study did show up the need to alter the wording of a few questions and this was done. The questionnaires were then administered in the other six areas during the period October 1970 to July 1971.

The results from the pilot area forewarned us of the immense amount of data that would become available. Arrangements were therefore made to conduct a preliminary computer analysis of the answers to each question on the six questionnaires. The initial computer analysis provided us with a simple count of all the answers given to each question asked of a respondent.

This preliminary analysis has enabled us to draw up a profile of the dominant characteristics of the mentally handicapped in our sample and this profile is presented in the next section. Chapter seven briefly outlines some of the other methods employed to analyse the information. The main findings relating to coordination and the provision of services are presented in more detail in chapters eight, nine and ten.

Chapter Six

PROFILE OF THE SAMPLE

The aim of this section is to outline the main characteristics of our sample which ideally should determine both the type of service and the degree of coordination required. In other words, we intend to quantify the parameters essential to describe the services. The major sources of this information have been the parents' and the case files' questionnaires.

AGE AND SEX OF THE HANDICAPPED

The distribution by age and sex is shown in Table II below. It is interesting that there were significantly more males than females in our sample.* We can offer no explanation for this difference. However, we carried out tests for significance on a number of factors to see if sex seemed to have any effect and in all cases, the probability of the result occurring by chance was of the order of five to one or less (that is $p \approx 0.20$). In other words, the sex of the handicapped person does not appear to have been an operative variable and so we can say with confidence that our sample has not been biassed by the fact that we had more males than females in the survey.

TABLE III

NUMBER OF SUBNORMAL IN THE SAMPLE: DISTRIBUTION BY AGE AND SEX

Age group	Male	Female	Total
0 - 4 years	10	7	17
5 - 9 years	18	16	34
10 - 14 years	20	21	41
15 - 19 years	23	17	40
20 - 24 years	28	16	44
25 - 29 years	19	17	36
TOTALS	118	94	212

Source: Case files and parents' questionnaires

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* $X^2 = 4.0$; $P = 0.05$

The age of the child was taken as his or her age on 31 December, 1969. The relatively low figure for the 0 - 4 years age group reflects the fact that not all handicapped children are known to the local authority at this stage and that many are not 'officially' discovered until they begin formal education. Some reduction in the mortality rate of the mentally handicapped over the past three decades seems to be reflected by the 80 cases (2/5 of the sample) in the two older age groups. It is therefore a fair assumption that most cases known to local authorities are going to need a range of services - more extensive than has been called for in the past-during their lifetime.

AGE OF THE PARENTS

The majority of the parents were middle-aged at the time of the survey. A disturbing result because of its implications for the management of the child was the number of parents who are over 60 years old; 12½ per cent of mothers and 23 per cent of fathers.* One of the most common problems faced by the parents as a group was the fear of what would become of the handicapped person when they, the parents, were no longer able to cope because of old age or ill health. At least two of the areas in our survey have been alerted to the problem revealed by these figures and have begun to plan ways of overcoming it. Another implication of this result is the financial burden the care of a handicapped adult must impose at a time when the family income is normally contracting.

AGE OF THE MOTHER AT THE BIRTH OF THE HANDICAPPED CHILD

The distribution of mothers' ages at the birth of their handicapped children is a bimodal distribution; that is, it has two peaks. The first and highest peak comes, as one would expect, in the 20 - 24 years age group (25 per cent of mothers). The second and only slightly lower peak comes in the 35 - 39 years age group (23 per cent of mothers). A further 20 mothers were 40 years or older at the birth of their handicapped children. This result is not altogether surprising because the connection between a late child bearing age and the incidence of subnormality is well documented. However comparison of our result with that of an earlier study[4] suggests that this factor may have been overemphasised as a cause of mental subnormality. In the Tizard and Grad sample, which covered a much wider age range of handicapped people, 32 per cent of the mothers were 40 years or older when they gave birth to the child. In our sample, only 11 per

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* Source: Parents' questionnaire

cent of mothers were in this age group; the difference is statistically highly significant*. The reasons for this difference are not known and, interesting as the search for an explanation may be, are outside the scope of this study. It does have implications however for the planning of residential accommodation.

PARENTS' OCCUPATIONS

The distribution of socio-economic groups in our sample was compared with the national distribution published in the latest edition of "Social Trends".[5] There were no really significant differences, except that there were comparatively fewer junior non-manual workers (eg clerical officers) and personal service workers in our sample. As far as the limitations of our data would allow us to make a comparison, there did not appear to be any significant differences between social classes. As far as confirming or denying the hypothesis that mental handicap is associated more with the lower social classes, our results in this respect are inconclusive.

FAMILY SETTING

Nearly 80 per cent of the handicapped children had both parents alive and living together. Of the remaining 20 per cent, 29 children (14 per cent) were part of one parent families. Moreover, the level of services received by these families was significantly lower than by all other families in our sample. It would appear therefore that from a welfare point of view, one parent families are especially 'at risk'. Another indication of this risk is that there was a higher proportion of lone parent families in our sample than exist in the community at large.** It would appear that the presence of a mentally handicapped child in the family unit places greater strain on marital relations, relationships with other siblings and/or the health of members of the family, which are not always resolved.

FAMILY SIZE AND POSITION OF THE HANDICAPPED IN THE FAMILY

The most common family size in our sample was 3 children with a mean size of 3.4 children. This is slightly higher than the average family size of the population as a whole

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* $X^2 = 20.3$; $p < 0.001$

** Percentage of lone parent families in the community (1966) - 9.1 per cent
Percentage of lone parent families in our sample - 14.2 per cent

although not significantly higher.

The position of the handicapped child in the families in our sample is more interesting. It has often been suggested that the birth of a mentally or physically handicapped child acts as a positive disincentive for the parents to have further children. We found that 43 per cent of the mentally handicapped children in our sample were the youngest born or only children, a figure which would tend to confirm this hypothesis. However, when this result was compared with the Tizard and Grad study mentioned previously, we found that significantly more parents in our survey were having further children.[4] There appears to be a trend therefore for parents of mentally handicapped children to overcome their fears of subsequent offspring being handicapped and thus to have further children. It is possible that the advice of general practitioners and paediatricians in particular is influential in this matter. When parents were asked the question "After the birth of your son/daughter, did you get any advice on having more children ?", thirty parents replied that they were advised to have further children and twenty-one parents that they were told to have no more. The most common providers of this advice were general practitioners and paediatricians. Apart from the disturbing thought that no advice was given or sought for in the great majority of cases, it is important to note that in only 10 of these 51 cases was this advice based on any genetic investigation. Indeed, if this trend for having further children does exist, it has vital implications for the role of genetic counselling facilities. In Chapter Nine, we look a little more fully at the need for genetic counselling.

FAMILY HISTORY

From the case files held by the local authority, we discovered that 28 children (13 per cent) had siblings who were mentally handicapped; 11 children, including some of the above, had a parent (or parents) who were also mentally handicapped. Unfortunately, we have not been able to find any earlier studies with comparable information which would give us a yardstick to measure this result against. These families, faced with a multiple burden, are in need of a great deal of support and assistance. In particular, the need for genetic counselling would appear to be paramount, but regrettably, as far as we could ascertain, not one of them received this service.

Chapter Six

CLASSIFICATION OF DEGREE AND TYPE OF SUBNORMALITY

The 1959 Mental Health Act introduced an administrative division of the mentally handicapped population into two groups, subnormals and severely subnormals. This study includes people from both groups. In our sample, the proportion of subnormals to severely subnormals was, overall, 31 per cent to 69 per cent respectively. However, like all centrally imposed administrative classifications, it tends to be interpreted to suit the particular circumstances of the local authority concerned. It was thus no surprise for us to find that the proportion of handicapped people defined by particular local authorities as severely subnormal ranged from 89 per cent down to 37 per cent. Participants from the seven areas felt that these wide variations in classification serve only to demonstrate that administrative classifications are often meaningless in practice. This general comment was borne out by an examination of the results, which revealed that there were no significant differences between the two groups in the average number of services received, although there were some differences in the type of services offered, such as short term care.

With many mentally handicapped children it is possible to define the handicap by clinical type. For example, the case files revealed that 23 per cent of our sample were mongols. The full details are listed in Table III below.

TABLE III

CLASSIFICATION OF SUBNORMALITY BY CLINICAL TYPE

	per cent
Mongolism	23
Epilepsy	15
Spasticity	9
Congenital abnormalities	8
Hydrocephalics	3
Microcephalics	2
Developmental retardation	2
No specific condition, other than mental handicap reported	41

NOTE: This table adds up to more than 100 per cent because some children were described as exhibiting more than one condition.

Source: 211 case files

It is more than likely that the information in Table III provided by the case files understates the true position because in many cases, the records were incomplete.

Chapter Six

HANDICAPS

The majority of children in our sample were multiply handicapped. Only 7 per cent were completely fit and healthy, 39 per cent had one handicap other than the subnormality itself, and the remaining 54 per cent had a number of additional handicaps, including three children who had six or more handicaps. The incidence of multiple handicap presents the greatest challenge to effective coordination of services, although variance analysis using indices (of which more will be said in the next chapter) showed that the more multiply handicapped children tended to benefit from a greater degree of coordination. It appears that one of the major gaps in coordination involves those children who suffer from only one to three additional handicaps.

Parents reported that many of the handicapped children had problems in performing a reasonable range of tasks. Table IV below lists these ability handicaps and the proportion of children suffering from them.

TABLE IV

ABILITY HANDICAPS

Ability	Percentage of children who had problems with this ability
* Writing	82
* Reading	80
* Understand money	75
Speech	68
* Telling the time	56
Dressing	23
Washing	23
Mobility (does not include children who cannot go out unescorted – 45 per cent)	16
Feeding	14

NOTE: The abilities marked * are to some extent dependent on age; the above figures do not include children who are too young to acquire these abilities.

Source: 204 parents' questionnaires

We do not know how many of these children could acquire these abilities in time and with suitable training. Many of them are severely handicapped by any definition of the term, and it must be recognised that some will never be capable of learning much. However, through the dedicated efforts of staff in many of our training centres, it is coming to be realised just how much can be achieved with these children. With the increase in the number of training centres since the mid 1950s, the major task now would seem to be improvements in coordination to ensure that as many children as possible gain the chance to make some progress, no matter how slight.

EDUCATION AND EMPLOYMENT

The improvement in the provision of special education facilities for the mentally handicapped since the stimulus of the 1959 Mental Health Act is demonstrated by the fact that very few children in our sample have not received some form of special schooling. Approximately 36 per cent of the children first attended a normal school, but within one or two years, most of them were accommodated in a junior training centre. Although we found that some of the older children in the sample did not attend a junior training centre, most of them were subsequently enrolled in an adult training centre.

As far as we could ascertain, 26 handicapped adults were in open employment at the time of the survey, compared with 120 of employable age. The case files revealed that, on the average, those in employment have had two jobs, that the average length of employment was less than one year, that almost all the jobs were unskilled and that the most common reason for leaving a job was because the employer considered the person unsuitable. The people most active in finding employment were the parents (14 known instances) and the youth employment officer (8 instances). We could find no trace of the disablement resettlement officer being active on behalf of the adults in our sample.

CHAPTER SEVEN

HOW THE DATA WAS ANALYSED

The various methods used to analyse the data are discussed in some detail, including statistical analysis, construction of indices, case histories, comments by parents and critical incidents.

Chapter Seven

METHODS OF ANALYSIS

This chapter describes in some detail the methods employed to bring some order into the mass of data gathered from six sets of questionnaires.

The magnitude of the information to be processed presented special problems. For the community sample of 212 children, we have received 922 completed questionnaires from 6 sources of information. Each questionnaire was several pages in length and on average asked 100 questions. It was decided that the use of computer facilities was necessary to overcome this particular problem and so the initial task of sorting and counting all the quantifiable information embodied in the questionnaires was done in this way.

However, we do not pretend that a catalogue of six sets of opinions and data can, in themselves, tell us all there might be to know about the coordination of services. From the beginning of the project, it was agreed that we had to treat each set of questionnaires organically and to reconstruct the history of each child in order to identify where the services failed to do either what they were supposed to do or what they might have done. No computer programme could be written to produce such a narrative. This task was undertaken by some of the staff involved in the interviews and it took two forms; the preparation of narrative case histories covering approximately 10 per cent of the sample and an analysis of the parents' verbal comments. In addition, a new method of constructively analysing 'horror stories' or illuminative incidents was developed. We have found that this multiple approach has provided a rich store of insight and understanding which has already been of benefit to some of the professionals participating in this project.

STATISTICAL ANALYSIS

The first task that had to be performed was a simple count of all the answers given to each question asked of a respondent. This task involved the preparation of coding designs which were required to classify the answers into separate distinguishable categories. Since nearly all the questions were open ended we had to think of coding designs that allowed for every conceivable answer. This task was undertaken after consultation with providers at the 'grass roots' and it produced a greater awareness of just how complex is

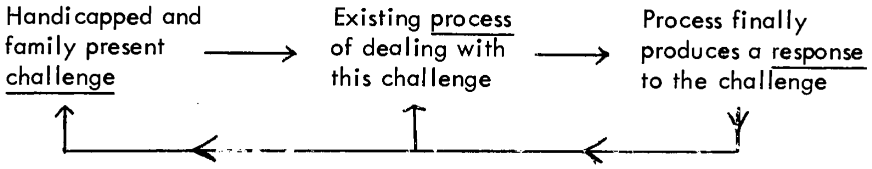
the provision of services for the mentally handicapped. On one variable, alone for instance, the action taken after referral of a handicapped child to a local authority, there are more than 90 possible actions that can take place involving at least 14 separate people or organisations. The data was then coded on to punch cards, a special computer programme was written and the answers to each question sorted out. The end result of this process was the production of 604 tables of selected information which have been distributed to the participating local authorities. These tables have already been used to promote discussion among social workers, health visitors and other providers about gaps in coordination that exist in their particular areas and ways in which coordination can be improved. They have also been used by some training officers to encourage in the new generic social workers a greater awareness of the needs of the mentally handicapped.

A MODEL OF INTERACTION

In Chapter Three we introduced a simple input-output model which the early participants in the project hoped would clarify the relations both of the services to the handicapped and between the various services. When it came to unravelling the mass of information we had collected, we found this model in a modified form to be of great use. We conceived the family and their handicapped child as presenting a <u>challenge</u> to the statutory services and to others. These respond with various services and coordinating functions, this <u>response</u> being partly determined by the existing <u>process</u> of meeting such challenges. Diagram III below summarises this modified model of interaction.

DIAGRAM III

MODIFIED MODEL OF INTERACTION



After further refinement of this model we identified six key variables and we found that the best way to examine their operation was to construct an index for each one, using all our available information.

The six indices are:

(D)	the disability of the handicapped person
(A)	the activity of the parents
(C)	the coordination of the services
(M)	the activity of the mental welfare officers
(S)	the services received by the handicapped
(F)	the satisfaction or fulfillment of the parents

DEFINITION OF THE MODEL AND THE INDICES

Challenge

Index of disability (D):

The handicapped person suffers a degree of disability (D) which can vary, from person to person, by a very wide range. The index of disability includes not only physical handicaps proper, such as deafness or immobility, but also their attendant embarrassments, such as double incontinence or an inability to feed, wash or dress. The source was the parents' questionnaire as it was considered by the participants that they had the best overall fund of information for this index. The degree of mental handicap as defined by the 1959 Mental Health Act was not included for the reasons discussed in the previous chapter.

Index of parental activity (A):

The family, in its trouble, will normally seek help to the limit of its need, motivation and competence, and the activity that it will display in this search will vary greatly from one family to the next. The index of parental activity was constructed by scoring their attempts to contact an official agency or person and all other attempts to seek assistance for themselves and their child. Membership of voluntary organisations was also included.

We suggest that the indices of (D) and (A) form a useful estimate of the challenge made by the family upon the services and we are satisfied that the demand upon the services normally mounts as (D) and (A) also mount. Thus we have taken the sum of our observed indices (D) and (A) as the first input into the model we are using to examine the system.

Process

Index of mental welfare officer's activity (M):

The agents who personify the supporting services, and whom the parents and the handicapped person often meet, can be of a wide variety, from the general practitioner to the consultant paediatrician. We have chosen the mental welfare officer as the key

representative of the services, not only because he was the person who, more often than not, had the most constructive contact with the family, but also because he was the agent of the local authority body, the old mental health department, who had statutory responsibility for the mentally handicapped. The critical function of this officer is twofold: he must help the family directly by his presence among them and he must see himself as an agent who stimulates others within the supporting services. * The index of the mental welfare officer's activity (M) was constructed by scoring each of his activities on behalf of a handicapped child and/or family, his contacts with other agencies and the frequency of his visits to the family. The sources for this index are the case files and the mental welfare officers' questionnaire.

Index of interservice coordination (C):

The quality of cooperation between the various services depends upon the extent and effectiveness of the contacts within the services. With (C) the index of interservice coordination, we attempt to assess the richness of these professional contacts. This index measures all recorded contacts between professionals, whether working within the statutory services or as individuals, such as general practitioners. The case files were used as the source for this index as they are the most comprehensive record of coordinating contacts and because they are in themselves a major tool of coordination.

The combination of these two indices, (M) and (C) can thus be taken as a useful measure of the processes of coordination and generation of statutory services, as these processes are set into motion by each particular challenge of (D) and (A).

Response

Index of services received (S):

The system, that is the totality of services, responds to the family appeal broadly in two ways. It provides observable help to the handicapped person and it gives comfort and encouragement to the family. We have measured this part of the response by our index

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* We did find however, that the mental welfare officer does not always see himself as the person who should stimulate others to action. Health visitors and general practitioners on the other hand did cast him in this role and there is no doubt that there is great potential for the mental welfare officer to be such a catalyst.

those cases where challenge exceeded response on the 'B' Index, the parents were repeatedly making the same sort of verbal comments, which had been faithfully recorded by interviewers completing the parents' questionnaires. Closer analysis suggested that these comments could be reduced to a few memorable phrases which were representative of those problems which were common to this group of families. By using the parents' actual words as slogans, we hope they will remain in the forefront of the mind long after the facts and figures have been stored away and, at the same time, arm the professionals with a guide to spotting those families who see themselves in need of support. The results of this analysis, and the slogans it gave rise to, are discussed in Chapter Ten.

CASE HISTORIES

We have already mentioned the early decision to treat organically each set of questionnaires relating to a particular case in our sample. The impressions given by the parents often form a useful starting point although we soon found that it was necessary to see what the doctor, the mental welfare officer, the health visitor and the training centre teacher had to say about the same handicapped person. By collating fragments of information about the child and also of the system providing care from six independent sources, we were able to construct a methodical narrative of each case. The aim of this is to establish in a clear and simple form all the available facts about each mentally handicapped person's life from birth up to the date of the survey. Particular regard is paid to the services offered to the child or young person and his family and to the coordination between the various statutory and voluntary bodies and the workers involved.

It was our experience that, while the completed narrative was a very instructive guide to what had happened in the past, the maximum value accrued to those engaged in constructing and writing these case histories. In Appendix D, we include the method of preparing them in the hope that they will be used by a variety of professionals to examine their own particular system. Appendix D also includes a few examples of the narratives that arose from this study.

CRITICAL INCIDENTS

When the Research Advisory Group began to consider the magnitude of statistical data

and high (H), corresponding to the first, second and third and fourth quartiles respectively. The raw scores and the corresponding quartile categories for each of the 212 cases were then listed on a master index table. Table V below depicts a sample of this master index.

TABLE V

SAMPLE OF THE MASTER INDEX TABLE

Case No	Age group	Disability index	Parental activity index	MWOs activity index	Interservice co-ordination index	Services received index	Fulfilment index
001	0-4	5L	3LM	7L	7L	11HM	22LM
006	10-14	7LM	7H	20HM	17H	12HM	36H
201	25-29	8LM	1L	7L	8LM	6L	19LM
306	25-29	5L	3LM	6L	8LM	-	-
328	5-9	13H	6H	20HM	18H	12HM	37H
415	10-14	10HM	3LM	14HM	15H	19H	39H
442	15-19	12H	2L	12LM	7L	18H	31H
516	20-24	7L	4HM	6L	1L	6L	23LM
610	15-19	3L	3LM	7L	12LM	6L	11L
626	5-9	13H	7H	17HM	16H	18H	30H
706	15-19	11H	5H	26H	6L	10HM	15L
716	20-24	2L	3LM	8LM	-	12HM	24HM

TABLE V: showing a sample of the master table of the indices used in the analysis of 211 mentally handicapped people.

It quickly became apparent from inspection of this table that there was an underlying pattern. Those cases where there was high parental activity and a high level of disability tended to have high values for all or most of the other indices; similarly, where there was low parental activity and low disability, generally speaking there was low service received, low activity by mental welfare officers and general practitioners, low inter-service coordination, and a low level of satisfaction or fulfilment. To test the significance of this pattern, we held each index in turn constant and measured all other indices against it. This was done by deriving the mean of each of the quartiles of the constant index and comparing the means of the other indices. For ease of comparison, these mean values were standardised.

Chi-square tests of significance were carried out for these variables with highly significant results; there was generally only one chance in a thousand, or often less, of these results occurring by chance. It was these results that led us to formulate a 'Law of Involvement' which will be discussed more fully in Chapter Ten.

If one criterion of a good service is that it gives a lot of help to those who need it most and not so much to those who need it least, there should be a balance between the demand for services (that is, the challenge part of our model) and the resulting supply of services (response). To demonstrate this identity in quantitative terms, we constructed a new index which was derived from the other indices. We called this derived index the Index of Balance, or 'B' Index; the closer the score on this index to zero, the greater the degree of balance between challenge and response. Cases that scored a minus value represented a situation of challenge exceeding response, while positive values represented a situation of response exceeding challenge.

The major function of the 'B' Index was to identify those cases where there was a situation of imbalance. The 'B' Index can therefore be considered as an expression of one of the major advantages of using indices; the ability to isolate and identify those individual cases which run counter to any existing pattern. Using the 'B' Index, for example, we were able to go straight to the particular cases which were radically different from the majority whose scores were grouped around the zero mark. Use of this index not only told us which cases to look at in more detail, but suggested some of the questions we should be asking of each case. If the response is less than challenge, why ? Is it because the services being offered are not adequate for the needs of the handicapped person, and if so, which services are failing to meet which particular needs ? The same process enabled us to identify those cases which were not obeying the law of involvement, the term that we used to describe the general pattern, already mentioned previously, that applied to all the indices taken together. It was at this stage, when we turned to an examination of individual questionnaires concerning particular handicapped children, that we developed another method of analysis.

COMMENTS BY PARENTS

One of the professional participants, a clinical psychologist, noticed that in most of

that was being collected, it became necessary to find ways of not only interpreting the figures but – following the fundamental thesis of the whole project – of linking findings with action. The Group decided that one way of achieving this would be to look at critical incidents where something went disastrously wrong. These would be actual episodes known personally to those recounting them: episodes which affected a mentally handicapped person either directly, or indirectly because the professionals concerned were affected. These would all be incidents which might have been prevented, if .....

Through the efforts of a few active professional participants, mainly in the context of a subnormality hospital, we have been able to develop a method of taking incidents that have actually occurred and using them to constructively analyse the situation.

An important function of these stories was to remind those engaged in the project to focus on three essential aspects: the mentally handicapped individual, the operational situation and the gaps in the service. In other words, to look at the way in which the Law of Involvement is at work: the challenge of the handicapped individual, through his parents (or in hospitals through doctor or nurse) and the response by the services; the coordination between the services; and finally, the way in which feedback from the challengers may improve this coordination.

Later, the incidents began to be used as a teaching device in nurse education by a clinical psychologist and by tutors, and then two other aspects emerged. One was the importance of individual responsibility in ensuring an effective and coordinated service; the other, the equal importance of making certain that the service would continue adequately in the absence of that particular individual, who could not be on the spot at all times for ever more. The phrase was coined: 'the-future-and-somewhere-else-and-the-patient-without-me' to make this forward thinking more vivid.

Finally, in analysing the critical incidents we can begin to identify the need to focus, not on the past – ' who was responsible ?' – but on the future: 'what needs to be done ?' producing a more constructive attitude of mind. In becoming aware of the moment when an incident could have been prevented, in illustrating diagrammatically the drama or the foolishness, the difficulties and the solutions that might have been tried, we are learning in a vivid fashion what to do when similar incidents occur in the future.

of services received (S). It attempts to measure the level of services provided by statutory services and other professionals, as these services are seen by the parents. It includes services provided in connection with diagnosis and assessment, education, short-term care, family planning, practical assistance and the contributions of particular professionals. The parents' questionnaire was chosen as the source of information for this index because it is the most complete source of information and because we were equally interested in taking into account the parents' perception of what services they received. Many other services which the parents would not know about were really coordinating services and these have been included in the index of interservice coordination.

Index of parental satisfaction (F):

The other part of the response is the fulfilment of family needs, usually indicated by a certain degree of satisfaction on the part of the parents. From information supplied by the parents we were able to construct an index of satisfaction or fulfilment (F) from the services received. We have included it in the response part of the model because we feel that it is the best gauge of the comfort and encouragement that has been given the family as a result of the totality of services. It has been constructed from a scale which gave high points to a high level of satisfaction and vice versa. It covers satisfaction with such services as assessment and confirmation, education, access to statutory services and the visits by mental welfare officers.

This refinement of the basic model produced a descriptive language which enabled us to relate the handicapped person and his family to the services in a quantifiable manner. Thus we were able to test and explore these relationships using customary statistical techniques. We have defined and explained this model in some depth because we believe that only by evolving a reasonably reliable way of describing any system can we begin to understand it - and perhaps thereafter to improve it.

USE OF THE INDICES

The initial aim was to find out if there was any underlying pattern between our indices. A frequency distribution was constructed for each index and the four quartiles determined. The raw scores could then be categorised as low (L), low medium (LM), high medium (HM)

When facilities become available for analysing in a similar way the parents' experiences, we shall have a comprehensive vade mecum, a guide to preventive action.

To find a broader formula so that a more positive attitude may be developed in all of us, whatever our profession, is more difficult. One way to generalise is by identifying the typology of these pathological incidents. This will not only encourage the habit of analysing situations before they become disastrous, and so prevent failures in coordination, but the habit itself could become a basis for developing an attitude of personal responsibility for minimising these incidents.

A second way of generalising, from another angle, is to try to develop awareness of the ways in which the roles of various professions concerned with mental handicap are seen, both by themselves and by others.

A third way is to develop awareness of typical job frustrations and see how they are illustrated by the stories since, by recognising the deeper personal problems behind the incidents, we may, again, be able to take preventative action beforehand.

All these attempts to develop constructive thinking will in themselves contribute to a greater involvement of all concerned with the mentally handicapped individual.

Thus from the original idea of looking at specific instances of breakdown in coordination to help make sense of statistics, has developed the wider application of using this as a teaching instrument both for those giving a service to the mentally handicapped and for other students of communication. In the next chapter we will discuss a few of the conclusions that we have been able to draw from those critical incidents that have so far been developed.

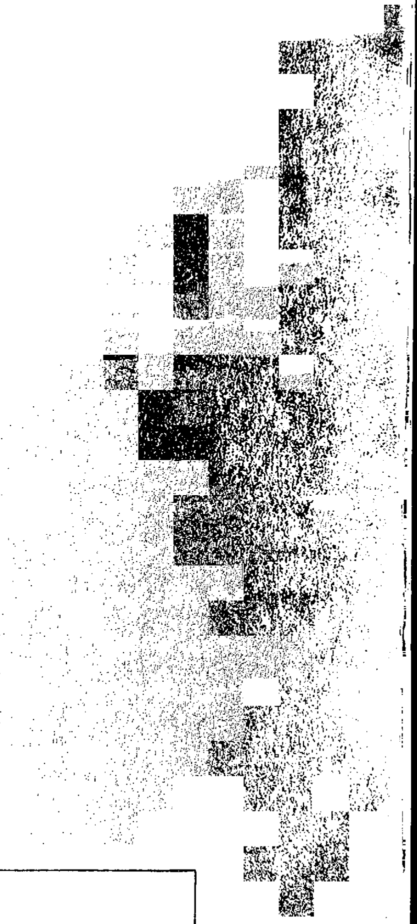
CONCLUSION

In this chapter, we have outlined some of the methods we developed to extract as much information as we could from the facts we had collected. Our prime concern was to suggest forms of analysis to be used by other providers of services, without undue recourse to sophisticated statistical treatments. As in all other aspects of this project, we

endeavoured to make the analysis a continuous exercise in self-motivated and self-directed learning. For some of the participants from the areas, this aim has been achieved, although we would, not unnaturally, have liked to have involved more of them. Nevertheless, we are confident that these methods can be gainfully used in other services and it is primarily for this reason that we have spent some time in describing our analysis.

We believe that only now, after we have developed a language for describing our systems, can we start meaningful exchanges of views and experiences among those who have long been familiar with them at the level of intuition and practical common sense.

CHAPTER EIGHT



CO-ORDINATION AS WE FOUND IT

The pattern of coordination existing at the time of the survey is outlined. Aspects discussed are what happens at the time of suspicion of subnormality, activity by the local authority mental welfare department and the mental welfare officer, and changes in the provision of services over the last thirty years. Some gaps in coordination are pinpointed.

Chapter Eight

THE PATTERN OF CO-ORDINATION

In this country, the past one hundred years has seen local authorities acquire responsibility for a comprehensive pattern of social services. Although the provision of services for the mentally handicapped constitutes only a small proportion of a local authority's social services budget, the number of different agencies involved reflects the complexity of the total system as it now stands. One of the prime aims of this survey was to disentangle the many strands of this complicated pattern in an attempt to discover exactly what constitutes the universe of care for the mentally handicapped. A wide range of different agencies include this disadvantaged group as one of their many responsibilites, while, on the other hand, a few people and organisations see them as their concern. Just how this multitude of agencies interact and combine in common aim, the ameliortation of the lot of mentally handicapped people and their families, was our concern.

With so many people active in providing some kind of service, a high degree of co-ordination is necessary if the common aim is to be achieved. What this co-ordination was, at what level is was operating, who was contacting who and what effect these contacts were having, were the topics that concerned us. In this chapter, we describe the pattern of co-ordination that was operative in the seven research areas during the period of our study. In the next chapter, we analyse the factors that appear to have produced this particular pattern.

Who Was Active in Providing Services

Our first task was to isolate those individuals or agencies who were active in providing a service direct to the handicapped person and / or family or who played a prominent indirect role. It was important to distinguish the active agents who were involved in a large number of cases from those who were only marginally concerned with a few handicapped people. On one particular service for example, advice to parents upon suspicion of the child being mentally subnormal, we found that sixteen different individuals gave advice however, only four out of this group of sixteen, paediatriciians, the local authority medical officer responsible for subnormality, the clinic doctor and a consultant specialist, accounted for more than twenty cases each. The remaining thirteen professionals,

ranging from general practitioners to a medical social worker, offered this service to only a few families.

Our task was complicated by the multiplicity of sources of information. When we arranged the agencies who provided a particular service in rank order, and then compared the rank orders arising from each questionnaire, the all too common result was disagreement on just who it was who provided that particular service. The school doctor, for instance, was ranked first by mental welfare officers as confirming the child's handicap, ranked second by parents and third by the case records. This example illustrates vividly the difficulty of ascertaining the reality of the situation, let alone acheiving effective co-ordination. Parents have to rely on their memory and as many of the relevant events occurred ten or twenty years ago, their recall of what happened may be far from perfect The case records are probably accurate as far as they go although, as we describe in the next chapter, they are all too often incomplete. Mental welfare officers have to reply on a combination of the case records, their memory if they have been acquainted with case for any length of time, and any personal notes they may have retained. However, despite these difficulties, it was possible in all cases to identify the three or four agencies who were most active in providing a service. We reduced the majority of services for the mentally handicapped to sixteen separate activities. We then examined all our sources of information to identify every person who provided some of these sixteen services. Summarising the results of this analysis, there were thirty different agencies and people who had been involved in some way in providing at least one of these services. In addition, there were a further sixteen agencies or people who had some degree of contact with the local authority mental health department concerning the handicapped child or his family. This array of participants reveals what at first sight appears to be an intricate web of relationships. However, from our standpoint of examining the totality of services, it is obvious that not all of these relationships were crucial to improving the overall pattern of co-ordination.

In Table VI, we list the eighteen most active providers of services and show the activities they were most concerned with. It must be stressed that Table VI, does not show _all_ the people who were involved at some stage but only those three or four whose level of activity was such that it was significantly greater than the remainder of professionals concerned with the mentally subnormal. Neither does it illustrate an ideal situation,

TABLE VI

AGENCIES WHO ARE ACTIVE IN PROVIDING SIXTEEN SELECTED SERVICES

Type of Service Required (CHALLENGER)

(RESPONSE) (PROCESS)

Provider of service	1 Who suspected the child's condition	2 Who gave advice upon suspicion of subnormality	3 Who gave advice on having further children	4 Who arranged for child to see a specialist	5 Who notified the local authority	6 Who provides advice and emotional support now	7 Who arranged assessment of IQ	8 Who assessed IQ	9 Who confirmed the handicap	10 Who helped parents in the first three years	11 Who arranged admission to nursery	12 Who helped parents to accept decision on education	13 Who arranged admission to special schooling	14 Who arranged employment	15 Who arranged short term care	16 Provision of education/ training facilities
1 The immediate family	x									x	x			x		
2 Relatives/friends/neighbours						x				x		x				
3 General practitioner	x		x	x		x										
4 MOH or his representative		x					x	x	x			x	x		x	
5 Mental welfare officer						x						x			x	
6 Health visitor					x											
7 Clinic doctor		x														
8 JTC/ATC/ESN school staff																x
9 Local education authority					x		x						x			x
10 Normal school staff	x															
11 School doctor	x			x			x		x							
12 Child guidance clinic/educational psychologist								x								
13 Hospital in which the child was born			x													
14 General hospital - paediatrician		x		x	x											
15 Subnormality hospital - paediatrician		x	x	x	x				x		x					
16 Clinical psychologist								x								
17 Consultant/specialist		x														
18 Youth employment officer														x		

TABLE VI: showing, the agencies who are active in providing sixteen selected services for a sample of 212 mentally handicapped children.

namely what should be happening All it shows is the situation we found to be the case with our sample of 212 mentally handicapped children and adults. Finally, the sixteen selected services then can be and are provided to the mentally handicapped. The basis of selection was the case with which it was possible to tell from the data who was responsible for carrying out a particular role. It does not include, for instance, who was responsible for arranging the supply of physical aids, such as wheelchairs or hearing aids. However, even if we take this limitation into account, we have still encompassed the broad areas of activity that occur at certain stages of the handicapped person's life viz., recognition and assessment, early assistance to the family, education and training, employment and provision of short-term care.

With these qualifications in mind, several inferences can be drawn from Table VI. It is clear that a thread of continuity is provided by one agency and its supporting services, that is, the medical officer of health or his officer responsible for subnormality together with his representative in the field, the mental welfare officer. It is this agency above all others who is active at all stages of the subnormal person's life, from the time it comes to learn of the child's condition, through assessment of the handicap and subsequent provision of educational facilities, to arranging residential accommodation if necessary when the parents are no longer capable of caring for their child. It is here that the case records are kept and maintained and it is clear that it is the focus for administrative co-ordination at least. Taking the organisation of local authority services for the mentally handicapped as they existed prior to the implementation of Seebohm recommendations (which is the period our survey covers), the mental health department, as it was then known, was meant to be the centre of activity and co-ordination. In the seven local authorities of our survey, it carried out this function for the majority of cases. Table VI therefore would be reassuring to those who wish to draw the inference that the system was working as it should, at least as far as the mental health department is concerned. However, what Table VI does not make clear is the absolute level of activity of any one agency. That is to say, it does not show in how many cases the mental health department was <u>not</u> the focus of activity and co-ordination. All we can infer from Table VI is that this agency was one of the most active participants. Later in this chapter we look a little more closely at the level of activity of this central agency.

Some of the other agencies listed in Table VI appear to concentrate their efforts at certain stages of the handicapped persons life. Thus we found that the hospital services, usually in the person of the paediatrician, were prominent during the stages of suspicion of subnormality, referral to other specialists and assessment of the nature and degree of handicap. The general practitioner was similarly prominent at this stage. The agencies concerned with education, especially the school doctor, were important during the period of suspicion for those cases where the handicap was not recognised early in the child's life and then in arranging assessment and confirmation of the handicap. Subsequent to confirmation and notification to the local authority, the mental welfare officers' primary activity appears to be the provision of ongoing advice and emotional support as well as working through his department to arrange various services such as short-term care. Then there are a group of people whose role appears to be limited to one or two activities, such as the clinical psychologist who is concerned with assessment and the youth employment officer who is of some assistance in finding employment for some of the adults in our sample.

If we look at the reverse side ot the picture presented in Table VI, some interesting inferences can be drawn about the agents who are not as active in certain areas, as one might have expected them to be. The health visitor, for instance, does not appear to have been of marked assistance during the first three years of the child's life or to have been an important source of advice to parents. This finding is particularly interesting because the overwhelming majority (93 per cent) of health visitors thought that advice and support to the family was their most important function. Discussions among some of the health visitors participating in this project indicated their genuine concern with the result. It was their belief, however that because of changes in training and role definitions over the past ten years or so, the younger health visitors were more aware of the problems posed by mental handicap. This belief was confirmed by our results which showed that it was the parents of the younger children in our sample who received the most support from this group of professionals. It is clear that general practioners also play a limited but immensly important role. Their activity is concentrated around the early period of suspicion and arranging for assessment. They are also important in the opinion of many parents for the advice and emotional support they provide from time to time. However, beyond this they are not very active at all. We recognise fully that with a total caseload of well over three thousand, most doctors are unlikely to have more than

three or four mentally handicapped patients on their lists. However, from examples of general practitioners actively participating in this project, we know that a general practitioner can play a constructive and powerful role in stimulating other agencies to play their part. Further, if for any reason, local authority services fail to meet the needs of the handicapped and/or the family, the doctor is often the only person to whom the parents can turn for help. The clinic doctors' role turned out to be surprisingly small. Quite a few parents (40 out of 204) said that the clinic doctor was of some assistance although this help was largely confined to emotional support at the time of suspicion of the child being subnormal. He does not appear to have been an important conduit for helping to arrange other services.

In identifying and discussing the activities of various agents in the way we have, our aim has not been to apportion praise or blame about the way they carried out their jobs but merely to examine the extent of the problem in achieving effective co-ordination.

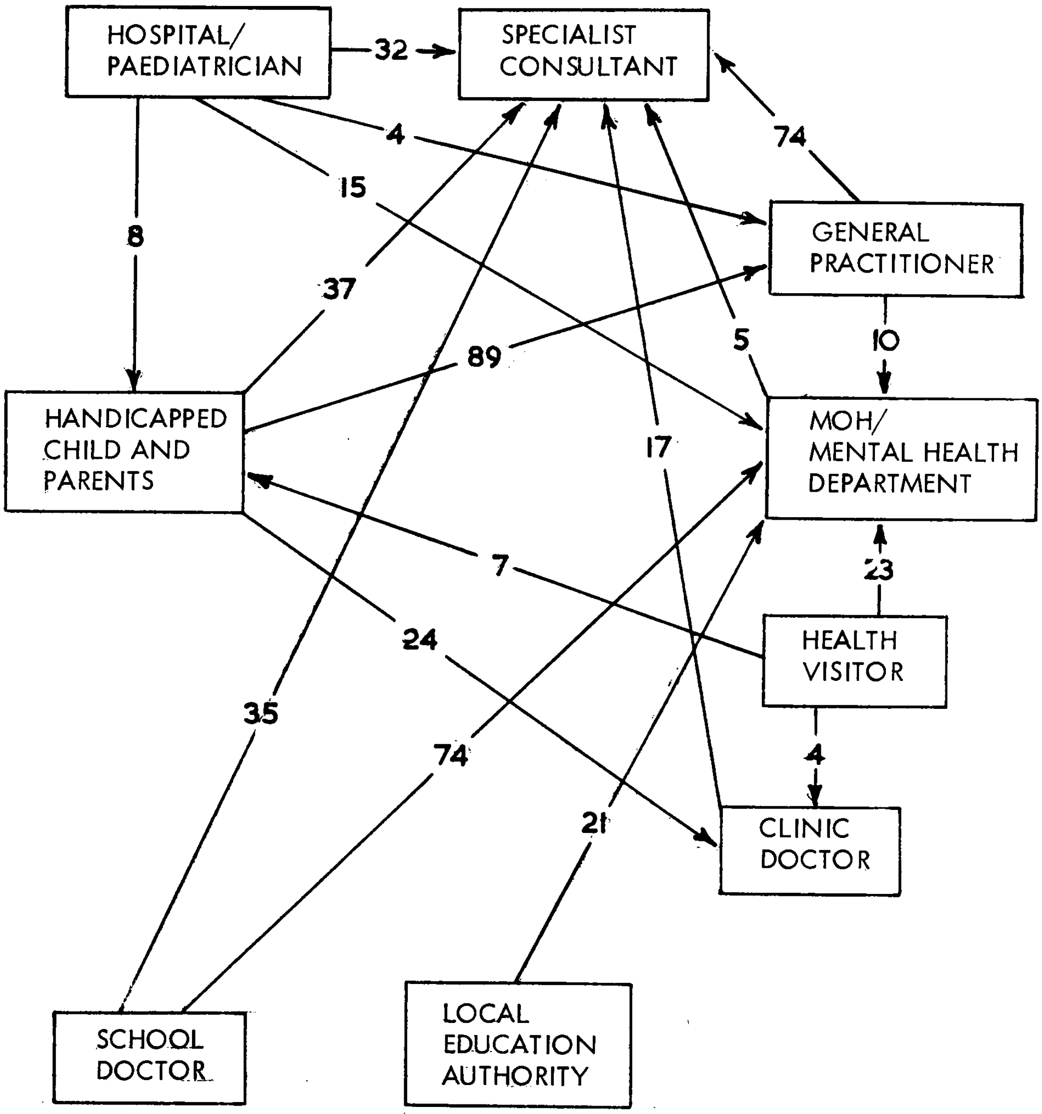
Because, as our results demonstrate, so many people are responsible for providing a service at some time or other, it is not surprising that difficulties will arise in drawing all these disparate elements together into an integrated and co-ordinated program of services. The old adage that too many cooks spoil the broth, has a particular relevance in this respect. The lesson to be drawn is not that the multitude of services now available should be reduced, or even that fewer people should be involved, but rather that more effective means of co-ordinating their activities have to be devised.

Co-ordination at the time of suspicion of subnormality

It was thought by the professional participants in this project that what happens immediately after suspicion of the child being mentally handicapped is crucial in any consideration of co-ordination. The essence of co-ordination is communication. In local authority services this communication mainly takes the form of written requests and acknowledgments, telephone calls and face to face discussion, which taken all together we can call the contacts between various agencies and between the family and these agencies. From the information supplied by parents, mental welfare officers, general practitioners and the case records, we were able to build up a picture of the contacts between agencies at the time of suspicion of subnormality. Diagram IV summarises the situation which as far as we can ascertain, existed for the handicapped people in our sample.

DIAGRAM IV

PATHS OF CONTACT BETWEEN VARIOUS AGENCIES AT THE TIME OF SUSPICION OF SUBNORMALITY



The links between each agency are not indicative of all contacts that occured but only the most frequent ones.

The figures in the diagram refer to the number of handicapped people who were the subject of the particular path of contact.

Source: completed questionnaires from –
204 parents; 147 general practitioners; 169 mental welfare officers and 211 case records

Chapter Eight

The central role of the medical officer of health and the mental health department is manifest, although at this stage, it is not yet a very active role. Most of the incoming contacts to this department are routine notifications of a child at risk or confirmation of subnormality if the condition has already been confirmed. For example, the ninety five contacts by the local education authority and the school doctor are predominantly routine notifications under the 1944 Education Act. However, five cases were recorded as being referred by the medical officer of health to a consultant.

Of more interest are the contacts made by parents and the follow-up contacts between agencies as a result of their initial efforts to seek assistance. An absolute majority of parents who make the first move go first to their family doctor. In most cases, he simply refers the child to a consultant or specialist who is normally a paediatrician at a general hospital or at a nearby subnormality hospital. If we take together the categories of specialist/ consultant and hospital/ paediatrician in Diagram IV, and consider that most of the children in our sample received an initial assessment from these agents, then their potential as catalysts in a chain of co-ordination becomes obvious. It is now only the general practitioner who refers cases to them the school doctor, the clinic doctor, the parents themselves and even the medical officer of health funnel children to them for a first assessment and confirmation of subnormality. Unfortunately, we were able to discover only fifteen recorded contacts going from the hospital/ paediatrician to the mental health department. We are sure that this figure underestimates the true picture and is more a reflection of the inadequacies of many of the case files. Nevertheless, from numerous comments made by professional participants from both the local authority and from the hospital, we seriously doubt if the flow of contacts from the hospitals and consultants equals the flow of contacts into them. In other words, we suggest that the agents responsible for the initial assessment do not always refer the children they confirm as being mentally handicapped on to the local authority or pass on relevant information to other professionals who could be of assistance, such as the family doctor. This situation constitutes one of the major gaps in co-ordination that we have been able to identify. This particular gap in co-ordination can be measureed indirectly in another way. When we compared the age of suspicion given by the parents with the age of referral to the local authority as shown on the case file, we found that at the very least 52 per cent of all children were referred more than two years after the age of suspicion of subnormality. This result takes into account the 22 percent of cases where a precise

Chapter Eight

TABLE VII

COMPARISON OF AGE OR SUSPICION WITH AGE OF REFERRAL TO LOCAL AUTHORITY MENTAL HEALTH DEPARTMENT

Age of suspicion and age of referral	Number	Percentage
Referral within two years of suspicion	38	18
Suspicion at birth but referral between three and four years old	9	4
Suspicion at birth but referral between four and five years old	6	3
Suspicion at birth but referral after age of five	27	13
Suspicion before two years old but referral between four and five years old	11	5
Suspicion before two years old but referral after the age of five	34	16
Suspicion before five years old but referral after the age of ten	21	10
Suspicion after age of five but referral more than two years later	21	10
Suspicion in five to nine age period but referral in ten to fourteen age period- indeterminate results	15	7
Not possible to make a comparison	30	14
	212	110

Table VII comparing the age of suspicion as told by 204 parents with the age of referral to the local authority mental health department according to 211 cases.

comparison was not possible because of incomplete information and the 9 percent of cases where the parents gave a significantly higher age of suspicion than the case file and therefore might be invalidated because of the doubt arising over the accuracy of the parents account. The full results of this comparison are detailed in Table VII above.

The reasons why this gap exists are many and varied, and some of them contribute to making this gloomy picture painted in Table VII a little brighter. We know that parents are the most frequent group to suspect that something is wrong. Most of them (66 per cent) reported initial difficulties in accepting that their child was mentally handicapped and we can only surmise that for many of them, there was a period of growing unease while they nursed their secret fears and worries until they reached the point where the truth could not be avoided. In many cases, this painful period may have lasted more than two years. Now, after the necessary period of adjustment, they can talk about that early period with a great degree of objectivity and pinpoint the age of first suspicion much earlier than previously would have been possible. However, there is no similar explanation for the twenty-seven cases who were suspected at birth but not referred until after they were five years old. This and some of the other categories in Table VII can only really be attributed to failures in co-ordination somewhere along the way. As an example of what this failure can mean in practice, we include one of the case histories prepared by one of the professionals participating in the project.

Case History - Keith

Keith is the eldest of two children. His mother has also had six or seven miscarriages and two stillborn children over the 18 years preceding the survey, but Keith's birth in the mid-1950s followed a normal pregnancy. The records state that Keith was noticed to be handicapped at the time of his birth by the health visitor, and the general practitioner says that he noticed that Keith was twitching and drawing up his legs and did not appear normal at six weeks but his mother reports that Keith's handicap was first drawn to her attention at the local authority welfare clinic when he was 11 months old. Keith showed marked spasticity on his right side and his mother was advised to take him to the local hospital weekly for treatment, Keith was seen, as soon as he was referred, by the hospital consultant and was provided with guiders for his feet and an iron for his right leg. He continued to wear these for a number of years. His parents were satisfied with all the help they had received from the hospital, but did not receive much other help outside the family during Keith's first few years, despite many problems with sleeping, feeding, walking and talking.

His mother reports that the family doctor seemed to be too busy to bother, the chemist never had the tablets he prescribed in stock, the health visitor only made a routine post-natal visit and she had no knowledge of the services of the local authority health department. Their present general practioner reports that he helped with medical needs, such as Keith's recurrent chest infections, but that he considers that the family copes well with his mental and physical handicaps.

Keith was referred to the mental health department when aged six and his parents were told that he would have to attend a special school. Keith was seen by a clinical psychologist at this time and found to have a mental age of less than two and a social age of one and a half. He was considered to be severely subnormal and to be suffering from cerebral palsy, epilepsy and severe speech defect. Keith was tested again when aged seven and eight without recordable results and was eventually sent to the special care unit of the junior training centre when aged nearly nine years. The mental welfare officer visited the family once or twice a year following Keith's referral to the mental health department and was able to help the family with advice on his schooling and clothing and later on how to claim social security benefits. His parents have a very limited income and have difficulty supporting Keith who needs regular new pairs of shoes and who cannot go out any distance without a wheelchair. Keith's mother feels that she would like to be visited more regularly as it helps her to have someone to talk to, but, although the mental welfare office is aware of this, he is unable to visit more often. Keith's mother reports that she has about monthly contact with the parents of other handicapped children when out shopping or at the social club and that she finds this opportunity to talk very helpful. She is unable to attend the meetings of the relevant local voluntary organisation because she cannot arrange a baby sitter for Keith and his small sister and because she lacks the money to join.

Keith's parents were satisified with his care in the junior training centre. When he was 15 he was reassessed and found to have a mental age of three and a social age of 2.8. A decision was made to transfer him to the special care unit of the adult training centre. His mother states that she was satisfied with this decision but the answers to the various questions in the survey reveal some disagreement over the reality of Keith's handicap. There is general agreement that he has a speech defect, but while the mental welfare officer says that it is total, the general practioner says that Keith has a limited

vocabulary and can make himself understood. All except the staff of the training centre are agreed that he is fully continent. The mental welfare, general practitioner and training centre, think that he is not competent to go out by himself but his mother reports that he is able to go out alone in the immediate neighbourhood. The training centre reports that Keith is a slow feeder but his mother claims no problems with feeding. Finally, while all parties report Keith's handicap as cerebral palsy and mostly controlled epilepsy, the training centre states that Keith is an epileptic but that he has no cerebral palsy. The unit instructor further states that they have never asked for a report on the trainee and that they did not hold case conferences.

The confusion over Keith's abilities was confirmed by a training centre instructor, not personally connected with his case, who interviewed his family for the survey. She reported that she observed Keith helping his mother with some simple housework and copying letters and symbols. This suggested to the instructor that he had abilities beyond those of trainees usually found in special care unit and that his potential would be better developed in an ordinary adult training centre. The reasons behind these discrepencies and the decisions which were made about Keith are not clear from the questionnaires, but his mental welfare officer reports that his case file provides insufficient information for him to help the family and he comments that he has too much information to wade through from too many sources to leave time for regular reassessment of his cases.

Keith's story shows that the needs of the family were not always perceived by the professionals, in spite of considerable activity according to their assessment of the situation. Above all, it illustrates lack of co-ordination, not only in the early year that we have been considering but right throughout his life so far.

Activity by the Local Authority Mental Health Department

On a number of occasions in the preceding discussion we have noted the central position of the mental health department and its representative in the field, the mental welfare officer. We therefore turn to a more detailed look at the nature and extent of the role it played in providing services for the 212 mentally handicapped in our survey.

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The mental welfare officer

The most important job of the mental welfare officer is, by definition, to look after the welfare of the handicapped people in his charge and their families. This task is predominantly executed by regular visiting to the family to ascertain their needs and take any remedial action that may be required. 153 parents (76 percent) reported that they were receiving visits from mental welfare officers although the frequency of these visits varied from once a month to once every two or three years. Most parents (116) said that they found these visits useful, chiefly because he was kind and sympathetic, explained what services were available and generally supported them in their problems. Interestingly however, when asked if they thought it would help if the mental welfare officer visited more often, 68 percent of the parents said no. Their reasons were equally divided between a knowledge that they knew where to get in touch with him if ever they needed his assistance, and a feeling that they really did not need his help because they were coping satisfactorily on their own. It appears from the parents replies that, although most parents find regular contact with a mental welfare officer useful, a majority of parents (64 per cent) are not completely staisfied with the extent and nature of these visits. A majority of mental welfare officers (57 per cent) on the other hand considered that the family would not benefit from increased visiting. The most common reason given for this judgment was that the family had no urgent problems and that they were coping well enough on their own. This response may be explained in part by pressure of work. When asked what more could they have done if the pressure of work was not so great, nearly half replied that more frequent visits would be a first priority.

The family are not alone in perceiving the mental welfare officer or his department as being central to satisfying their needs. The mental welfare officer also sees himself or his department as the most important agency able to help the handicapped and his or her family, not only with present problems but also with any future problems that are envisaged. For example, 50 per cent of mental welfare officers consider that they were in a position to help the family with their present problems. The next agency who could have been of assistance was an imprecise 'local authority' (40 per cent) of which they are an intergral part, followed by voluntary organisations(26 per cent).

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Since the mental welfare officer was in regular contact with approximately three quarters of the families in our sample, it could be suggested that he is the logical person to act as the focus for co-ordination of services. In order to explore this potential we included the following question on the mental welfare officers' questionnaire 'There are many voluntary services in the community to help the families of handicapped children. Have you or othermental welfare officers ever been approached by any of these for any help for this family?' The results were quite startling and contary to expectation; 86 per cent of the mental welfare officers replying said that no one had contacted them.* Similarly, when we asked mental welfare officers who they had contacted concerning the family or their handicapped child, 72 per cent replied that they had not approached anyone. The agency which was most prominent in both sets of contacts was the voluntary organisation, an interesting comment on the mental welfare officer's faith in his fellow professionals' ability to be of much assistance. When this particular result was discussed with a number of ex-mental welfare officers (who are all now generic social workers in the wake of the Seebohm reorganisation) there was a certain amount of disbelief that it was an accurate representation of reality. However it must be noted at this point that when mental welfare officers were replying to the questionnaire most of them had the case file at their side. Further, when we look at the various functions that mental welfare officers thought they should be performing, we find that only a minority see themselves as co-ordinators, a finding which reinforces our belief that the mental welfare officer was not in fact the person who saw that the whole range of services available were brought to bear upon the needs of the family and the handicapped. In the next chapter, where we consider some of the factors affecting co-ordination, this area of how the professional providers see their various roles is discussed in greater depth.

One other factor, which was mentioned above and which surely has an important effect on the ability of the mental welfare officer to do his job satisfactorily, is the pressure of work with which he has to cope. It must be remembered that the mental welfare officer was not only responsible for the mentally handicapped; he also had a responsibility to help the mentally ill.

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* These contacts with the mental welfare officer are distinct from contacts with the mental health department which have been recorded separately and are discussed later in this chapter.

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On average, the mental welfare officers in the seven areas of our survey had a caseload of 10 to 20 short-term mentally ill, 10 to 20 long-term mentally ill (that is a total of 20 to 40 mentally ill clients), and a caseload of 40 to 50 mentally handicapped*. This is a prodigious load for any social worker to handle and the unfortunate effect on the oftern time consuming activities of co-ordination can be guessed at.

The Mental Health Department

This agency carried the brunt of administration organisation of services for the mentally subnormal. Its activities impinge upon the whole range of services that may be available. The majority of parents came into direct contact with this department for a whole host of reasons, although there was a heavy concentration of contacts centring on education and training facilities.

The activities of the seven local authority departments in this survey included, in order of importance the visiting function of mental welfare officers admission to training centres of various kinds, (junior training centres, adult training centres, industrial training units) arranging short term care in subnormality hospitals or local authority hostels providing holidays for the handicapped child and sometimes the family as well periodic assessment of the degree of handicap admission to sheltered workshops, and assisting in obtaining employment. They are also responsible for bringing together all these strands of activity into an integrated whold.

We found that one of the most active people in this development was the medical officer of health, or more commonly, the medical officer responsible for subnormality. A majority of parents (55 per cent) reported that they had seen this officer at least once. A host of people, including the parents, arranged these meetings which were mainly around the time of confirmation of subnormality. The purpose of these meetings was to advise the parents on services available, particularly education and training, but they also embraced assessment of the handicap, admission to an institution for short term care and general advice on problems connected with subnormality. Most parents who received advice thought that it had been useful, and were encouraged by the feeling that, for three quarters of them, medical officer of health was easy to contact if help was required.

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* In two areas, the most common case load of mentally handicapped was over 60 cases, while in two other areas, the model case load was 20 to 30 cases.

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TABLE VIII

Agencies/people contacted by the mental health department

Agency or person	Total No. of contacts
The family	143
Training centres or special schools	108
Local authority health department	43
Subnormality hospitals-short term admission	30
General practitioners	25
Clinical psychologist	21
Subnormality hospitals-long term admissions	20
General hospital-Outpatient department	17
Health visitor	17
Voluntary organisations	14
Local education authority	14
Department of Health and Social Security	13
Educational psychologists	13

Agencies/people contacting the mental health department

Agency or person	Total No. of contacts
The family	88
Local education authorities	71
Training centres or special schools	58
Local authority health department	42
Health visitors	21
General hospital, paediatric out-patient department	19
Subnormality hospitals-long term admissions	18
Subnormality hospitals-short term admissions	17
General practitioner	14
General Hospitals-outpatient department	13
Educational psychologist	13
Local churches	13

TABLE VIII showing the agencies and people most frequently contacted by the mental health department and, conversely, contacting mental health, for a sample of 211 mentally handicapped people

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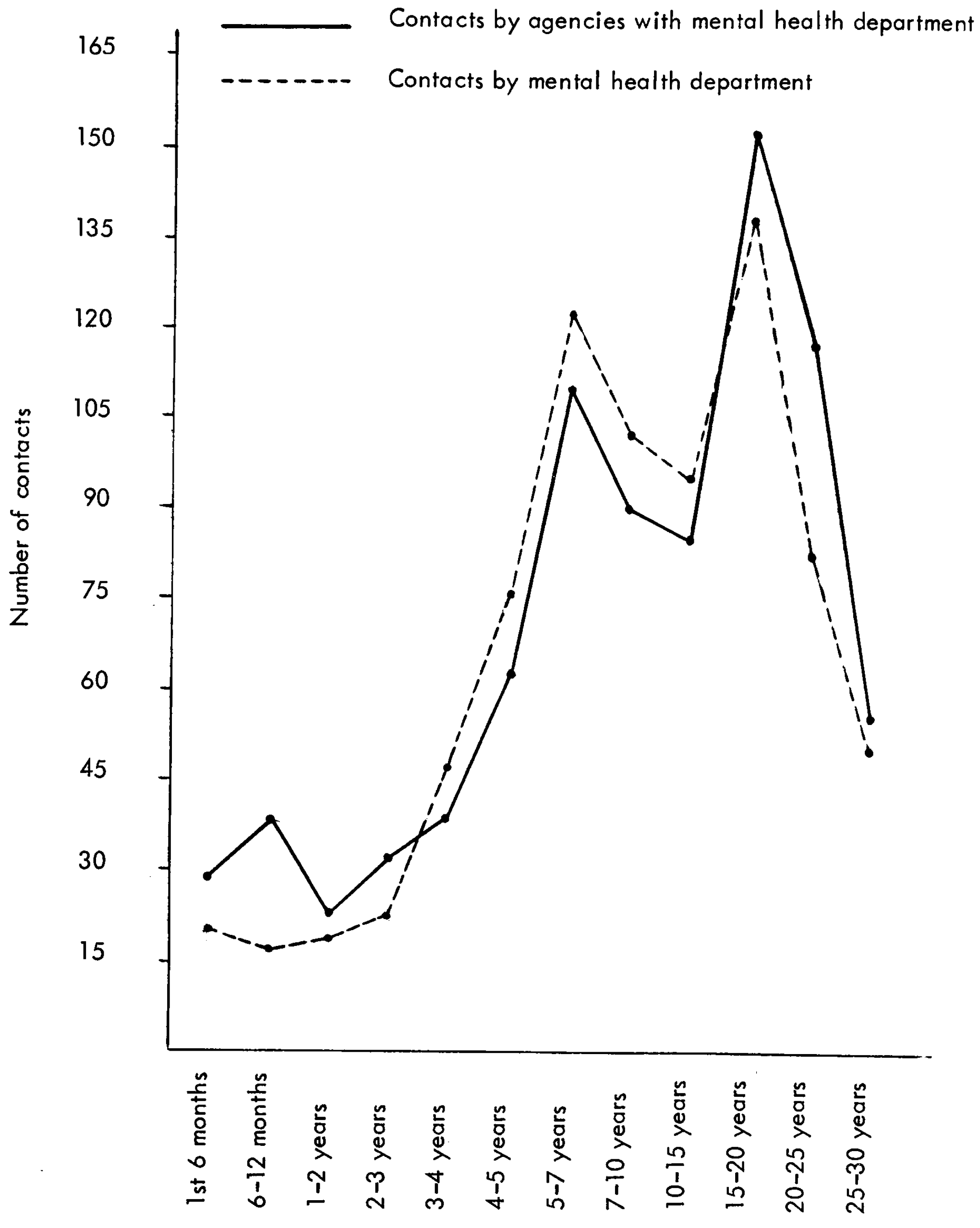
An indication of the part played by the mental health department in co-ordinating the services can be gleaned from the record contained in the case files of contacts between the department and other agencies. Table VIII on the previous page lists the agencies and/or people most frequently contacted by the mental health department and who, in turn, contacted the mental health department. The source for this table are the case files, which, in themselves, are a partial record of all those in authority who have had contact with the child and the contacts between those authorities.

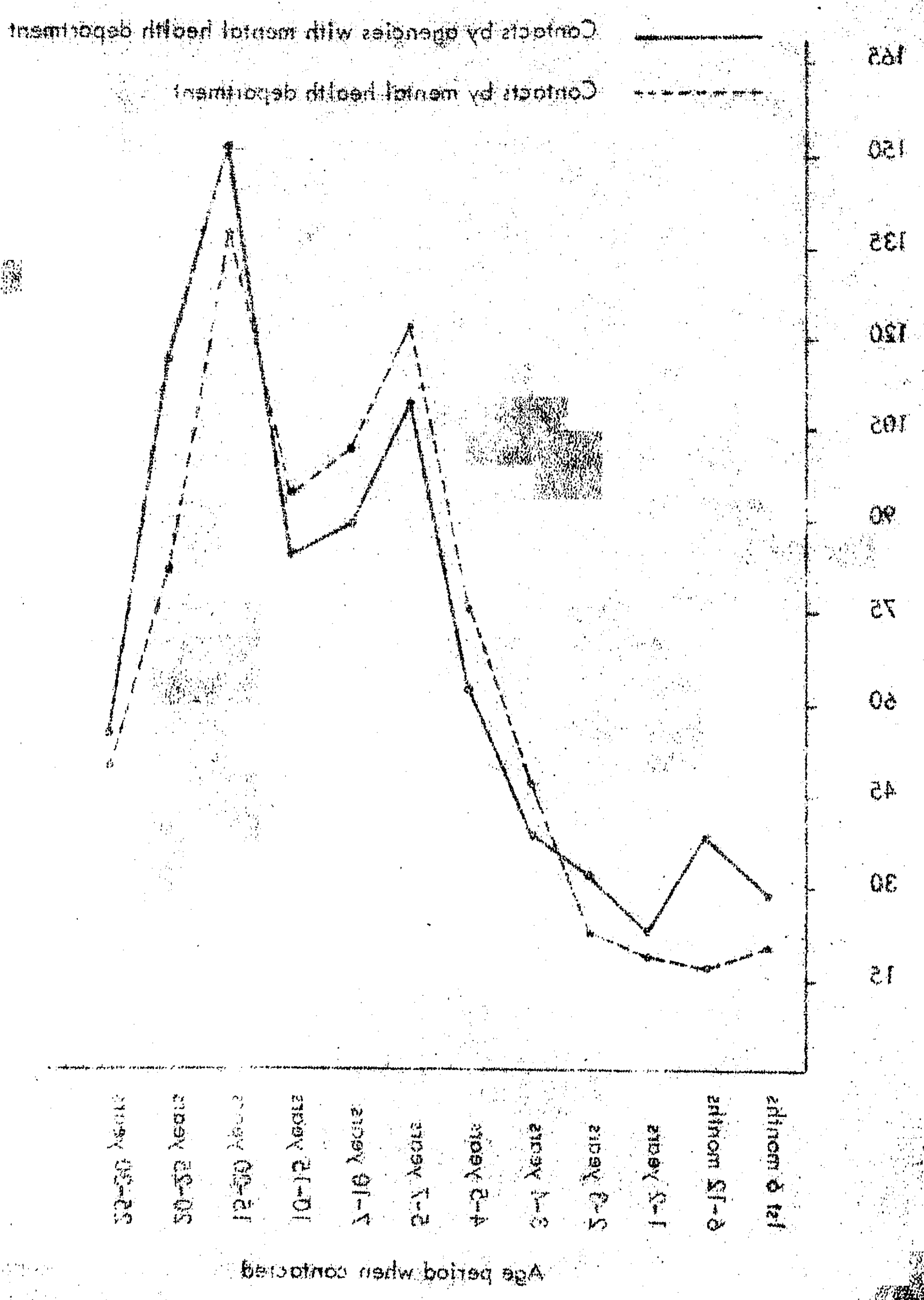
A number of points need to be made about this table. The number of contacts refers to the total number of contacts with or by each agency/person listed for the 211 handicapped in the sample. When one considers that some cases are the subject of more than one contact, the number of handicapped people with whom mental health departments has been involved in some co-ordinating contact is quite low. This result is even more marked if contacts with parents are excluded. Even here, the level of activity has not been very high, for only 105 of the 211 families had any recorded contact by mental health department. (For instance 38 families had two or more contacts). The 13 agencies listed in both halves of Table VIII are not exhaustive, our list details only those agencies with the most frequent contacts. After these most frequent ones came a long list of agencies who had established a few contacts with the mental health department. It includes probation officers, local authorities children's officers, police officers, housing department staff and so on. Further, insofar as we are measuring co-ordination in Table VIII, it is only by recorded contacts, that is, those communications which for one reason or another have found their way onto the case file. Table VIII therefore is as much a comment on the state of record keeping as it is on the level of contacts. Telephone calls, personal visits, notes and messages may not have been recorded on the case file, even although these forms of communication may have been very important in co-ordinating services. Finally, this form of analysis is only numerical, it makes no comment on the quality of the contacts. It goes without saying that co-ordination as measured by inter-service contacts that does not lead in the main to some improvement in the condition of the family or the handicapped is no co-ordination at all.

DIAGRAM V



This diagram depicts the age periods when contacts were made by the mental health department with other agencies and also contacts with mental health department by those agencies, for a sample of 211 mentally handicapped people.

DIAGRAM V



This diagram depicts the age periods when contacts were made by the mental health department with other agencies and also contacts with mental health department by those agencies, for a sample of 211 mentally handicapped people.

An examination of the ages of the handicapped people when these contacts were made is summarised in Diagram V. It demonstrates quite clearly the two peaks of activity at school-going age and school-leaving age. The small increase in activity by people contacting the mental health department during the 6 to 12 months age range, corresponds with the incidence of suspicion and confirmation during this period. We suggest that the period after school-going age should be studied more closely as a number of parents of this older group are already at, or approaching old age, which means, in practical terms, that their need for future support and assistance is now all the greater.

In conclusion, then, we suggest that although the mental welfare officer and his parent department are foremost in co-ordinating services, the perceived level of co-ordination is not all that high, in what co-ordination that was provided by this agency was only effective for a minority of families in the sample. It appears that once a handicapped child has been settled into a particular pattern of services provided, that pattern changes very little over the years. If the needs of the family or the child change in any way, this change is not always perceived and, when it is, the co-ordination necessary to bring about a change in the pattern of services provided is seldom achieved. A comparison is made in the next chapter of the needs of the child and the family with the various kinds of help provided by different agents.

The Pit of Isolation

Above we suggested that there were gaps in the provision of services to the family. Since these gaps occured for most children in the years between birth and the age of five, we believe that this period is absolutely vital for the emotional and psychological well-being of the parents.

We have already noted that there were significant differences between the age of suspicion of subnormality and the age of referral to the local authority mental health department. To recapitulate the relevant sections of Table VII. 37 per cent of the children were suspected before the age of two but not referred to the local authority until they had attained the age of four. Since the provision of a number of services, from a place in a nursery to the supply of physical aids, often depends upon prior notification to the local authority, the time differential between suspicion and subnormality can often mean the failure of vital services to reach those who are at a stage when they may desperately need them. This situation expecially applies to the provision of skilled social work

assistance by the mental welfare officer. The realisation, or even the suspicion, that one has a mentally handicapped child can be a psychologically traumatic experience that seldom fails to leave its mark. The strains this situation creates on the family unit can be destructive to marital relations and bring about all manner of emotional problems for other children in the family. The period of adjustment can be protracted, if indeed the parents ever learn to adjust at all. The mental welfare officer reported that at least a third of the parents had initial difficulties in accepting the handicap and that approximately 15 per cent still cannot completely accept it.

It is during this very difficult period that parents need most of all the advice and emotional support that a skilled social worker with experience of the mentally handicapped can provide. To have togo through this period without any advice at all, relying only on their own inner reserves of courage, must be an almost unendurable burden for many parents. It therefore came as a shock to the professionals involved in this subject to find that fully one half of the parents claimed that no-one at all helped them during the first three years of the child's life. We asked parents the question (Who helped you most in respect of the care of the child during the first three years?) the results are tabulated in Table IX below.

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TABLE IX

PEOPLE WHO WERE SEEN TO HAVE HELPED THE PARENTS DURING THE FIRST THREE YEARS OF THE CHILD'S LIFE

Person or agency who helped	No. of parents who received help from this source
Nobody helped	102
Other members of the immediate family	35
Grandparents	28
Relatives, friends, neighbours	9
Voluntary organisations	1
General practitioners	13
Health visitors	11
Clinic doctors	5
Mental health department	1
Other official persons or agencies but not clear exactly who it was	14
No reply to this question	21

Table IX showing the people and/or agencies seen to have helped the parents of the sample of 204 mentally handicapped children during the first three years of the childs life.

It is important that we first put Table IX into perspective. The figure of 102 parents saying that nobody helped them during the first three years does not necessarily mean that 102 parents needed help. If the handicap had not been suspected by the age of three, one would not expect any official help specifically directed to the problem of subnormality to be provided. Of our sample of 204 parents, approximately one third had not suspected their children of being mentally handicapped by this age. On the other hand, handicapped children nearly always exhibit developmental problems and irregularities during the first three years although subnormality itself may not be suspected. Thus only 17 parents could report that their children had no developmental problems at all during these years. The conclusion that a serious gap exists is inescapable.

We find Table IX disturbing for two reasons. First, there appears to be a pit of isolation that a large number of parents have, willy nilly, fallen into. Although the picture may not really be as black as it appears, the fact that so many parents see themselves in such a pit is disturbing. Second, the relatively low figures for official agencies who were able to be of assistance suggests that with the system of care as it is presently structured, the statutory services may not be capable of meeting the needs of parents during this early period.

We have other evidence to support our assertion that a pit of isolation exists. The parents of the children who were in the 1 to 4 group at the time of the survey were the most dissatisfied with the services they were receiving when compared with the parents of the children in the other five age groups. Further, they tend to receive proportionally fewer services than the families of older children (although this may be explained by the fact that a narrower range of services are available for the mentally handicapped in their early years).

Finally, in the chapter on methods of analysis we mentioned that one of the indices we constructed was the Balance or 'B' index. The 'B' index, it will be remembered, measured the degree of equilibrium between the challenge imposed on the system by

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Finally, in the chapter on methods of analysis we mentioned that one of the indices constructed was the Balance or 'B' index. The 'B' index, it will be remembered, measured the degree of equilibrium between the challenge imposed on the system by the child's level of disability and the parental activity on the one hand (D plus A) and the response of the system represented by the services provided and the level of parental fulfilment (S plus F). Having arrived at a figure on the Balance index for each child in our sample, we divided our sample of 204 cases* according to the age of the handicapped persons and calculated the average values of these residuals. The average values by age groups of the differences between challenge and response are given in Table X.

TABLE X

Age group	-0-4	5-9	10-14	15-19	20-24	25-29
	+0.214	-0.971	+0.564	+0.525	+0.1.238	+0.91.2

Average value of (D + A) - (S + F)

TABLE X: showing, the range in average differences between challenge and response during the early life of 204 subnormal children.

There is, from the most casual inspection of Table X, no mistaking in the 5 to 9 age group, the low value of the residuals we are trying to measure.** It would seem that

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* Our sample is reduced to 204 because the index of parent activity was confined to the total of 204 parents responding to our questionnaire.

** The result is significant at 2 per cent x = 2.30 for 202 degrees of freedom using a test of significance of the difference between the means of the 5-9 responses and those of the others.

the children who were in this age group at the time of the survey were faced with a pit of isolation similar to the one we had already described for the younger age period. Our hypothesis would be that the pit of isolation faced by most parents during the early years of the child's life all too often carries on over into the school-going period and it is during these latter years in particular that the family begins to encounter with unendurable force the bewildering and unexpected cruelties by which society proclaims the family to be different.

In conclusion then, the average family in our sample seems at first sight obliged to cross a pit during at least the first five years of its child's life. From a reading of the verbal comments of the parents' experiences during this period, the trials and tribulations they faced, all too often unaided, has left an indelible impression on their attitude towards the services nominally responsible for their succour. We should endeavour to discover why some manage to cross the pit without further observable harm, while other families are plunged into still deeper abysms of misery.

Changes in the Provision of Services over the last Thirty Years

One of the interesting features of this survey is that it covers a wide age range of handicapped people and so it is therefore looking at events which go back as far as 1940. The spread of ages has enabled us to compare the services from one five year period to the next and determine what changes, if any, have occurred.

With the questionnaires administered to the case files, we had grouped all the services the family and the child had received into five year periods. For example, we coded all the services the family received during the first five years of the child's life, during the next five years, and so on up till the present age of the child. By comparing the results of that sort with the age of the child, we were able to tell what services had been provided for each five year period from 1940 up till 1969,

the year in which the case records were examined.

We found that there has been a gradual but steady increase in the average number of services provided to both the handicapped people and their families. In 1940 to 1944, the average number of services provided to each child (as recorded on the case file) was 0.86 services, by 1960-64 it had risen to 2.15 services, and then fallen slightly to 2.08 services in 1965-70. A similar result was obtained for services to the family.

The overall increase in the provision of services marks expansion and contraction of certain services. As regards services for the handicapped child, the most dramatic increase has been in the field of education and training and the various services associated with it. Provision of short-term care has also been expanded. The figures show a marked discontinuity after 1954 and we can probably attribute this to the influence of the 1959 Mental Health Act which gave local authorities new responsibilities in this field. Many of the changes that the 1959 Act hoped to precipitate were already beginning to appear well before it became law and in many ways, this legislative measure was only a legitimation of a process of change that had already begun. Our figures certainly confirm this belief.

Assessment of IQ mental age tended to remain fairly constant over the 30 year period under review, while admissions to ESN schools declined.

As far as services to the family are concerned, there was a marked increase in supervision of families by a mental welfare officer. Advice to parents on the educational prospects of their child also increased, although this activity probably reflected the growing availability of places in training centres. While advice on financial matters increased, general help and support with the day to day care and management of the handicapped child remained constant.

If one were to speak to a group of professionals in the field of mental handicap, most of them say that facilities for the subnormal population have improved immensely the year in which the case records were [illegible]

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If one were to speak to a group of professionals in the field of mental handicap, most of them say that facilities for the subnormal population have improved immensely over the last fifteen years. We would not disagree with that judgment although we would add the qualification that this improvement has been confined to a few areas of activity, chiefly educational and training facilities and places in residential accommodation.

In this chapter we have examined some of the findings from this project which give us a picture, albeit somewhat shadowy, of the pattern of coordination existing in the seven local authorities. We have shown that the variability from case to case in the coordination of services for the mentally handicapped is great indeed. In the next chapter 'Factors Affecting Coordination' we discuss a few of the myriad of determinants that have contributed to this situation.

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In this chapter we have examined some of the findings from this project which give us a picture, albeit somewhat shadowy, of the pattern of coordination existing in the seven local authorities. We have shown that the variability from case to case in the coordination of services for the mentally handicapped is great indeed. In the next chapter 'Factors Affecting Coordination' we discuss a few of the myriad of determinants that have contributed to this situation.

CHAPTER NINE

SOME FACTORS AFFECTING COORDINATION

Some of the factors that appeared to be producing a particular pattern of coordination are highlighted. In particular, the use of case files, perceptions of the needs of the handicapped person, and perceptions of the roles of certain providers of services, are examined. The role of genetic counselling as it applies to this sample is also discussed.

a complete list of the items used in this index). The scores on this index ranged from one file with no items missing to three files with 26 items missing. Although the mean number of items absent was only eight, the most common number of items lacking was 19; in other words, the relatively low mean score was because a comparatively few files were very complete while the great majority were deficient in 12 or more categories of essential information.

The items that tended to be most faithfully recorded were details of family composition, education and training, assessment of IQ/mental age, employment, and the kinds of services provided at various times throughout the handicapped person's life. Items that were poorly recorded were the state of the parents' health, the mother's prenatal and postnatal history, and the child's developmental milestones. These, however, are only the extremes. Within these limits, categories of information that might be judged necessary for coordination exhibited the same variability as the other categories of information. Table XI below lists a few of what we might call coordinating items of information and the percentage of files on which they did not appear.

TABLE XI

ITEMS OF COORDINATING INFORMATION
PRESENT ON OFFICIAL CASE FILES

Category of information	Percentage of case files on which this item did not appear
Name of present general practitioner	46 %
Persons who suspected subnormality	46 %
Persons who made assessment of degree of handicap	20 %
Details of family history	21 %
Details of problems faced by the handicapped child and the family at present	32 %
Details of who has contacted the mental health department in the past	5 %
Details of who the mental health department has contacted	4 %

TABLE XI: showing, the percentage of case files on which selected categories of coordinating information does not appear.
Source: 211 case files.

Chapter Nine

SOME FACTORS AFFECTING COORDINATION

In the preceding chapter we attempted to unravel some of the strands from a complex web of actions, contacts, activities and various services in order to establish what had been the prevailing pattern of coordination for the thirty year period covered, to some extent, by this survey. In this chapter, we endeavour to delve a little deeper to disentangle cause from effect, by outlining some of the factors that appeared to us to be affecting the coordination of services. Briefly, in order of discussion, we look at the official case records, at the provider's perceptions of the needs of the family and their own professional roles, and, finally, at the degree of understanding of one particular service.

The official files

One can consider the handicapped person to be at the centre of a social microcosm that moves with its own characteristic rhythm; its observable activities and communications advance at a common speed and with a common intensity; each microcosm is throughout and in its own way active or torpid, rich or feeble, controlled or aimless. This impressed character is reflected by the Law of Involvement. One observable characteristic of this little universe is the file kept at the office of the local authority. If this file is rich and accurate, informative and accessible, we may assert that the officers who use these records will be immeasurably assisted by the element of continuity it can provide in assessing the progress, or stagnation, of each child and his family. In this age of increasing job mobility - a feature of our technological society to which professionals in the health service are as prone as anybody else - any device that provides an uninterrupted record of what has gone before is of great value. An indication of the necessity for a continuing record that is full, accurate and up-to-date is the fact that more than half the mental welfare officers replying to the survey had served less than five years in their present local authority.

An examination of the case files revealed enormous differences from one file to another, not only in the quantity of information present, but also in the categories of information recorded, not only between local authorities, but also within the same area. An index of case record completeness was constructed from a list of forty categories of information considered by participants in the project to be of prime importance (see Appendix F for

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The details of contacts to and by the local authority mental health department, which at first sight would appear to have been well recorded, should be treated with caution was we have no way to telling if all contacts have been recorded. Although only 4 per cent of case files have no record at all of who, if anyone, the mental health department contacted concerning the child, we are certain that for most children, the case records indicate only a fraction of the coordinating activity that has occurred.

If we, who have invested a great deal of time and effort and consulted many sources of information, have encountered immense difficulties in reconstructing the complex history of each handicapped child in all its richness, how much more difficult must it be for isolated workers in the social services who have neither the time or the range of information that we had at our disposal ? To someone newly charged with the responsibility of providing a particular service to a mentally handicapped child, the case file is inevitably the starting point from which he must glean the essential pathology of the situation. No formal, written record can ever replace personal contact with the child or its family, nor is it meant to, but it should be capable of not only indicating the relevant past, but providing clues for future action and forewarning of problems to come. Our investigations give us cause to doubt that this potential is being realised.

Perception of the needs of the handicapped child and its family

The aim of any improvement in coordination is an increase in the quantity and quality of services provided for the care of the handicapped child and maintenance of the family. Moreover, improved coordination should lead to a better matching of available services with the real requirements, expressed or unexpressed, of these people in need. However, what happens when the needs of the family and their handicapped child, as perceived by the parents, differ from the way in which the providers of services perceive what is required ? Obviously, one of two situations may well result. The family may find themselves the attention of services which, although not unwelcome, fail to meet what appears to them to be their most pressing needs; alternatively, the official and unofficial services may fail to perceive any need at all, and secure in the belief that all is well, ignore a situation that may suddenly erupt in a crisis.

On the questionnaires administered to general practitioners, mental welfare officers and health visitors, we asked the question, 'What help does the handicapped child need

The [illegible] of contacts to and by the local authority mental health department, [illegible] of [illegible] would appear to have been well recorded, should be treated with [illegible] we have no way of telling if all contacts have been recorded. Although only 4 per cent of case files have no record of all of who, if anyone, the mental health department contacted concerning the child, we are certain that for each child the case records indicate only a fraction of the coordinating activity that has occurred.

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[illegible] the needs of the handicapped child and its family

The [illegible] any improvement in coordination is an increase [illegible] equality of services provided for the care of the handicapped child and [illegible] of the family. Moreover, [illegible] coordination should [illegible] a better [illegible] services [illegible] requirements, a [illegible] of [illegible]. However, what [illegible] the needs of the family [illegible] by the [illegible] the way in which the provision of [illegible]. Obviously, one of [illegible] situations may well [illegible] themselves the attention of [illegible] which, although not unwelcome, fail to [illegible] appears to them to be their [illegible] needs. Alternatively, the official [illegible] services may [illegible] and secure in the belief that [illegible] a situation that may suddenly erupt in a crisis.

On the questionnaires administered to general practitioners, mental welfare officers [illegible] health visitors, we asked the question, "What help does the handicapped child need because of his/her handicap ?' A similar question was asked of the parents. Comparison of ths results showed wide divergences between the four groups of respondents, apparently due to the different functions and interests of each of them. For instance, general practitioners considered that general medical care was the most important requirement but that many children were in no particular need of any help. Mental welfare officers on the other hand saw the provision of suitable education and training as the prime requisite. Parents took a different position again, with the provision of holidays, clubs, leisure time activities, and other measures to break down the social isolation of the handicapped person, being first on their list of services needed.

A similar question was asked concerning the needs of the family, as distinct from those of their handicapped child. A similar divergence of opinions was present, although not quite as marked as before. The mental welfare officers thought that general support and advice to the family about the many difficulties of coping with a subnormal child was what was most needed. The general practitioners tended to agree with them, although it must be noted that more than two thirds of the doctors were of the opinion that no help was needed at all. Parents on the other hand were more concerned about their isolation from normal social contacts and the immense strain the almost total commitment to a handicapped child calls for.

The preceding paragraphs, however, are merely general impressions culled from the total picture. As is so often the case with social data, the real lessons are to be learned from individual cases. What we did was to compare the parents' statement of what their pressing needs were, and the needs of their child, with what the mental welfare officer perceived their needs to be. The differences in perception that appeared were then classified into four types of disagreements. We can see from Table XIIbelow, which summarises this analysis, that out of 136 children where it was possible to make a comparison between the opinions of parents and mental welfare officers, there was at least some disagreement as to what was required in the majority of cases.

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TABLE XII

COMPARISON OF THE PERCEPTIONS OF PARENTS AND OF MENTAL WELFARE OFFICERS OF THE NEEDS OF HANDICAPPED CHILDREN AND THEIR FAMILIES

Category	Number of cases
Agreement on the needs of the child	43
Agreement on the needs of the family	21
Type 1 - disagreement on the needs of the child	45
Type 2 - disagreement on the needs of the family	29
Type 3 - parents state nothing is required, MWO says otherwise	32
Type 4 - MWO states nothing is required, parents say otherwise	16
Not possible to make a comparison	76
Number of cases compared	136

TABLE XII: showing, a comparison of the perception of the needs of 136 handicapped children and their families by parents and mental welfare officers.

One must be careful about drawing any conclusions about the effectiveness of mental welfare officers from Table XII, and anyway, this is not our intention. The lesson to be drawn from these figures is that where perceptions of the same situation differ so much, not only will coordination of services be more difficult to achieve but the relationship between parent and professional may well be, in some cases at least, on shifting ground. Mental welfare officers participating in this project by conducting some of the interviews with the parents were quite shaken to realise that some of the families they had been regularly visiting for years viewed things in a way totally different to the way they, the mental welfare officers, had previously supposed. It was only through the opportunity that this project presented to delve a little more deeply, that a process of self-learning and restructuring of old assumptions was initiated.

We may draw a further example of differences in perception or knowledge, one that has perhaps greater relevance to our theme of coordination. Basic to the provision of any pattern of coordinated services is an agreed understanding of the extent of the child's handicaps, especially his physical ones. We compared the assessments made by

TABLE XII

COMPARISON OF THE PERCEPTIONS OF PARENTS AND OF MENTAL WELFARE OFFICERS OF THE NEEDS OF HANDICAPPED CHILDREN AND THEIR FAMILIES

Category	Number of cases
Agreement on the needs of the child	[illegible]
Agreement on the **needs** of the family	[illegible]
Type 1 - **disagreement** on the needs of the child	[illegible]
Type 2 - **disagreement** on the needs of the family	[illegible]
Type 3 - parents state [illegible] is required, MWO says [illegible]	[illegible]
Type 4 - MWO states nothing is required, parents say [illegible]	[illegible]
Not possible to make a comparison	[illegible]
Number of **cases** compared	[illegible]

TABLE XII: showing a comparison of the perception of the needs of [illegible] children and their families by parents and mental welfare officers.

One must be careful about drawing any conclusions about the effectiveness of mental welfare officers from Table XII, and anyway this is not our intention. [illegible] drawn from these figures is that where perceptions of [illegible] not only will coordination of services be more [illegible] between parent and professional may well be, in some cases at least, [illegible] Mental welfare officers participating in this project by conducting [illegible] interviews with the parents were quite shaken to realise that some of the families they had been regularly visiting for years viewed things in a way totally different to the way they, the mental welfare officers, had previously supposed. It was only through the opportunity that this project presented to delve a little more deeply, that a process of self-examining and restructuring of old assumptions was initiated.

We [illegible] a further example of differences in perception or knowledge, and their [illegible] has particular relevance to our theme of coordination. Basic to the provision of any [illegible] wanted services is an agreed understanding of the extent of the child's handicap, especially his physical ones. We compared the assessments made by general practitioners, health visitors and mental welfare officers of the extent of four physical disabilities present in our sample of mentally handicapped children. The disabilities compared for each child were speech, eyesight, incontinence and mobility. In addition we also compared their assessment of the child's state of general health. In Table XIII we set out the overall level of agreement that we found to be the case from this comparison.

TABLE XIII

COMPARISON OF PERCEPTION OF PHYSICAL HANDICAPS

Level of disagreement		
- on one handicap	46	22 %
- on two handicaps	24	11 %
- on three handicaps	7	3 %
Complete agreement	54	25 %
Not possible to make a comparison	81	39 %

TABLE XIII: showing, a comparison of certain physical handicaps as seen by 169 mental welfare officers, 147 general practitioners and 33 health visitors.

Table XIII suggests that there is some difficulty on agreeing on basic facts like the extent of physical disabilities. The reality behind this table, however, is somewhat more complex than a simple failure to agree what is wrong or not wrong with the child. For a start, the health visitors replying to our questionnaire about individual children were nearly all concerned with the younger children in our survey, and since many physical conditions associated with subnormality do not deteriorate until later in the child's life, she may become aware only at the onset of later difficulties. Conversely, some disabilities, notably mobility, improve over the years. If we recognise the parents as the most reliable judges of a child's present state of physical handicap, we find that mental welfare officers are the closest to the parents' assessment of the child's conditions. This is no doubt because they are normally in periodic contact with the family, although, as we have noted previously, some of these visits are few and far between. If the handicapped child's general health is good there is often little contact with the family doctor and so, in many cases, his understanding is limited and often out-of-date.

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Although all of these qualifications may help to explain the results given in Table XIII, they do not minimise the importance of this apparent lack of knowledge for effective coordination. Taken together, these two sets of perceptions, those relating to the needs of the child and the family and those relating to the extent of physical handicap, constitute one of the most important factors affecting coordination. Knowledge is a necessary prerequisite for any activity, but especially for coordination which is nothing more than the transfer of information in such a way that the appropriate activity follows. However, since the person who is responsible for providing the desired service will adjust his activities in the light of his understanding of the situation, it is imperative that the information supposedly common to all agents in the equation be reasonably accurate and agreed.

Perception of professional roles *

Our perception of the facts surrounding an individual situation may determine our set of actions pertaining to that situation, and even to other situations similar in structure, but is unlikely to affect our attitude and approach to our vocation and relationships with other vocations in an integrated environment. However, how we see the purpose of our job, that is, perception of our own role, and the roles of others who impinge upon our professional universe, is of cardinal importance to our total pattern of behaviour in any situation. It was in order to explore these concepts that we asked the providers of services to define not only their own role in relation to the handicapped person and his family, but also the roles of his professional colleagues. We found that the easiest way to simplify the many roles mentioned in reply was to divide them into professional and coordinating roles. A professional role, for instance, was giving advice to the family on how to cope with the many problems associated with subnormality and, in the case of the general practitioner, the actual treatment of its attendant conditions; coordinating roles mostly consisted in arranging for the provision of some particular service or contacting the relevant agency responsible for providing it. In Table XIV we list the responses of mental welfare officers, general practitioners, health visitors and parents to the questions on the roles of four providers of services, the answers being divided into our two categories of professional and coordinating roles.

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* A further dimension of this aspect has already been discussed by Professor Revans in his foreword.

TABLE XIV

PERCEPTION OF THE PROFESSIONAL VERSUS COORDINATING ROLES OF VARIOUS PROVIDERS OF SERVICES AS SEEN BY THEMSELVES AND BY PARENTS

P = Professional role
C = Coordinating role

	Role of MWO		Role of GP		Role of HV		Role of MOH	
	P	C	P	C	P	C	P	C
Opinion of MWO	42	25	56	14	45	12	15	33
Opinion of GP	52	50	104	50	109	42	13	98
Opinion of HV	74	111	134	44	126	70	27	147
Opinion of parents	129	61	127	16	-	* -	48	63

TABLE XIV: showing, how the providers of services see their professional versus their coordinating roles.

Interpretative note: The important thing to note in this table is not the absolute figures but the ratio between the professional and coordinating roles in each box.

The first thing to note from this table is that everybody sees the local authority medical offer of health (or his officer in charge of subnormality) as primarily a coordinator. Most parents go to him, not so much to seek advice (although that is still a vital function), but to arrange for some service such as schooling or short term care. The people most concerned with providing services for the mentally handicapped living in the community also see him in this light. But this is not surprising. He is (or was) the nominal (or active) head of the local authority organisation whose primary task was to be the focus of statutory services for the subnormal population. It would be surprising if people did not see coordination as his principal role.

Then there is the question of the ambivalent position of the mental welfare officer. Family doctors and health visitors see him just as much as coordinator as a dispenser of professional skills. However the mental welfare officer does not see himself this way. A number of questions arise from this contrast: if the general practitioners and the

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* Parents were not asked to state the role of health visitors.

health visitors see the mental welfare officer as a coordinator, to what extent do they constrict their own activities in this direction because they do not believe it is their function to become involved in coordination. To what extent does the mental welfare officer see coordination as a departmental rather than a personal responsibility ? Finally, if parents fail to see him as a coordinator, is this because they have been conditioned by experience rather than the expectation of what he, or others, might do ?

Table XIV also raises substantial questions regarding the contemporary post-Seebohm situation. If the medical officer of health, and by association, the former mental health department, were believed to be the principal agency for coordinating activities for the mentally handicapped, has this perception been transferred intact to the director of social services and his new department ? Similarly, if the mental welfare officer was thought to be a coordinator by other colleagues, is the new generic social worker seen to be the inheritor of this role ? If not, then a hiatus of considerable importance to the mentally handicapped may have been created that will demand not a little ingenuity to restore.

Lack of understanding - genetic counselling

On occasion, a complete misunderstanding of the purpose of a particular service - or of a person's proper role in providing it - can be just as great a bar to coordination as the factors we have already discussed. Genetic counselling is one such area of misunderstanding that this survey brought to light.

We have already noted in Chapter Six that of the 28 families with more than one mentally handicapped child, not one, as far as we could ascertain, had received genetic counselling. Only ten parents in the survey received genetic counselling or at least recognised the advice they received as such.

The low take-up rate may be explained in part by the confusion in the minds of health visitors, mental welfare officers and general practitioners as to the nature of genetic counselling. To the question, 'Who should arrange genetic counselling ?' both health visitors and mental welfare officers listed the general practitioner as foremost in arranging this service. However, the general practitioners reply to the question, 'For what reason would you refer patients for genetic counselling ?' casts grave doubts on

their ability satisfactorily to perform this role. Table XV lists the reasons cited by the 147 family doctors in our survey for referring patients for genetic counselling.

TABLE XV

REASONS GIVEN BY GENERAL PRACTITIONERS FOR REFERRING PATIENTS FOR GENETIC COUNSELLING

Reasons given	Number	Per cent
If there is a mongol child in the family	13	9
If there are congenital abnormalities in the family	24	16
If there is a history of epilepsy or diabetes	5	3
If the parents are around 40 years or over	2	1
If there is a family history of subnormality	53	36
If the parents ask for it	32	20
Other reasons	19	12
Don't know	5	3
No reply to the question	40	26

Source: 147 general practitioners

NOTE: Some general practitioners gave more than one reason, thus percentages will sum to more than 100.

It will be realised that few of the doctors appreciated the real meaning of genetic counselling and only a small percentage were able to give a correct answer to the question. And, if the general practitioner has not fully understood the clinical nature of genetic counselling, can we reasonably expect that other professionals, such as the clinic doctor, the local authority medical officer and even the health visitor, are suitable.

It must be understood that genetic counselling is one thing only: it is a service to parents and their children and their family doctors, providing adequate and accurate information on the risks of any abnormality that has already occurred in a family occurring again; it is information also expressed in a way immediately comprehensible their ability satisfactorily to perform this role. TableXV lists the reasons cited by the 147 family doctors in our survey for referring patients for genetic counselling.

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It must be understood that genetic counselling is one thing only. It is a service to parents and their children and their family doctors, providing adequate and accurate information on the risks of any abnormality that has already occurred in a family occurring again. It is information also expressed in a way immediately comprehensible to parents and to their family doctors. Recent developments in the technique of counselling, together with the fund of knowledge built up over many years about risk situations, can enable the person giving genetic counselling to place before the parents simple 'odds' situations, such as a 4:1 risk of cystic fibrosis developing in subsequent siblings if the first child is affected.

All this, however, is useless unless the members of the caring professions in the field of mental handicap know what genetic counselling is and who can give it. One measure which would go some way to improving this situation is to include health visitors, mental welfare officers and others working in the field of mental handicap on the distribution list for the Department of Health and Social Security's handbook 'Genetic Counselling'.

CHAPTER TEN

THE LAW OF INVOLVEMENT
AND
DANGER SIGNALS

This chapter explains how the law of involvement was discovered and discusses some of its implications for providing better services to the mentally handicapped. A method of using parents' comments to identify their needs is outlined together with examples of comments made by some of the parents in this survey.

Chapter Ten

THE LAW OF INVOLVEMENT AND DANGER SIGNALS

THE LAW OF INVOLVEMENT

In looking at the services for the mentally handicapped our task was not merely to describe the existing situation but also to look for any unifying patterns or generalisations that would serve to bring some order into the chaos of the unorganised information. One such generalisation is that which we have called the 'Law of Involvement'. Simply stated, the law of involvement maintains that in general, the more disabled the child, the more active will be the parent, the more engaged the mental welfare officer, the more prolific his contacts with others in the services, the higher the level of help received and the greater the satisfaction of the family.

In Chapter Seven, we have described how the law of involvement arose from an examination of the indices which had been constructed to examine in more detail the relevant variables working to produce a particular pattern of coordination. We have left the statistical demonstration of the law of involvement to Appendix D where the interested reader will find a complete explanation of the methods used in arriving at this generalisation. Our purpose in this chapter is to discuss some of its implications and show how it was used as a constructive tool of analysis.

Fulfilment and disability

The Law of Involvement carried with it the proposition that, in this sample of families with handicapped children, there is a positive relation - or more accurately a significant statistical link - between the severity of the child's handicap and what is seen by the family as fulfilment, satisfaction, support, help, and so forth. Not only do the services offered to the handicapped person rise with the degree of disability, but so also does the comfort or relief perceived by the parent. This result, while a testimonial to the services in general, seems of such interest that we illustrate it by its extreme examples. We examine the values of parental fulfilment for all fifty-five cases in our sample at the four corners of the disability and fulfilment array; these are therefore about 25 per cent of our total sample. We divide them, firstly, by the level of disability, mild or severe, in accordance with an 8 - point scale: classes 0 and 1 represent low disability, classes 6 and 7 represent high. We then divide them again, in another

dimension, by reported level of parental fulfilment, by classes 0 and 1, of low satisfaction, and by classes 6 and 7, of high. The result of this double sort is shown in Table XVI

TABLE XVI

	Low Disability (0, 1)	High Disability (6, 7)
Low fulfilment (0, 1)	20	9
High fulfilment (6, 7)	9	17

TABLE XVI: showing, from a sample of 204 cases, distribution of 55 extremes of fulfilment and disability ($X^2 = 6.49$; p = 1 per cent).

Table XVI leaves no doubt about the association; of the 29 parents with children suffering a low degree of disability, one third only are satisfied with their experience of the services. Of the 26 with severely handicapped children, one third only are relatively dissatisfied. We suggest that this result arises, not because parents prefer to have severely handicapped children, but because in the first instance the higher degree of disability evokes a greater level of activity on the part of the parents, and secondly, the resulting deeper involvement in a well run system gives them a more satisfying sense of achievement.

Parental activity and involvement

If the degree of disability present in the handicapped son or daughter seems in some way to determine the extent to which the parent will be active in seeking assistance, the quantity and quality of services received in turn seems to be determined by the level of parental activity. An analysis of the pattern of services for each child suggested most strongly that it was what the parents did rather than what was wrong with the child that was the determinant factor in most cases. The law of involvement confirms then the judgment made by many that, in the main, social services in the past have been essentially passive, reacting rather than acting, responding to demand dimension, by reported level of parental fulfillment, by classes 0 and 1, of low satisfaction, and by classes 6 and 7, of high. The result of this double sort is shown in Table XVI

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However, the relationship between the handicapped person, the family, the providers of services and other agents involved is highly organic. The law of involvement implies that greater activity all round can be stimulated by someone other than the parents; the paediatrician, the health visitor, the mental welfare officer, for instance. If the level of disability is not particularly high and the parents are not stimulated to any great activity, it does not mean that the child is not in need of a wide range of services. This is where coordination at the time of suspicion of subnormality is vital; we suggest that the more people who become actively - but cooperatively - involved at an early stage, the more chance there is of continuing activity and an acceptable 'mould' being established. Since we cannot be sure that all parents will adequately respond to every case of high disability, our concern should be to identify the ways and means by which others can break into the circle and stimulate the degree of services necessary to meet the needs of the child. Anyway, our long tradition of self-help notwithstanding, a service which is apparently geared to respond only to the demands of parents is one which will inevitably neglect many dark corners where the needs of disadvantaged children may be great but not so visible.

Relevance of the law of involvement to action research

The law of involvement may not announce a truth previously unsuspected. Far from it, for the proposition that what one gets in this life depends upon how strongly one pursues the goal, is almost a truism. Indeed, most people active in the field of mental handicap (and other areas of the health and social services) have long realised the connection between parental activity and the extent to which services are provided. Our enunciation of this law came as no surprise to the great majority of people participating in this project. In fact, the most common reaction could be summed up by the comment, 'There's nothing new there. I could have told you that.'

However, we felt reactions like this were extremely reassuring. One of the most common charges made against research in the social sciences, often justified, is that it has no basis in reality. It must be remembered that in this project, the responsibility for research design and operation rested with the providers of services, people in the rather than to need.

However, the relationship between the [illegible] of services and other agents involved is highly [illegible] implies that greater activity all round can be [illegible] parents, the paediatrician, the health [illegible] If the level of disability is not particularly [illegible] any great activity, it does not mean that the [illegible] services. This is where coordination [illegible] we suggest that the more people who [illegible] at an early stage, the more chance there are [illegible] making assumptions. Since we cannot [illegible] every case of high disability, we [illegible] should [illegible] the ways and means by which others can [illegible] not necessary to meet the needs of the child. [illegible] our long [illegible] notwithstanding [illegible] involvement is expected only to [illegible] of parents is one which will inevitably neglect many dark corners where [illegible] disadvantaged children may be treated but not as equals.

[illegible] of the law of involvement to [illegible]

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DANGER SIGNALS

The tendency for the active parent to achieve relatively high satisfaction and for his more disadvantaged child to secure a richer service is not one that occurs in every case. It has many exceptions, as do many long accepted laws. These deviations may be worth studying, and it is one usefulness of the law of involvement that it enables us to identify the nature and magnitude of what the exceptions may be. It is also an advantage of using indices that we can identify those individuals that are exceptions to the law.

This section is an examination of some outstanding exceptions to the law of involvement and is based on two assumptions: one, that when a law is obeyed by the majority one can learn a great deal by studying the minority - in this case those who are struggling to swim against the tide; and secondly, that in medicine and education alike, much has been learned in the past by studying the pathology of a system. It seemed reasonable to us to apply the same principle to our case, that is, the system of care for the mentally handicapped living in the community.

The 'Balance' Index

In Chapter Seven, the 'B' Index is described. This was constructed to show the balance between challenge and response: between the needs of the handicapped family and the response of the services. At the extremes of this index are those cases where the challenge is far greater than the response, and the needs of the family do not seem to be met; and those cases where the response is far greater than the family has asked for, or perceives itself as needing.

Chapter Ten

The main part of this section is based on the 15 parents whose 'B' Index is a minus quantity, and whose needs are not therefore seen as satisfied, and on a matched group whose index is positive and around the mean. In addition, another 70 parents' questionnaires have been scanned, where one or other of the six main indices did not fit the pattern of the law of involvement. This has enriched the tapestry, since the information gleaned from these latter comments agrees wholly with the findings on the 30 cases.

Scale of needs

The first result that came from the search of actual comments from parents (as distinct from the strictly statistical data) was a common and strident expression of need. This significantly differentiated in both quantity and quality, those parents who seem to be 'swimming against the tide', from the rest who, like white horses on a choppy sea, are seen to be riding over the waves. Since the four major needs are also significantly differentiated each from the other, they can be formed into a scale. Such a scale might well become the basis for a system of 'danger signals'.

It is with such a purpose in mind - arming the professionals with a guide to spotting those families who see themselves in need of support - that parents' actual words have been used, and used in the form of slogans which may remain in the forefront of the mind long after the facts and figures have been stored away.

So, in the parents' own words and in descending order of significance, the gaps are as follows:

1. 'no advice was given us'
2. 'no help was given'
3. '<u>this</u> is what we really need - or needed'
4. '<u>we</u> don't know how this person, or service, could help us'

Under these headings were clusters of comments ranging from: 'they didn't say what was wrong with her', to: 'she told me how to feed the baby, but I knew that already - this was my fourth child'; and from: 'if only the school coach stopped nearer to our house, and not 1½ miles away'; to: 'she went to one social evening and got dirty. The organisation sent her back. They don't try to understand. If she gets dirty, it's not her fault'.

Chapter Ten

It must be remembered that this was a particular exercise; looking at the parents' feelings about their own world, their problems, in order to devise some constructive ways of offering them a better service as they see the need for it. Many of the comments quoted in this section will, therefore, inevitably seem adverse to the services - a long catalogue of bewilderment and struggles as the parents try to find a ladder to climb out of the pit. However, the intention is neither to hurt nor to shock: this is our way of trying to construct a positive solution from a tangled skein of anxiety, ignorance and apathy. The appreciative comments are there; we choose to learn from the others.

1 'No advice was given us'

These parents seemed to feel that they had spent a great deal of time shadow-boxing: they sensed often, or indeed said they knew from a very early stage, that something was wrong with their child, but did not grasp exactly what it was they were up against. Some of these mothers were anxious soon after the birth of the child, and had to wait for as long as three years' before their fears were put into meaningful terms by those whose advice they had been so assiduously seeking.

> 'I heard this funny cry and thought: I hope that's not my baby, and asked the nurse: "Is he mentally retarded ?" - "Good gracious", she replied, "You think you know too much."'

Another parent who sensed her child was different in the early days, was the one who went five times to her doctor and 'he told me I was a fussy mother and laughed.' There are in fact 18 parents in the sample who still have not been told, they say, that their child is mentally handicapped, and when asked by the interviewer what is wrong, can only reply: 'We don't know, he's a strange child.'

Others were half told, like the mother of Beth, whose first experience was of a professional who said the child was: 'lazy and jealous of her sister', and the next, of one who said that she was mildly spastic. No further advice was given.

> 'They should have explained. They never had time'. - Patrick had had both eyes removed.

Such parents as these felt the need for answers to their questions about diagnosis: if a label can be put to a disaster, some relief is felt, and what then has to be faced becomes tangible and realistic. Vague anxieties or black imaginings are far more worrying and use up energy which could more constructively be spent on dealing with the child.

Questions needed to be answered, parents said, about the practical problems that crop up in the infancy of a handicapped child, but ... 'No one ever came.' One father said: 'My wife died six months back. I really thought they might have come, but they haven't.'

'They didn't say! .... 'No one came.' These are the two slogans which, like the: 'It's not my business', of the professionals' world, are danger signals indicating a deeper anxiety than is perhaps apparent on the surface.

2 'No help was given'

In other words, specific help was needed .... none was suggested. Or perhaps, none that matched the current situation. This was another area of significant difference in the perception of those parents who felt they had been given appropriate encouragement and those whose needs were apparently met with 'energetic irrelevance'. 'He said there was no point in bothering about him, as he wouldn't live .... if we'd followed his advice, Jim would have been dead within a few weeks. Why were we never referred to someone with special knowledge ?' (Jim is now nine years old). Or Philippa's step-mother, feeling she would like her home with the family more often than once a year, but worried by her own children's fears: 'I didn't understand her, and someone from outside could have helped, if they'd explained things to us.' Another parent 'used to say that one foot was shorter than the other - "Oh, no it's not", they'd reply ... and the next man said she couldn't be educated, and I knew she could .... sometimes you could scream.' Ferdie's mother 'used to teach him his letters, and how to write. No one bothers to tell you that you should do it.' These are the 'trial-and-error' parents who 'had to cope as best we could.'

Both these groups of parents, feeling the need for advice and practical help, perceive themselves to be abandoned. 'You are rather on your own when you have a Richard.' To the professionals, it may seem adequate to tell an anxious mother: 'You're worrying about nothing', or: 'Just talk to her a lot.' These parents think otherwise. And they reflect the 50 per cent of our sample who said of the first three years' of their child's life: 'No one helped.' Only 14 per cent named the professionals as their source of support during these early years.

3 'This is what we really need'

The next two needs are perhaps more easily assessed since they tended to be concrete statements and to evoke less emotion in the parents. Such facilities, for instance, as baby sitters, playgroups, help in the home, transport facilities, social clubs; such apparently normal things as school reports from the training centres; reassurance in the form of some kind of plan for the child's education and for his adult life, or for his future when there is no one at home to care for him. Such needs, though more widely expressed in the 'Swimmers against the Tide' group, were nonetheless common throughout the sample. Less easy to assuage, perhaps was the plea for greater understanding: 'Mothers' can't take such children to the surgery. Everyone stares at them. People talk.' One might think these parents' have enough of a burden to bear ....

4 'Who can help us'

Again, lack of knowledge of help provided by the services was common to the entire sample in some degree; so too, was lack of understanding of roles of the various professionals. Here again, the 'Swimmers' group was significantly more disabled, though to a lesser degree. 'I have no knowledge of how to get in touch - or even that anyone is available.'

Parents 'At Risk'

We can give life to this classification by imagining the families of the children in our sample to be like the victims of a ship-wreck.

The Survivors are those parents who, apparently no longer present a problem; they are, perhaps more persistent, or rather more tough. They themselves say: 'Advice has to be fought for.' On the other hand are The Drifters who do not seem to be facing up to the problem realistically, or who perhaps cannot do so, although the professionals are well aware that a problem exists. These parents assert: 'There's nothing wrong with him - he's just lazy', or 'He'd be quite all right with proper treatment.' Rather more 'At Risk' are The Drowners, who just repeat: 'No one came!' These parents seem to have given up hope of help or support, and just struggle on in a state of bare competence. Finally, The Strugglers, who seem to be in a perpetually ice-thin equilibrium, outwardly

coping, inwardly resigned, certainly in danger: 'We just manage, that's all there is to it.'

If those who have any contact with parents can learn to be particularly alert whenever such phrases are heard, or seen on case notes or memoranda, then perhaps some of the energy in the system, the skills, the knowledge and the goodwill that is abundantly manifest, could be diverted from those parents at the other end of the scale who are served with such irrelevant persistence far beyond their stated needs.

Breaking the news

Professionals, in talking to the parents of a mentally handicapped child, may face one of two problems: the breaking of desperately serious news of very severe handicap, or the conveying of a slighter degree of misfortune, that the child is mildly handicapped. How that news is broken, is clearly of paramount importance to the parents at the time. What may not be realised is that the first telling sets the whole tone of the parents' subsequent attitude to the professionals, lingering in their memory and reinforcing their bitterness or their patient appreciation long after the moment of telling has passed. Their comments make this very evident.

Parents find news that is unhappy, but not disastrous, can be broken in one of three ways: firmly, but in perspective; with ponderous solemnity; or, and herein lies the skill of the true clinician, with due regard both to the news and to the recipient. News that is really tragic by any standards can also be broken in these three ways. Our parents have experienced the whole range.

Compare the 'appropriate encouragement' of the general practitioner who: 'explained the nature of the handicap and said it was too early to make a definite decision regarding his future, but he would see him again after nine months,' with the 'vigorous irrelevance' of another general practitioner who took the trouble to find and present to one mother a book called: 'To the Parents' of a Mongol Child', - the first she knew of the diagnosis. Or the mother, who upon requesting dentures for her adult daughter, was told: 'Why worry about dentures, who's going to look at her.' Or: 'He'll never be able to take employment - except as a dustbin man.' But the paediatrician who broke the news to Christopher's parents evidently satisfied their immediate need for advice when he 'told coping, inwardly resigned, certainly in danger. 'We just manage, that's all there is to it.'

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Summary

This study of parents' comments, in enlightening us on the reasons why a particular group of parents was not, in their own opinion, receiving the support they needed at the time of their greatest need, has made one thing quite clear: it is not only the actual services that are given to the child and his family, nor even the advice and help and support that count: it is the way in which the parents perceive these things.

The providers of services can give to their utmost what they perceive to be help, over and over again: but without, impact. The mother quoted at the beginning of this section who was being taught to feed her fourth child although she already knew how, really wanted to know was how to cope with a handicapped child, at that moment, over the next few years, during childhood, adolescence and adulthood. A panorama, even if necessarily sketchy in detail, would have given her some facts and some labels to ease her anxiety; and would have set these in perspective.

Within the sample are parallel tales, told by some with bleak despair, by others with a feeling of triumph over disaster. What counts for the parents is how they see the people who are supposed to be the agents of help; their words, their actions, are as nothing unless the parents can see and understand their relevance. This is the gap between the families and the services; of all the gaps that we have discovered, it is the most important.

SECTION 3

IMPACT AND GUIDELINES

CHAPTER ELEVEN

ACTIONS STIMULATED BY PARTICIPATIVE RESEARCH

This chapter deals with the participants' own perception of this project and also describes some of the actions that have been generated in the research areas as a result of this project.

Chapter Eleven

THE MAIN OUTCOMES

The primary achievement of this method has been the creation of pre-conditions for change and improvement in the organisations involved. There appears to have been considerable learning by individual participants. This learning, showed itself in the form of greater understanding of the needs of the mentally handicapped and of the relationships between various providers of services. This implies that participants are now more conscious than previously of dysfunctions in the system and, as a result, are more likely to want to work on these problems. This major achievement is in line with the underlying thesis of the project. For most participants however, exposure to the learning situation provided by this project was brief. Whatever learning and understanding have developed will need further support to withstand erosion and the traditional norms of the system. Apart from the active participants, the learning so far achieved should not be seen as self-perpetuating.

The research has concentrated on a sample of 212 randomly drawn mentally handicapped people under the age of thirty from seven local authorities in the country. For each case in the sample approximately six research instruments were used. Each interview took about an hour. There are about 200 items of information pertinent to the theme of coordination on each instrument. These entries, about 200,000 in all, have been analysed by computer. It is clear that a data-bank of some importance is already available, perhaps also capable of indicating what the survey has been unable to detect.

All this information has been collected and analysed with the support of a wide range of providers of services to the mentally handicapped. This is a strong feature of the project because it brought together, (in a spirit of objective curiosity) all the people who do not normally discuss their points of view with others working in the same service. Topics for discussion were also chosen by the providers of services. They posed their own questions, found their own answers and they did so in conditions of the greatest practical relevance to their own tasks and their own problems.

Although our opportunity of feeding back the data to the participants was very limited, we are convinced - judging by their reactions - that it will provide a further stimulus for individual learning and organisational change. The data will clarify real issues

requiring action. It is important that the project is not seen as having been concluded at the end of data collection and analysis stage. A much longer period, is needed to observe, assimilate, digest and react to the information collected and for the participants to work out solutions to the problems they have identified.

It would seem, however, that involvement is of value not only as a tool for learning but also as a means of improving our concepts of social research. Our experience of this project suggests that involvement speeds up research operations and increases the researchers' power to discern the reality and complexity of the system studied. Perhaps this approach gives some real meaning to the term 'action research'. It may also take social scientists a little further along the road of developing analytical tools more appropriate to social situations than the natural science laboratories where our present concepts of 'scientific' methods were first developed.

This approach is capable of direct application by providers of any service to their problems. Individuals with relevant skills - such as training project officers in hospitals or research and training officers in social services - can immediately use this method both to develop capacities in their colleagues for adaptation and learning and to collect data about their organisations. We now examine what use some of those involved in the research have made of their experience.

EXTENSION OF PARTICIPATIVE RESEARCH

If it could be presumed, with any degree of confidence, that what man learns from other people's experience is sufficient for him to carry out his own responsibilities adequately, then the purpose of this project becomes insignificant. In our view, however, no programme of action, no matter how impressive, sophisticated or comprehensive, in itself produces action, not, at least, for a large number of people to whom the plan is addressed. We have attempted to discover the mechanics of helping providers of services to become action orientated. They were involved, as far as an experiment of this kind allowed, in examining the services they had been offering and, at the same time, evaluating the needs of their clients and of other providers of services. Once the providers had identified, on their own, some aspects of the total problem, they became motivated to take action in solving them. We had not designed this project to discover a formula for

solving actual day-to-day problems but we had hoped to help those engaged in providing and receiving services to become more aware, individually and together, of the system they were responsible for running. Some of them, as a direct result of their involvement, have attempted to apply their own learning to fields of action and responsibility. The following examples of their efforts illustrate the potential this kind of project has for institutional learning.

An appreciation of complexities

Social workers, health visitors, training centre staff and local paediatricians in one area participated in a study of a 5 per cent sample of mentally handicapped people. As a result they felt that a lot more needed to be known about all the mentally handicapped under the age of ten. Voluntarily they completed the questionnaires used in the main study. This group interviewed parents, teachers, general practitioners, mental welfare officers, and health visitors involved with 46 mentally handicapped children under the age of ten. They also examined the records of these cases kept at the mental health department. The full benefits of this survey will only be known when all the data is analysed but the participants already feel that they now appreciate the complexity of the organisation of community services and in addition have become more aware of their interdependence in the common task of helping handicapped people and their families.

Team building

A few months before the implementation of Seebohm mental welfare officers in one area decided to use the participative research approach to make all social workers in the area more aware of the needs of mentally handicapped people and their families. Up until then these social workers had lacked any contact with mentally handicapped people but were now likely to be involved with them. At their own initiative the group involved health visitors, child care officers, hostel staff, teachers from training centres and representatives from voluntary organisations in the study of the problems of coordination and evaluation of services in one administrative unit of the local authority. The reorganisation of social work services following the Seebohm Report disrupted the activities and plans of this group. However they succeeded in overcoming any resistance by generic social workers to accepting the responsibility for supporting the mentally handicapped and solving actual day-to-day problems but we had hoped to help those engaged in providing and receiving services to become more aware, individually and together, of the system they were responsible for running. Some of them, as a direct result of their involvement, have attempted to apply their own learning to fields of action and responsibility. The following examples of their efforts illustrate the potential this kind of project has for institutional learning.

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Overcoming resentment

When the project started meetings in London were held in the hope that participants would communicate the decisions of the Research Advisory Group to their other colleagues. When we began the fieldwork we discovered that this did not always happen. Maximum involvement occurred in areas where those higher up the hierarchy believed that this project provided an opportunity for learning linked with institutional and administrative development. Consequently they supported our activities. In one area, where such support was missing until the reorganisation of services, the newly appointed director of social services sensed a certain resentment by some of the social workers and health visitors because they had not been informed what the project was about. Through the expression of this resentment and antipathy we discovered that the purpose and method of the project should be effectively communicated in its early stages to all those whose cooperation would eventually be needed. With the help of the director of social services we attempted to eradicate the negative feelings by concentrating on a local issue which interested most providers of services in that area. The parents and teachers of all the handicapped above the age of 16 and attending a special day centre were interviewed. The analysis of the questionnaires completed by social workers and teachers helped people in the area to make realistic plans for the future services.

SOME CHANGES

We had initiated this project believing that changes in organisations as complex as health and social services can best be generated from within those services. We had used our skills and judgment to encourage the staff to accept responsibility for the evaluation of services. This inevitably led some of the participants to feel a need for change and encouraged the more involved and competent people to bring about changes at levels where they operate or have influence. This project was undertaken at a time when many organisational changes were taking place in the local authority services. The changes arising from Seebohm recommendations over-shadowed the changes resulting from this

project and also made the perception of those changes very difficult. How far the changes described below are the consequence of national trends and how far they owe their origins to the method of the project is a matter for debate. There have been other changes in procedures, practices, organisation and - not the least important, in attitudes - which were not considered significant enough to be reported to us. In one area, for instance, the research officer accidently discovered that the social workers had invited the local general practitioners to discuss matters related to coordination over a working lunch. The social workers explained that, through the research, they had realised that there is a gap between themselves and the general practitioners and therefore, had arranged a face-to-face meeting so that they could find out what support each needed of the other.

The following descriptions presented in their own words by various participants, illustrate changes in the approach to work with the mentally handicapped and their families. All participants claim that these changes occurred as a direct result of this project.

Meeting a need

> 'Basically we discovered a crying need for short term care for children. We arranged this care. If you offer something somebody wants, you encourage referrals. The word will get around. This encourages coordination because it encourages the clients and others. Apart from being a service, such things are symbols of caring.' (Assistant director of social services)

Changes in procedure

> 'There is little doubt that, as in the other areas involved in the research, the staff involved in this part of the country have experienced an enrichment of their insight and knowledge of the needs of the mentally handicapped and their families that no lecture or text book could ever hope to provide. In the health visitor field both newly qualified and more mature staff have benefited greatly. This fits in with the national pattern but other changes or benefits relate to our local situation only because they are changes in the organisational procedures adopted as a matter of policy.
>
> It is well known that in any system there is room for improvement, none is perfect and we are no exception to this. It was known that the record system can be slow and a major overhaul of recording keeping and referred precedures can be postponed again and again because of the need for service to continue during the changes. The research provided the necessary impetus for change to be brought about.

Referrals to an assessment centre were usually made verbally by telephone or by written memorandum. The research showed that the clinic record cards, although printed to contain a full family social and medical history, often had little more than the name, date of birth and address of the child. Referrals are still to be made in the same manner but on referral the health visitor is now required to complete the clinic record card from her own records. Should the referral be made by someone other than the health visitor, she will be informed of this by the clinic clerk and will complete the card accordingly. This ensures that the examining doctor has a comprehensive factual record of the child's development available and if further information is required, this can be asked of the parent at interview. It also eliminates for the mother the tedious task of having to repeat the history from memory, thus saving clinic time.

In addition to this important aspect of procedure the research also went some way in providing guidance and information in the reorganisation of the department's records of handicapped children, which was being carried out at the same time. Communication has been isolated as the major problem. It has been very revealing to the communicators to see what impression has been made on parents by their efforts at communication, and procedures are being studied to improve matters. We are studying plans to have a central record for every child, which could bring in computer help in the future, but this is very much in the planning stage.

The cooperation between the paediatric and the local health authority services in the town has been improved upon over the years, but what is hoped will be a major contribution is the appointment of a senior health visitor to be responsible for the coordination of services for handicapped children.'
(A medical officer of health and a senior social worker)

Bringing people together

'The first meeting to discuss the research in this town served to bring people together, which was obviously not a common occurrence. The mental health department had not had any previous contact with the new deputy medical officer of health for instance, and the representative of the local association for the mentally handicapped, (herself a parent of a mentally handicapped child) was able to get together with the staff member from the junior training centre and discuss the possibilities of further contact and action.

The health department representatives, the deputy medical officer of health and the two nursing officers were interested in the project, both in concept and in application, as were some of the mental welfare officers. To them, an important realisation was of the project as a form of training, and as such it was welcome, since they felt this was something which was lacking in the department.

The progress has come, we feel, where people have faced up to the implications for themselves.' (Research assistant in one of the areas)

Chapter Eleven

The impact of involvement

'Perhaps the research made its impact because it was about involvement. It's all right an academic doing something because you can say "What does he know about it ?" You can hardly say that with this research because they are saying "What do the providers of the service think about it ?" ' (Assistant director of social services)

The beginning of coordination

'Mental handicap is an area where you can appoint a specialist to make sure your services are coordinated. It's all very well to talk of one door on which to knock. We have five offices. What happens if a paediatrician sees a case and notices that we're not involved ? If he can contact one name at one address we are offering a service. That's the beginning of coordination. We can also feedback through that person. Feedback isn't easy without having someone who's accountable; who is known. Fact is, he is there, he is a known quantity and, most important, he is a known quantity to people who might not take the trouble to study our services.' (Assistant director of social services)

A clinic and a course

'One tends to enter general practice knowing about pneumonia, bronchitis and sore throats, and not about the problems of the family which has a mentally handicapped child. This attitude springs from a general practitioners' undergraduate years in medical school. The general practitioner's awareness of the problems connected with mental handicap and his knowledge of the existing services directly affects the quality of care a mentally handicapped patient receives from him.

As a general practitioner my involvement in this project has resulted in identifying the need for a training programme for the providers of services - general practitioners, health visitors, social workers etc relevant to the needs of the mentally handicapped.

I have been able to establish a weekly clinic with an attachment of a health visitor, to look at the growth and development of children. To equip myself better I am attending a course in developmental paediatrics at the local university, and am encouraging my other colleagues to do the same.' (A general practitioner)

Overcoming resistance

'If there are resistant people, the research can be used to show them that there is a need for involvement.' (Assistant director of social services)

Chapter Eleven

Increased awareness

> 'I did not know one of the families I interviewed in order to complete the research questionnaire. The subnormal girl was an 18 year old attending the adult training centre in a London borough. Both mother and daughter appeared, at first sight, to have adjusted themselves extremely well, but during the interview it became apparent that the mother had many anxieties about the future of her daughter. Her husband had died two years before my visit, and since his death she had no-one on whom to unburden her anxieties. It was all too clear that here was a woman who appeared to everybody with whom she came into contact as self-sufficient, but in fact was in need of a great deal of reassurance and support. This family was unknown to me because they had had no children born in England since arriving from Ireland when the girl in question was two years of age. The child was referred by her general practitioner to the local hospital where she was assessed by the paediatrician and later admitted to the junior training school. This is an example of lack of coordination between hospital, general practitioner and local authority health visitors.
>
> General practitioner attachment schemes are now developing in our borough, so the general practitioner will in future be better informed about any mentally handicapped person on his list through his health visitor, who because of her involvement in this project, will know the stage of mental development reached.
>
> As the health visitor sees the families of all newly born infants and makes regular follow-up visits, she is often the first person to suspect handicap of any kind and suggest a mother takes the baby to the local authority clinic, where the child can be assessed and if necessary referred to the mental health department. I used to rely on the parents to keep me informed or had to telephone the mental health department to find out about decisions taken. However, since this project, people in the mental health department and health visitors in our area have become more aware of the other's role and now have an excellent rapport; finding it easier to approach each other over difficulties arising in a particular family and offer support between them. This is important to the clients and much more satisfying to the fieldworkers who have in the past tended to work in their own isolated spheres.' (Health visitor)

Motivation and help

> 'People are always motivated to provide a better service. This research helped them to see that there is a need and shows them that they are not bucking the hierarchy.' (Assistant director of social services)

Cause and effect

> 'The research caused us to write a special section on mental handicap in our social services handbook; setting out the service which should be provided and

> stating that we would do our best to provide them. This gave us an incentive to provide that service.' (Assistant director of social service)

A more detailed account of the actions stimulated by this research and of people's reactions to it, can be found in Appendix G, a report of a conference held at the Hospital Centre to describe the project.

CHAPTER TWELVE

SUGGESTED GUIDELINES FOR THE APPLICATION OF PARTICIPATIVE RESEARCH

In this Chapter an attempt has been made to present guidelines for those who are interested in involving staff in the evaluation of services they provide.

Chapter Twelve

INTRODUCTION

These guidelines present an option to those interested in the question of assessing the effectiveness of existing services and in making realistic plans for future needs. There are many practices, grand and elegant, academically sophisticated and administratively feasible, now in operation dealing with the organisation and functioning of human systems and having a bearing on the behaviour and performance of the staff serving those systems. Experts in organisational development, management sciences, change strategies, communications, operational action and sociological research have all made considerable impact on the highly complex field of service delivery. The development of our method of participative research, under the auspices of the King's Fund, will interest those who recognise and appreciate the need for its examination so that improvements can be realistically suggested. We do not claim to have developed a method, or a magic formula, to overcome all problems related to the field of service delivery. This is merely a method which can now be applied with some degree of confidence by others. The theory and philosophy guiding this work simply reflects the mood of a time when significant changes in the field of administration, management, education and politics are taking place. Established values are being challenged and the legitimacy of leadership is being questioned. In such a climate, together with many others, we have advocated an increased participation of those at the cutting edge of the system in running it. We have also developed mechanics for achieving such participation. These mechanics no doubt need further testing and refinement.

The suggested guidelines are not intended to be a blueprint to be rigidly followed everywhere. They provide some suggestions on developing tools that depend on the involvement of staff at all levels. These tools can lead to the collection and analysis of information and ideas of immediate practical use to those engaged in providing the services.

INVOLVEMENT OF PEOPLE AT THE GRASS ROOTS

The cardinal principle to adhere to throughout a project is to encourage and nurture full involvement. People learn in an action situation, they grow and develop in an organisation if they try to solve their own problems.

This method effectively challenges the providers of services to participate, in a down to earth fashion, in an evaluation exercise. It firmly places the responsibility for action with the people who manage and run a system rather than have them depending upon departmental circulars or experts from outside.

Obtaining the deep involvement of the providers of the service in carrying out a serious and thorough examination of it is a departure from conventional types of research activity. The emphasis has to be placed on a true concensus from all-level, multi-disciplinary groups. This distinguishes the approach from any other form of management by persuasion or any of the more traditional management devices in human relations. In fact the participative research method is not a management approach in the sense of the 'superior and subordinate' or 'leader and led' relationships; in contrast the assumption is that a consortium of providers must, by its own decisions, improve its operating methods initially to evaluate the system, and having done so, to improve the service provided.

In a climate which will be built over the period of a project, sometimes rapidly and easily, sometimes with difficulty and more slowly, initiators or experts must quite deliberately avoid taking initiatives which could be construed either as determining the path of the evolution of the project or minimising or eliminating the participation of the providers of the service.

INVOLVEMENT OF THOSE IN AUTHORITY

Time must be spent by the instigators of the project in obtaining the interest and cooperation of those responsible for the administration of the whole service, part of which a project team may wish to scrutinise.

For any programme to be effective and successful, the consent and cooperation of those who have the power to encourage the initiative of an arbitrarily set up research group is imperative. Research of this type, if conducted in a climate of resistance, would disillusion participants and sow seeds of failure.

Chapter Twelve

GUIDELINES

Stage A: Research Design

1 A need for research

For a project to become effective, it is essential that a genuine need to undertake it must be recognised by all members running the service.

The more widespread this recognition, the greater the impact of the programme. The need to undertake a project could be prompted by government policy (such as a coordination of some services) or local matters of concern (such as housing needs of people in a locality).

2 The Initiator(s)

Someone, preferably from within the service, may suggest to the providers that participative research methods are put to the test in an area or in relation to a particular problem – perhaps in some aspect of health, welfare, communication, management, education or planning.

Any person or group of persons may have the inspiration actually to become involved in doing something to improve a service or a system. The idea can spring from a meeting or from one person's experiences. The initiator could be someone in authority or someone working more closely with those in need of the service.

3 Assembly of Participants

To find an effective solution it is necessary to bring together all those members of the system who directly or indirectly can influence or can be influenced by the area or subject for research. Once assembled, this team of professionals from all levels should be given a name, such as, for example, The Advisory Group. The chairman could perhaps be chosen because he is on the fringe of the service to be provided and is able therefore to be more objective in his outlook.

The technical adviser on aspects of research may be, for example, someone invited from a neighbouring college or university or from the research section of the authority in which

the study is being undertaken. It is essential that he recognises the value of involvement and is prepared to sacrifice the conventional standards of scientific validity. Such a person would be invaluable when it comes to advising on matters such as the construction of tools, sampling and analysis.

Membership of a group should always be flexible enough to include others at subsequent stages of the development of the programme. Often the original members of the group cannot continue their involvement, not because of lack of interest but owing to other commitments, promotion or transfer. Substitutes or representatives for such members can be brought into the group.

Different roles can be assigned by the group to different participants. All levels of all professions should be encouraged to take a share of the work. Who does what can depend upon the time they have available, their skills, enthusiasm or willingness to assume responsibility. Some may be prepared to negotiate for funds, others to write, to help in conducting interviews or the processing of data. The participants must judge their own capabilities and volunteer for the roles of their own choice.

All members of the group, irrespective of their status, need to be treated equally. Any attempt to establish a hierarchy within the group will be harmful to the essential feeling of togetherness. The role of the initiator, the coordinator, the researcher, could easily be undertaken by one and the same participant or more than one participant. The group must identify special skills of its participants and utilise their enthusiasm. If the group has faith in the principle of involvement it will tend to regard the programme as a worthwhile exercise.

All coming together should be given an opportunity to contribute to the discussions on the diagnosis of problems and planning the programme of study. Suggestions for solutions which will follow at a later stage will come more readily and be more realistic if these early decisions have been taken collectively.

To achieve a good team spirit, support enlisted must be voluntary. An effective team only emerges when its members willingly participate in its activities. People need the opportunity to opt out of the project when they feel out of sympathy.

In order to make it possible for a variety of professionals to be engaged in an exploratory exercise, a non threatening climate should deliberately be created. The members of the group should not find themselves in a position where they need to defend themselves or their profession. Collectively the group should decide how to run its own activities.

4 Organisation of the Group

Participants at all levels of a service and covering all professional interests must be encouraged to help in the organisation of the group. Depending upon the size and nature of the study, certain participants will take up certain roles. Perhaps these roles will be transferred to others as the study changes and progresses. Besides the initiator who presumably calls the first meeting, the group will need to elect from among themselves, a coordinator, and a chairman for meetings and to acquire an adviser on technical aspects of research.

The coordinator could act as secretary for the meetings, enlist support for the project, facilitate field work and provide continuity. The larger the project, the greater the facilities needed. The coordinator perhaps is the one who needs to arrange a place for meeting, look for funds for travelling and consultancy fees etc. (In this type of participative research costs can be minimal).

5 Initial difficulties to overcome and keep at bay

Winning the confidence of the participants is crucial to the smooth running of the group. Time has to be allowed for people to overcome their initial distrust of new methods and threats of incompatible change. There are some more or less standard reactions to new methods of study, for example:

> The myth of excellence - the initiator, more than any other participant, is likely to be told, time and time again, that the system works well as it is and no probing is required.
>
> We know the answers - some people arrive at a certain diagnosis of the pathology of the system. Perhaps they have the correct diagnosis but they resent anyone offering a measurement, and to produce some facts and figures.
>
> A waste of time - some will say 'Let's get on with the job rather than waste time talking about it.' Those feeling this way feel threatened and want to maintain the status quo. They may join the group but without due preparation this could undermine the work in progress.

Conformity - some feel insecure unless there are well defined roles and rules to follow. They are completely lost when faced with having to re-examine their own roles and those of others. They would join in the project provided they can keep to their own code of behaviour.

No clear directive - many people feel happier working in a situation where they do as they are told. In a project such as this, where they have to contribute to the planning, they are lost and repeatedly complain of lack of direction and no clear statement as to what the project is about.

Apathy - some operate on a 'contract level' and resist the transition to 'participation level'. They want only to work from ten to five and then only do what their contract states.

Formation of a group and making a team requires skills in interpersonal relationships. It is not an easy task and there must be patience and perseverance on the part of the initiator, coordinator, research adviser and the participants. There is a likelihood of tensions arising amongst the participants due to personalities, or to the unstructured nature of the group in the initial stages. Such anxieties and tensions should be resolved by the group as a whole by focussing on the subject under study. Participants must be assured that their individual performance is of some consequences and will not be attacked.

6 Decisions on the scope and method

The group of participants should decide upon the scope of the programme and select methods of carrying it out. As a team they should:

Decide on the choice of objectives (define the project)

Translate such decisions into practice (construction of tools and planning of fieldwork)

Learn from the results of practice (analysis and interpretation of data)

Diffuse such learning (discuss it with others in the field, hold meetings and write articles and reports)

In a field where little is known it may not be profitable to start out with a clear and well defined hypothesis. It may be advisable to start with a broad idea, that a change, for example, is needed in some activity or that certain work needs evaluating.

When deciding on the choice of objectives the group needs first to agree on the following

What subject to study

The depth in which it should be studied

What questions to raise

To whom the questions should be addressed

Discussion on these matters gives the participants an opportunity to increase their awareness of the system they choose to study. At the stage of questions needing clarification and answer, the group should also consider the use to which it will put the collected information. This will bring about an understanding of how to discriminate between all information interesting to all parties and what information is highly relevant to the main objective of the exercise. The members of the group should be encouraged to examine in this way the questions they are asking because it will throw more light on the system under study and enable them to make constructive suggestions for improvement at a later date.

At this stage the group should attempt some time-table for the whole study. A fairly elastic time-table is needed to make it easier for providers of the service to participate in the research without having to disrupt their normal duties or, better still, to absorb their contribution to the research into the service they give. Time has also to be allowed for discussions as well as more formal meetings to enable the participants to consider aspects of their work and responsibilities which do not normally come under question.

7 Knowledge of research methods

Since these guidelines advise the use of standard techniques of survey research, a person with such skills should be available for consultation. This person, however, must necessarily follow the decisions of the group and should not influence the course or scope of the research programme.

The research adviser must be able to appreciate the full value of the involvement of service staff in research and should be willing to sacrifice the conventional scientific validity of research methods for this reason. The size of the programme and the complexity of the issues to be studied will largely determine the extent to which a group need depend upon the research skills of such a person. In a simple and straight forward programme the use of such skills could almost be non existent and be met by someone within the group with previous experience in research.

The participative research method affords members of staff a valuable opportunity to learn about research methods and the need to be motivated to design their own study.

For this reason it is not recommended that a programme tried elsewhere should be copied. In any case, what has proved a good model in one area is not necessarily going to be as good in another one.

8 Research tools

Since to make the diagnosis some information is needed, the research group should decide on methods of data collection.

The group should regularly review what information is pertinent and what is marginal, what is relevant and what is crucial. The responsibility for discriminating one type of information from another must be left to those who are the providers of the services. All the participants must then decide what information has to be collected and analysed and what information, though not crucial, has fringe benefits. Examples of the latter would include information which would help in filling in the background to the picture emerging, or which would help to persuade and encourage the activity and enthusiasm of some members of the multi-professional group who may have difficulty in associating with the main theme of study.

The group and not the skilled researcher should decide on which source of information to be tapped, and what sources are reliable and relevant to the issue. The expert on social survey techniques will need to be consulted for advice on technical problems. Similar help may be needed by the group from time to time when they design, test and modify their research tools.

Stage B: Fieldwork

1 Involvement in fieldwork

At this stage, the research programme becomes 'a learning by doing' exercise. The value of this method depends upon the participants carrying out the fieldwork. The participants should be encouraged to use the research instruments on their own.

Once the research tools have been designed by the group they should be tested and modified by all in the group in order to consider all variations.

Although some of the participants will not be too familiar with the techniques of interviewing and recording answers, the important thing to remember is not the scientific nature of the investigation but the opportunity for learning and the chance for the participants to evaluate their own day to day work in the field in the light of discussions taking place in the group.

Academic researchers may criticise this 'free for all' method of investigation fearing distortions of the data. The King's Fund project has shown very clearly that, if the participants define the aims of their own programme, no significant distortion in the data occurs.

2 Meetings during this phase

Formal and informal meetings between the members of the research group and other professionals assisting the group at any time are necessary.

The participants should meet each other and discuss the problems they face during the fieldwork. In this way they determine the pace at which the work can be conducted. Since a large number of extra people may become involved in the fieldwork at this stage it is essential to inform them of the scope and purpose of the programme.

3 Acceptance by the authority of the need to involve others

The opportunity to take part, no matter how briefly, in the objective examination of the service will stimulate those involved to think more about the need of the clients, the quality of the service, their own roles and the organisation of their daily work.

The length of time each member of staff will need for fieldwork can be small and of course the more staff released to help in the survey the less each individual will be required. This exercise increases the interest of the professionals in the research results and subsequent action.

If there are insufficient staff to assist in the fieldwork and if funds are available, part-time researchers, students for example, can usefully be employed. Such researchers should be made aware of the programme and should be prepared to help the professionals use the research tools. The purpose, at all times, is to create opportunities for the

professionals to learn more of the service they are providing.

4 Time-table for data collecting

An elastic time-table for the collection of data is necessary.

It is not possible to plan an exact time schedule for a fluctuating team membership, because holidays, illness and emergencies in day to day work cause unexpected delays in gathering facts.

Stage C: Analysis and interpretation of data

1 Processing the data

The original members of the research group who initially design the programme should come together at this stage to decide upon the data they would like to see analysed and which items need priority.

A programme involving a variety of people with diverse professional interests will inevitably end up with a vast amount of information. This is a technical stage and consultations with the skilled researcher will be necessary. With his help schemes of data processing can be worked out. The decisions on what is not needed or unmanageable must be taken on the advice and judgment of the participants.

The actual mechanical operations of coding and processing data, either for paper and pencil analysis, or for computer tabulations, can be entrusted to the participants. The time required for this depends on the size and complexity of a research programme. The skills of data processing can easily be acquired by those willing to learn them. The use of participants at this stage lends depth to the analysis of data. This, however, cannot be done as an extra-curricular exercise and the consent of the appropriate authority for the involvement of the staff for this purpose must be obtained because this activity, unless undertaken out of hours, would interfere with routine work. Again if sufficient numbers of staff cannot be found, part-time researchers can be employed.

2 Interpretation of data

Opportunities for members of the research group to meet each other and discuss the

application of the analysed information must be provided.

The principle of involvement of all participants in the interpretation of the data should be adhered to strictly. Smaller groups with specific interests could gather to look at and interpret selected sections of data.

Stage D: Feedback

1 Meetings and draft reports

At the time of feedback, a fresh attempt should be made to invite all those who could benefit from the accumulated information and those who could benefit the research programmes by giving their views on the material presented in draft reports and at meetings.

The invitation to learn the facts should include any of the professionals who shared initial interest at the beginning of the project but for some reason were not able to sustain it.

A wide circulation of draft reports is important as a method of spreading the information, enabling it to be used and encouraging interest in possible further action.

It is important that participants and others whose work has a bearing on the subject of the research should be allowed to digest, assimilate and recognise the nature of the problem in a constantly changing local situation. Suggestions for improvements should then lead to further action.

2 Feedback time-table

A broad plan of activities to stimulate action on the project findings has to be made.

As with other stages in the project, there can be no exact time-table drawn up.
A decision as to what action to take, if any, needs to be made but not all participants will grasp the relevance of the facts together; some will need further reassurance and a chance to air their doubts while some will need encouragement and help in understanding the full impact of the research and their involvement in it.

The research group needs to change at this stage into an action group and time is needed for all participants to adjust to the change. The sense of togetherness fostered during the development of the project needs to be maintained in order to turn the group of people into a working instrument capable of dealing with the practical problems they have brought to light.

As the members accept the principle of sharing responsibilities they should also agree to share the credit for the success of the group's activities.

Stage E: Final outcomes and diffusion

1 Final report

Writing of the final report should take the value of involvement into consideration. A deliberate attempt should be made to include the views and recommendations of all those who attended feedback meetings or commented on draft reports.

Working together on writing a report can be a learning process for all those who wish to participate in this task. By making report writing a collective effort, individual biases can be controlled. It takes longer to write a joint report than to have one author.

2 Evaluation

The success of the programme can be judged in terms of the impact it has had on the participants involved.

A major programme at one stage or another needs to prove its value. It has to show how far it has succeeded in what it set out to do. The practice of using objective and detached evaluators is widely accepted. Evaluators are selected for their special analytical skills and the knowledge of technical problems.

In evaluating a programme of this type, which in any case does not claim a high degree of academic sophistication, the danger of the evaluator misjudging the motives of the participants is quite real. It was found in the King's Fund study, that subjective accounts of those who have been involved in the study were sufficient proof of validity of the method. A statistical analysis of the facts collected has proved that providers of services are capable of collecting valid information.

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3 Diffusion

If a study is successful, that is if those engaged upon it make useful findings, the methods of study should be made available for application in other situations.

Researchers are usually unwilling to have free discussions on their techniques or instruments until their study has been completed. All questionnaires and methods as they develop should be shared not only with those who are providing the services but also with those who have shown an interest either in the approach or findings. The involvement of the staff in research promotes, in itself, a form of diffusion in the field of study and in allied fields where the staff have many other responsibilities. Such diffusion should facilitate change as and when it is felt by the participants to be necessary. When studying a human system the people running it should be allowed to take actions as they see the need. Timely action to alleviate a need is more important than proving academically a year or two later, that there was a need.

Papers and reports on the progress of the project should be circulated among participants and others sympathetic to the idea of involvement. The opportunity should be taken, where offered, for the active participants to speak about the project at outside meetings and seminars. Such activities result in attracting considerable correspondence and enquiry which needs to be attended to even after the project is over.

Conclusion

These guidelines are not presented as some sort of do-it-yourself blueprint for the evaluation of services. Our method can be of interest to those who feel obliged to interest themselves in the problems of changing organisations, and search for plans generating action through participation and involvement of the members at the cutting edge of the system.

The guidelines we have given do not, of course, dispense with the standard and widely practiced methods of social survey research. We have only attempted to strike a realistic balance between highly technical and rigorously planned academic designs worked out by experts and the practical wisdom and experience of all those with a first-hand fundamental knowledge of the real life interactions of services and consumers.

We have charged those carrying out day to day tasks with the responsibility of undertaking serious programmes for diagnosis (identification of problems) and the treatment (suggestions for improvements) at the same time. Mixing the strategies of diagnosis and treatment did present some problems but we have developed ways to minimise such difficulties to some extent.

There appears to be five distinctive, yet interdependent stages for a project of this kind to go through from its first conception to the final outcome. A wide variety of diverse skills will need to play a role in succeeding, and often overlapping, stages of the project.

[illegible] have charged those carrying out day to day tasks with the responsibility [illegible] undertaking serious programmes for diagnosis (identification of problems) and [illegible] treatment (suggestions for improvements) at the same time. Making the [illegible] diagnosis and treatment did present some problems but we have [illegible] minimise [illegible] difficulties to some extent.

There appear to be five distinctive, yet interdependent [illegible] kind to [illegible] ough from its first conception to the final [illegible] diverse [illegible] will need to play a role in succeeding [illegible] the [illegible]

APPENDIX A

SAMPLING OF COMMUNITY CASES

(Selection of Respondents)

There are many ways of sampling a population to be studied. In this Appendix, the methods of sampling used in this project are discussed.

Appendix A

METHOD OF SAMPLING

Size of the sample

The Research Advisory Group had agreed that a 5 per cent sample should be drawn from the TOTAL subnormal population known to be living in the community on 31 December 1969. Such a 'total population' had to include ALL age groups. The cases which are not 'active' were excluded from this TOTAL POPULATION.

Stratification

The total population(N) was stratified into Males (N_1) and Females (N_2). Five per cent of the total male population is designated (n_1) and 5 per cent of the total female population is designated (n_2).

'Sampling universe'

The population from which the actual sample is drawn had one dominant characteristic, and that is that it included all those known cases of subnormality who were born between 1 January 1940 and 31 December 1969, and are receiving services.

From the total male subnormal population (N_1) we separated those born between the above dates. This list of males under 30 (N_3) was our SAMPLING FRAME for males. Similarly, from the total female subnormal population (N_2) we took out females born between 1 January 1940 and 31 December 1969. This list of females under 30 (N_4) was our SAMPLING FRAME for females.

Systematic random sampling

Out of the two totals, namely N_3 and N_4, we drew a list of those to be surveyed.

In order to give a system to the selection of the first case, the sampling frames N_3 and N_4 were arranged on the basis of the date of birth. The OLDEST person was on the TOP of the list and the YOUNGEST at the BOTTOM. The arrangement for all cases between the top and the bottom was in descending order.

Appendix A

The first cases in N_3 and N_4 were therefore automatically selected. To get the sampling intervals (k_1 and k_2) at which the rest of the sample were drawn we divided N_3 and N_4 by n_1 and n_2 respectively, ie:

$$\frac{N_3}{n_1} = k_1 \quad \text{and} \quad \frac{N_4}{n_2} = k_2$$

In other words, our formula was:

$$\frac{\text{Total number of mentally subnormal males under 30}}{\text{5 \% of the total mentally subnormal male population}} = k_1$$

and similarly:

$$\frac{\text{Total number of mentally subnormal females under 30}}{\text{5 \% of the total mentally subnormal female population}} = k_2$$

(An arbitrary decision was made in those cases where sampling intervals (k_1 and k_2) were not round figures, but also had some fractions. For example, the value of k_1 and k_2 might have been 14.6 or 21.4. If the value was less than .5, eg 14.4 or 21.4, then we counted it as 14 or 21. If on the other hand it was .5 or more, eg 14.5 or 21.6 then we counted it as 15 or 22).

The number of cases drawn

We selected n_1 number of male cases from N_3 and n_2 number of female cases from N_4. The oldest case in N_3 and N_4 was automatically selected. We then proceeded to select every k_1th case in N_3, and every k_2th case in N_4 until we completed our required number of n_1 and n_2.

Illustration from Hounslow (the pilot area)

The sampling procedure used in Hounslow is used here as an illustration.

The total MS population living in the community and receiving services (N) was 403. N_1 was 199, and N_2 204. Five per cent of N_1 was approximately 10. In other words, $n_1 = 10$.

The total male MS population under 30 (N_3) was 156. To get the sampling interval at which the sample had to be drawn N_3 (156) was divided by n_1 (10).

$$\frac{156}{10} = k_1 \quad 15.6 \text{ (approximately 16)}$$

Appendix A

The cases were arranged in descending order. The first case, that is the oldest person in our sample frame, was thus selected. In all ten cases were needed.

The selection of cases was systematic:

1st case was the case on top of the list
2nd case was 1+16 = 17th on the list
3rd case was 17+16 = 33rd on the list
4th case was 33+16 = 49th on the list
5th case was 49+16 = 65th on the list
6th case was 65+16 = 81st on the list
7th case was 81+16 = 97th on the list
8th case was 97+16 = 113th on the list
9th case was 113+16 = 129th on the list
10th case was 129+16 = 145th on the list

Since we anticipated that some of the families selected would not cooperate, ten more names were drawn on the same basis.

The first substitute case was 145+16 = 161. But we had only 156 males on the list, and therefore the 5th case from the top became our first substitute case. The same procedure was applied to get the rest of the substitute sample.

1st was 5th on the list
2nd was 21st on the list
3rd was 37th on the list
4th was 53rd on the list
5th was 69th on the list
6th was 85th on the list
7th was 101st on the list
8th was 117th on the list
9th was 133rd on the list
10th was 149th on the list

The female sample in Hounslow had also been made in the same way.

There are many other methods of sampling a population, but our experience has shown that the procedures described above were satisfactory for the purposes of this survey.

Selection of professionals

The selection of general practitioners was not made from information contained on the case files because a high proportion of the files did not have recorded the name of the present or past GPs. Instead they were made on the basis of information provided by the parents.

Appendix A

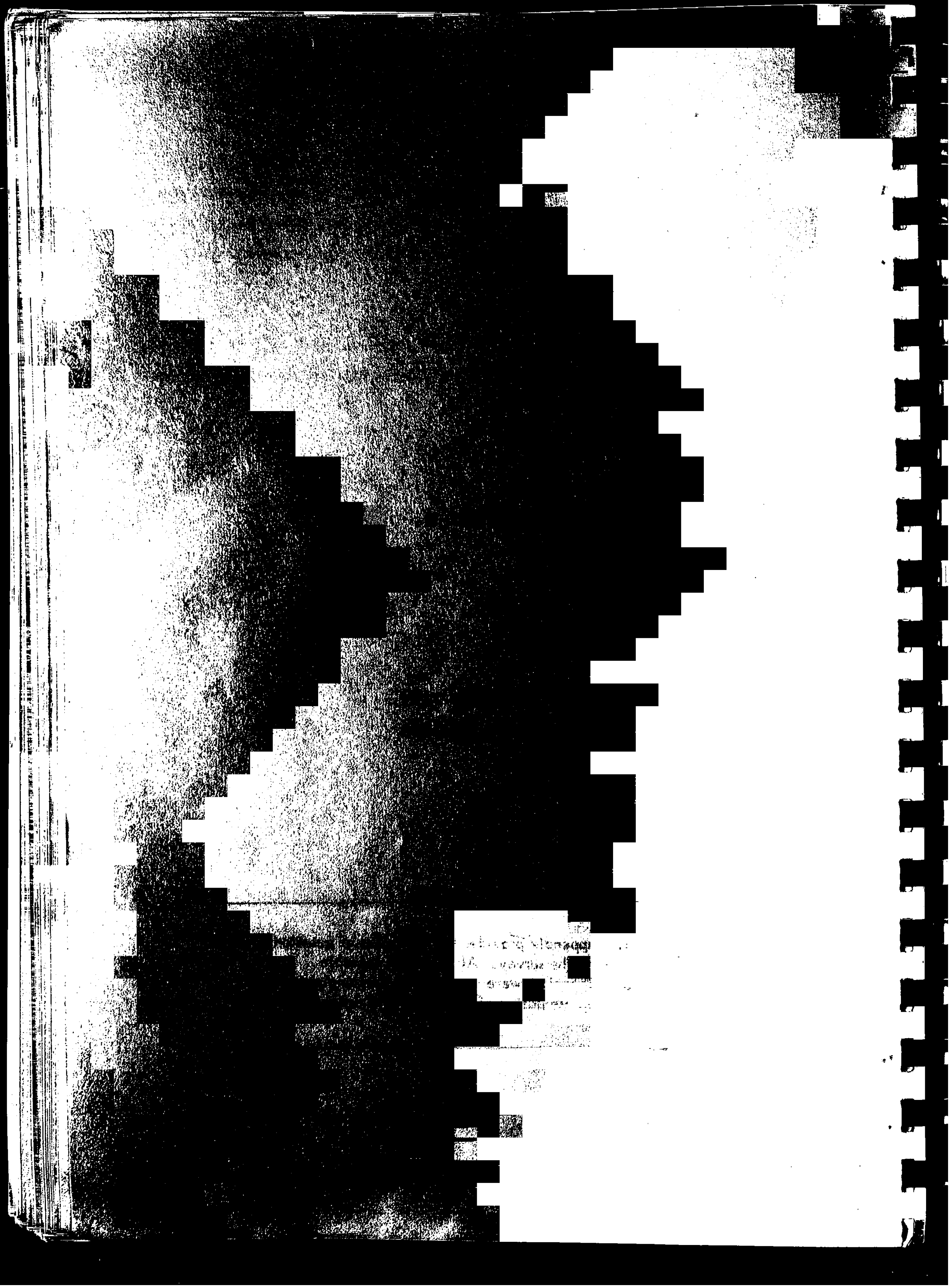
The local authorities' health department were given a list of the sample and only those mental welfare officers who had exercised supervision of the case were asked to respond. Similarly with the health visitors, except that those health visitors who were responsible for the area in which the child lived, but had not necessarily visited the family, were asked to respond.

The sample list was provided to all junior training centres, adult training centres and all other schools for the handicapped. Those teachers who had personal knowledge of the case were asked to respond.

APPENDIX B

COPIES OF TWO QUESTIONNAIRES

This appendix provides two examples of questionnaires used in the survey. Although six separate questionnaires were used, the two examples provided are representative of the types of questions asked.



Appendix B

QUESTIONNAIRE FOR PARENTS*

Code number of the handicapped
Name of local authority
Name of the interviewer
Length of the interview
Date of the interview
Handicapped living in hospital .... community ....

PERSONAL DETAILS (OF THE HANDICAPPED)

1 Surname 2 Christian names
3 Date of birth Age 4 Sex
5 Address(es) How long has your family lived here ?
5.1 Present (from .... until ....)
5.2 Past (from .... until ....)
6 PLACE OF BIRTH OF THE HANDICAPPED
At home At hospital
7 PARENTS
Father Age Specify occupation
Mother
Other spouse if natural spouse dead or separated or divorced
8 SIBLINGS (Mark the 'place' of the handicapped in the family)

Name	Sex	Date of birth	School	Occupation	Marital status	Living at home or not

(Ask about any miscarriages or stillbirths - record order in which miscarriage occurred and ask about length of pregnancy)

9 Could you please tell me what do you believe is wrong with your child ?
10 Where does the handicapped normally reside ?

Foster home) Q 11
Adoptive home)
Own home Q 13

LA Children's home)
LA hostel)
Hospital hostel) Q 12
Hospital)
Weekly boarding unit)

11 Ask only if S/N person is being looked after by relatives or people other than parents. Do not ask of those living in institutions.

---

* This appendix merely lists the questions asked and does not indicate the format of the questionnaire .

Appendix 8

QUESTIONNAIRE FOR PARENTS*

Code number of the handicapped

Name of local authority

Name of the interviewer

Length of the interview

Date of the interview

Handicapped living in hospital . . . . community . . . .

PERSONAL DETAILS (OF THE HANDICAPPED)

1 Surname 2 Christian names

3 Date of birth Age 4 Sex

5 Address(es). How long has your family lived here ?

5.1 Present (from . . . . until . . . .)

5.2 Past (from . . . . until . . . .)

6 PLACE OF BIRTH OF THE HANDICAPPED

At home At hospital

7 PARENTS

	Age	Specify occupation
Father		
Mother		
Other spouse if natural spouse dead or separated or divorced		

8 SIBLINGS (Mark the 'place' of the handicapped in the family)

Name	Sex	Date of birth	School	Occupation	Marital status	Living at home or not

(Ask about any miscarriages or stillbirths - record order in which miscarriage occurred and ask about length of pregnancy)

9 Could you please tell me what do you believe is wrong with your child ?

10 Where does the handicapped normally reside ?

Foster home)
Adoptive home) Q 11
Own home Q 13

LA Children's home)
LA hostel)
Hospital hostel) Q 12
Hospital)
Weekly boarding unit)

11 Ask only if S/N person is being looked after by relatives or people other than parents. Do not ask of those living in institutions.

---

* This appendix merely lists the questions asked and does not indicate the format of the questionnaire.

Appendix B

11.1 What is your relationship to the handicapped child ?

(Specify) Foster parent .... Adoptive parent ....

11.2 Composition of the family in which the child resides:

Name	Sex	Date of Birth	School Education	Occupation	Marital status

Ask only if handicapped person is residing in an institution (hostel, hospital etc) for long term care.

12 Could you please tell me the name of the hospital/hostel ?

12.1 How long has he/she been there ? From ....

12.2 Who arranged his/her admission ?

12.2.1 Why was the admission arranged ?

12.2.2 How long did he/she have to be on the waiting list for long term admission ?

12.3 How far is the hospital/hostel from your house ?

a In distance b In travelling time

12.3.1 How often do you see him/her in hospital/hostel ?

12.3.2 Does he/she come home ? Yes/No

12.3.3 (If yes) How often and for how long ?

12.4 Are you satisfied with this arrangement ? Yes/No

12.4.1 (If no) Why not ?

12.5 Are you satisfied with his/her stay in hospital/hostel ? Yes/No

12.5.1 (If no) Why not ?

13 How old was the child when you first suspected that he/she might be handicapped ?

13.1 What made you suspect it ?

13.2 What did you do about it ?

13.2.1 (If seeking advice mentioned) What happened, and what advice was given to you ?

14 Who referred your child to a specialist in the first place ?

14.1 Who actually confirmed that the child was handicapped, who was the specialist and what advice did he give you ?

14.2 How long did you have to wait before your child was actually seen by a specialist ?

14.2.1 How was the assessment made ? Was your child admitted to hospital for observation and investigation ? Or was your child assessed as an outpatient ?

Inpatient .... Outpatient ....

14.2.2 Were you satisfied with the consultation and advice given ? Yes/No

14.2.3 (If no) What did you do then ?

14.2.4 Looking back, do you think you were able to accept the advice given to you ?

14.2.5 (If yes) In what way ?

1.1 What is your relationship to the handicapped child ?

(Specify) Foster parent . . . . Adoptive parent . . . .

11.2 **Composition** of the family in which the child resides

Name Sex Date of Birth [illegible] Education Occupation Marital status

Ask only if handicapped person is re[illegible] in an institution (**hostel**, hospital etc) for long term care.

12 Could you please tell me the name of [illegible]

12.1 How long has he/she been there ?

12.2 Who arranged his/her admission ?

12.2.1 **Why** was the admission arranged ?

12.2.2 **How long** did he/she have to [illegible] admission ?

12.3 **How far** is the hospital/hostel from your house ?

a In distance b In travelling time

12.3.1 How often do you see him/her in **hospital**/hostel ?

12.3.2 **Does** he/she come home ? Yes/No

12.3.3 (If yes) How often and how long

12.4 Are you satisfied with this arrangement

12.4.1 (If no) Why not ?

12.5 Are you **satisfied** with his/her stay in hospital ? Yes/No

12.5.1 (If no) Why not ?

13 **How old** was the **child** when you **first** suspected that he/she might be handicapped ?

13.1 **What made** you **suspect** it ?

13.2 What did you do about it ?

13.2.1 (If **seeking advice** mentioned) What happened, **and** what advice was given to you ?

14 Who [illegible] child to a specialist in the **first place** ?

14.1 Who [illegible] confirmed that the child was handicapped, who was the specialist and what **advice** did he give you ?

14.2 **How** long did you have to wait before your child was actually seen by a specialist ?

14.2.1 How was the assessment made ? **Was your** child admitted to hospital for observation and investigation ? Or was your child assessed as an outpatient ?

Inpatient . . . . Outpatient . . . .

14.2.2 Were you satisfied with the consultation and advice given ? Yes/No

14.2.3 (If no) What did you do **then** ?

14.2.4 Looking back, do you think **you were** able to accept the advice given to you ?

14.2.5 (If yes) In what way ?

14.2.6 (If no) Why not ?

14.3 Were you satisfied with the manner in which you were told that the child was handicapped ? Yes/No

14.3.1 (If no) Why not ?

15 After this first referral your child was perhaps seen by other specialists. Could you please recall who these were and what happened ?

Specialist & hospital	Referred by	Diagnosis	Age of child on diagnosis	Satisfaction with diagnosis Very satisfied Satisfied Very dissatisfied Dissatisfied

16 Who is your own doctor ?

Name and address

16.1 Is he the same doctor you had at the time the child was born ? Yes/No

16.1.1 (If no) Could you please tell me the names of the other doctors ?

Name and address

Let us now talk about the first three years of his/her life.

17 Did you face any special problems in looking after the child in the first three years of his/her life ? (Please read out the following categories. Put a cross against categories where problems faced).

Sleep pattern ...
Feeding ...
Drinking from cup ...
Sitting up ...
Incontinence - control of bladder and bowel ...
Walking ...
Talking ...
Weaning ...
Dressing ...
Other ...

18 Who helped you most in respect of the care of the child during the first three years ?

18.1 In what way do you think (name the person mentioned above) helped you ?

19 Did your own doctor help you ? Yes/No

19.1 (If yes) In what way do you think he helped you ?

19.1.1 (If no) Did you seek his help ? Yes/No

19.1.2 (If yes) What advice did he give you ?

19.2 How best do you think family doctors could help parents with mentally handicapped children ?

19.3 Is it fairly easy for you to consult your own doctor about the mental handicap of the child ?

20 What help and advice did you get from your health visitor regarding your child ?

20.1 Do you think that the advice you received was useful ? Yes/No

20.1.1 (If yes) In what way ?

20.1.2 (If no) Why do you think so ?

20.2 Do you think your health visitor got the necessary help ? Yes/No

20.2.1 (If no) How long did you have to wait to be referred ?

Appendix B

20.2.2 (If obtaining help mentioned) Whose help did the health visitor get, and what was the help ?

20.3 Has it been fairly easy for you to consult your health visitor on matters pertaining to the mental handicap of your child ? Yes/No

20.3.1 (If no) Why is that ?

21 Did you receive any advice from the clinic doctor regarding the mental handicap of your child ? Yes/No

21.1 In what way do you think he/she helped you ?

21.1.1 (If no advice was received) Why not ?

22 Have you/your husgand ever seen the medical officer from the local authority health department regarding the handicap of your child ?

No or never - go to Question 22.4

22.1 How often do you see him ?

22.2 Who referred you to him ?

Own effort ....
Medical officer of health invited ....
Someone referred (specify who) ....

22.3 What advice did he give you ?

22.3.1 Did you find this advice useful ? Yes/No

22.3.2 (If yes) In what way ?

22.3.3 (If not) Why not ?

22.4 How best do you think a medical officer from the local authority health department can help you ?

22.5 Is it fairly easy for you to get in touch with the medical officer from the authority health department ? Yes/No

22.5.1 (If no) Why is that ?

23 Are you visited by a mental welfare officer ? Yes/No

23.1 (If yes) How often does he call ?

23.1.1 Do you find these visits useful ? Yes/No

23.1.2 (If yes) In what way ?

23.1.3 (If no) Why not ?

23.2 What do you suggest his role should be in relation to the families with handicapped children ?

23.3 Would it help if he visited you more often ? Yes/No

23.3.1 (If yes) How would it help ?

23.3.2 (If no) Why do you think so ?

24 Have you got any friends and neighbours or relatives who help you in any way with regard to your handicapped child ? Yes/No
(If no) Go to Q 25.

Appendix B

20.2.2 (If obtaining help mentioned) Whose help did the health visitor get, and what was the help ?

20.3 Has it been fairly easy for you to consult your health visitor on matters pertaining to the mental handicap of your child ? Yes/No

20.3.1 (If no) Why is that ?

21 Did you receive any advice from the clinic doctor regarding the mental handicap of your child ? Yes/No

21.1 In what way do you think he/she helped you ?

21.1.1 (If no advice was received) Why not ?

22 Have you/your husband ever seen the medical officer from the local authority health department regarding the handicap of your child ?

No or never — go to Question 22.4

22.1 How often do you see him ?

22.2 Who referred you to him ?

Own effort ....
Medical officer of health invited ....
Someone referred (specify who) ....

22.3 What advice did he give you ?

22.3.1 Did you find this advice useful ? Yes/No

22.3.2 (If yes) In what way ?

22.3.3 (If not) Why not ?

22.4 How best do you think a medical officer from the local authority health depar can help you ?

22.5 Is it fairly easy for you to get in touch with the medical officer from the autho health department ? Yes/No

22.5.1 (If no) Why is that ?

23 Are you visited by a mental welfare officer ? Yes/No

23.1 (If yes) How often does he call ?

23.1.1 Do you find these visits useful ? Yes/No

23.1.2 (If yes) In what way ?

23.1.3 (If no) Why not ?

23.2 What do you suggest his role should be in relation to the families with handicapped children ?

23.3 Would it help if he visited you more often ? Yes/No

23.3.1 (If yes) How would it help ?

23.3.2 (If no) Why do you think so ?

24 Have you got any friends and neighbours or relatives who help you in any way with regard to your handicapped child ? Yes/No
(If no) Go to Q 25.

24.1 (If yes) What sort of help do they give you ?

Kind of help Given by friend/neighbour/relative

25 Do you meet other parents with handicapped children ? Yes/No

25.1 (If yes) Where do you meet them ?

25.1.1 How often ?

25.1.2 Does it help to meet such parents ? Yes/No

25.1.3 (If yes) In what way ?

25.1.4 (If no) Why do you think so ?

25.2 (If does not meet parents) Would it help to meet such parents ? Yes/No

25.2.1 (If yes) In what way ?

25.2.2 (If no) Why do you think so ?

26 Are you a member of any voluntary organisations ? (If needed please name the organisations known in the area) Yes/No

(If no) Go to Question 26.1.2

26.1 (If yes) What are they ?

26.1.1 How active are you in these organisations ?

26.1.2 Do voluntary organisations in this area help you in any way ? Yes/No

26.1.3 (If yes) In what way ?

26.1.4 (If no) Why is that ?

27 We have so far been talking about your child when he/she was very young. When he/she was under school age did he/she go to a day nursery or play group ? Yes/No

(If no) Go to Question 28.

27.1 (If yes) Which one ?

27.1.1 For how long ?

27.2 How long did he/she have to wait to be admitted ?

27.2.1 (If delay was mentioned) Why do you think there was this delay ?

27.3 Who helped you to get him/her into a nursery ?

27.3.1 Did going to this nursery help the child in any way ? Yes/No

27.3.2 (If yes) In what way ?

27.3.3 (If no) Why not ?

28 Now let us talk about the education and training of the child. What type of education/training were you told he/she should receive ?

28.1 Who decided it ?

28.1.1 How old was the child when this decision was made ?

Appendix B

28.1.2 What sort of assessment was made ? Could you please describe it.

28.1.3 Did you get a written report or were you informed verbally ?

Written report ..... Verbally .....

28.1.4 (If verbally) By whom ?

28.2 Who helped you to understand and accept this decision at that time ?

29 Please tell me about the school and training centres the child has attended, and for how long ? Were you satisfied with the training and education he/she received there ?

Institution	From	Until	Type of Training	Very satisfied Very dissatisfied	Satisfied Dissatisfied

FOR THOSE IN EMPLOYMENT

30 Is your son/daughter working somewhere ? Yes/No Inapplicable Too young to work

(If no) Go to Question 31

30.1 Did anyone help him/her to find employment ? Yes/No

30.1.1 (If yes) Who was it ?

30.1.2 What happened ?

30.1.3 (If no) Did you seek help ? Yes/No

30.1.4 (If yes) Whom did you ask ?

30.1.5 What happened ?

30.2 (If disabled person's register or disabled resettlement officer NOT mentioned) Has he/she been in touch with the DRO ? Yes/No

30.2.1 (If yes) What happened ?

30.2.2 (If no) Why not ?

IF S/N IS OF EMPLOYABLE AGE AND IS UNEMPLOYED

31 Do you think he/she can be employed ? Yes/No

(If no) Go to Question 32. Inapplicable Too young - Go to Question 32.

31.1 (If yes) What kind of job do you think he/she could do ?

31.1.1 Who could help him/her find such a job ?

31.1.2 Have you ever asked for such help ? Yes/No

31.1.3 (If yes) What happened ?

31.2 (If disabled person's register or disablement resettlement officer not mentioned) Has he/she been in touch with the DRO ? Yes/No

31.2.1 (If yes) What happened ?

31.2.2 (If no) Why not ?

FOR THOSE IN COMMUNITY

32 Has he/she ever been admitted for short term care ? Yes/No
(If no) Go to Question 32.3.

FOR THOSE IN LONG TERM CARE

32.1 Before being admitted to the hospital this time, was any short term care arranged for him/her ? Yes/No
(If no) Go to Question 32.3.

Appendix 8

28.1.2 What sort of assessment was made ? Could you please describe it

28.1.3 Did you get a written report or were you informed verbally ?

Written report ...... Verbally ......

28.1.4 (If verbally) By whom ?

28.2 Who helped you to understand and accept this decision at that time ?

29 Please tell me about the school and training centres the child has attended, and for how long ? Were you satisfied with the training and education he/she received there ?

Institution	From	Until	Type of Training	Very satisfied Very dissatisfied	Satisfied Dissatisfied

FOR THOSE IN EMPLOYMENT

30 Is your son/daughter working somewhere ? Yes/No Inapplicable Too young to work

(If no) Go to Question 31

30.1 Did anyone help him/her to find employment ? Yes/No

30.1.1 (If yes) Who was it ?

30.1.2 What happened ?

30.1.3 (If no) Did you seek help ? Yes/No

30.1.4 (If yes) Whom did you ask ?

30.1.5 What happened ?

30.2 (If disabled person's register or disabled resettlement officer NOT mentioned) Has he/she been in touch with the DRO ? Yes/No

30.2.1 (If yes) What happened ?

30 2.2 (If no) Why not ?

IF S/N IS OF EMPLOYABLE AGE AND IS UNEMPLOYED

31 Do you think he/she can be employed ? Yes/No

(If no) Go to Question 32. Inapplicable Too young - Go to Question 32.

31.1 (If yes) What kind of job do you think he/she could do ?

31.1.1 Who could help him/her find such a job ?

31.1.2 Have you ever asked for such help ? Yes/No

31.1.3 (If yes) What happened ?

31.2 (If disabled person's register or disablement resettlement officer not mentioned) Has he/she been in touch with the DRO ? Yes/No

31.2.1 (If yes) What happened ?

31.2.2 (If no) Why not ?

32 FOR THOSE IN COMMUNITY

Has he/she ever been admitted for short term care ? Yes/No

(If no) Go to Question 32.3.

FOR THOSE IN LONG TERM CARE

32.1 Before being admitted to the hospital this time, was any short term care arranged for him/her ? Yes/No

(If no) Go to Question 32.3.

32.2 (If yes) Where and for how long ? Who referred him/her ?

Age of child	Referred by	Institution	Waiting period	Type of care short/long (specify)	Reasons for admission	Very satisfied Satisfied Very dissatisfied Dissatisfied

32.3 What help do subnormality hospitals offer to the mentally handicapped and their families ?

33 How is his/her general health ?

Sound .... Poor ....

33.1 Any defect in speech ?

No defect .... Slight defect .... Severe defect .... Total disability ....

33.2 What about his/her eye sight ?

No defect .... Slight defect .... Severe defect .... Total disability.....

33.3 And his/her hearing ?

No defect .... Slight defect .... Severe defect .... Total disability ....

33.4 Is he/she incontinent ?

Fully continent ....
Semi-incontinent ....
Occasionally incontinent ....
Totally incontinent ....

33.5 Are there any problems with his/her sleep ? Yes/No

(If yes) Getting to sleep .... Waking up during the night ....

33.6 Are there any problems with feeding ? Yes/No

(If yes) Unable to feed himself .... Unable to drink from an ordinary cup ....
Unable to use a knife and fork.... Other (specify) ....

33.7 Can he/she go outdoors ?

Yes	No ....
Goes everywhere on his/her own	Child too young.....
Unable to go out for a walk on his/her own	Unable to sit without support ....
Unable to use public transport without escort	Unable to walk at all ....
Uses wheelchair	Uses wheelchair ....
Has difficulty in negotiating stairs	Difficulty in negotiating steps ....
	Can negotiate steps ....
	Is house bound ....
	Is bed ridden ....

33.8 Can he/she wash himself/herself ?

Yes .... No .... Inapplicable - Too young ....

33.9 Can he/she dress himself/herself ?

Yes .... No .... Inapplicable - Too young ....

33.10 Can he/she read ?

Yes - no problem ....
No . can't read ....
Yes - with some difficulty ....
Inapplicable - too young ....

Appendix B

33.11 Can he/she write ?

Yes - no problem ....   Yes - has some difficulty ....
No - can't write ....   Inapplicable - too young ....

33.12 Can he/she tell the time ?

Yes ....   No ....   Inapplicable - too young ....

33.13 Can he/she understand money ?

Yes - no problem ....   Yes - has some difficulty ....
No - doesn't understand money ....   Inapplicable - too young ....

33.14 Has he/she got suitable friends, playmates ?

Yes - plays with other siblings ....
Yes - friends at school ....
Yes - friends in neighbourhood ....
Yes - goes to clubs, camps ....
No - no friends at all ....

33.15 (If the handicapped is an adolescent or adult) Are there any problems regarding his/her sex life ?

Yes ....   No ....   Inapplicable - too young ....

33.16 Are there any other problems that he/she faces now which we have not talked about so far ?

33.16.1 (If yes) What are they ?

34 What problems do you and other members of your family face now because of him/her ?

34.1 Have you asked for any help from any authorities or services with regard to problems faced by him/her, or by your family ?

(If no) Go to Question 35.

34.1.1 What were the problems for which you needed help ?

34.1.2 Whom did you ask ?

34.1.3 What happened ?

35 After the birth of this son/daughter, did you get any advice on having more children ? Yes/No

(If no) Go to Question 36.

35.1 Did you ask for advice or was it given to you ?

Advice asked for ....   Advice given ....

35.1.1 Whom did you ask ?   35.1.3 Who gave it to you ?

35.1.2 What advice was given ?   35.1.4 What advice was given ?

35.2 Was any investigation or examination done to find out if you should have more children or not ? Yes/No

35.2.1 (If yes) What sort of investigation was it ? Who arranged it and who did it ?

33.11 Can he/she write ?

Yes - no problem . . . . Yes - has some difficulty . . . .
No - can't write . . . . Inapplicable - too young . . . .

33.12 Can he/she tell the time ?

Yes . . . . No . . . . Inapplicable - too young . . . .

33.13 Can he/she understand money ?

Yes - no problem . . . . Yes - has some difficulty . . . .
No - doesn't understand money . . . . Inapplicable - too young . . . .

33.14 Has he/she got suitable friends, playmates ?

Yes - plays with other siblings . . . .
Yes - friends at school . . . .
Yes - friends in neighbourhood . . . .
Yes - goes to clubs, camps . . . .
No - no friends at all . . . .

33.15 (If the handicapped is an adolescent or adult) Are there any problems regarding his/her sex life ?

Yes . . . . No . . . . Inapplicable - too young . . . .

33.16 Are there any other problems that he/she faces now which we have not talked about so far ?

33.16.1 (If yes) What are they ?

34 What problems do you and other members of your family face now because of him/her ?

34.1 Have you asked for any help from any authorities or services with regard to problems faced by him/her or by your family ?

(If no) Go to Question 35.

34.1.1 What were the problems for which you needed help ?

34.1.2 Whom did you ask ?

34.1.3 What happened ?

35 After the birth of this son/daughter, did you get any advice on having more children ? Yes/No

(If no) Go to Question 36.

35.1 Did you ask for advice or was it given to you ?

Advice asked for . . . . Advice given . . . .

35.1.1 Whom did you ask ? 35.1.3 Who gave it to you ?

35.1.2 What advice was given ? 35.1.4 What advice was given ?

35.2 Was any investigation or examination done to find out if you should have more children or not ? Yes/No

35.2.1 (If yes) What sort of investigation was it ? Who arranged it and who did it ?

36 There are various services and facilities provided for mentally handicapped and their families. What could help you and your child to lead an easier life now and in the future ?

OBSERVATION

Type of accommodation

Whole house .... House shared with others ....
Bungalow .... Self contained flat - upstairs ....
ground floor ....

Rooms .... Council house .... Council flat ....

Ownership

Owner/occupier .... LA .... Private rented (furnished) ....
Private vented (unfurnished) ....

Amenities

Toilet facilities inside - upstairs .... downstairs ....
Toilet facilities inside - both upstairs and downstairs ....
Toilet facilities outside ....
Toilet facilities convenient for handicapped person ....
Toilet facilities inconvenient for handicapped person ....
Bathroom in the house ....
No bathroom in the house ....
Garden or yard available for play in safety ....
No place accessible for handicapped child to play ....

Interviewer's assessment

	Good	Adequate	Poor
Structure			
Decoration			
Furniture			

Response of the family

Family had agreed to be interviewed after the first letter ...
Family had initially refused but agreed after subsequent contact through letter/telephone/visit of MWO/hospital ....

Cooperation

Both parents cooperative ....
Mother cooperative, father uncooperative ....
Father cooperative, mother uncooperative ....
Both parents uncooperative ....

Who else was present at the time of the interview ?

Both parents present all the time ....
Mother was not present ....
Father was not present ....
Other children were present ....
Other adults were present ....

Appendix B

QUESTIONNAIRE FOR MENTAL WELFARE OFFICERS *

Code number of the handicapped

Name of local authority

Name of the interviewer

Length of the interview

Date of the interview

Handicapped living in hospital or community

If handicapped in hospital – name and address of this hospital

PART I

1 Surname of the handicapped 2 Christian names

3 Address

4 How long has this case been known to your department ?

4.1 Who referred him/her to the mental health in the first place, and when ?

5 How long have you been supervising the case ?

6 When did you last visit the family ?

6.1 How often do you visit the family ?

7 Do you think this family would benefit if you could visit more often ? Yes/No

7.1 Why do you say that ?

8 What do you think is the handicap of this child ?

9 What help does he/she need because of this handicap ?

9.1 Who do you think can provide this help ?

10 What problems do you think this family faces now because of this handicap ?

10.1 Who could offer this help to the family ?

10.2 What major problems are likely to occur for the family in the future ?

10.3 Who could help the family then ?

11 How competent in your opinion are the mother and father to cope with this problem ?

11.1 Are there any relatives, or friends or neighbours who offer help to this family ?
Yes/No
(If no) Go to Question 12.

11.2 (If yes) Do you know who they are, and what kind of help do they provide ?

12 When the family became first known to your department, what kind of support was provided to the family ?

12.1 What support is being provided now ?

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* This appendix merely lists the questions asked and does not indicate the format of the questionnaire.

Appendix 8

QUESTIONNAIRE FOR MENTAL WELFARE OFFICERS *

Code number of the handicapped

Name of local authority

Name of the interviewer

Length of the interview

Date of the interview

Handicapped living in hospital or community

If handicapped in hospital - name and address of this hospital

PART 1

1 Surname of the handicapped 2 Christian names

3 Address

4 How long has this case been known to your department ?

4.1 Who referred him/her to the mental health in the first place, and when ?

5 How long have you been supervising the case ?

6 When did you last visit the family ?

6.1 How often do you visit the family ?

7 Do you think the family would benefit if you could visit more often ? Yes/No

7.1 Why do you say that ?

8 What do you think is the handicap of this child ?

9 What help does he/she need because of this handicap ?

9.1 Who do you think can provide this help ?

10 What problems do you think this family faces now because of this handicap ?

10.1 Who could offer this help to the family ?

10.2 What major problems are likely to occur for the family in the future ?

10.3 Who could help the family then ?

11 How competent in your opinion are the mother and father to cope with this problem ?

11.1 Are there any relatives, or friends or neighbours who offer help to this family ?
Yes/No
(If no) Go to Question 12

11.2 (If yes) Do you know who they are, and what kind of help do they provide ?

12 When the family became first known to your department, what kind of support was provided to the family ?

12.1 What support is being provided now ?

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* This appendix merely lists the questions asked and does not indicate the format of the questionnaire.

Appendix B

12.2 If you were not under so much pressure of work, what help could you have given to this family ?

13 How old was this child when it was first suspected that he/she might be mentally handicapped ?

13.1 Who first suspected it ?

13.2 What made them suspect it ?

13.3 Who actually confirmed that this child was mentally handicapped ?

13.4 How was this confirmation done ?

13.5 How old was the child then ?

13.6 Did the family accept the handicap at that time ?

13.7 Does the family accept it now ?

14 Who is the family's general practitioner now ?

15 There are many voluntary and statutory services in the community to help such families. Have you or other MWOs ever been approached by any of these for any help for this family ? Yes/No

15.1 (If yes) Who are these, and what sort of help was requested of the mental welfare officers ?

Name of agency Reason for contact Date

15.2 Have you or other mental welfare officers ever contacted any of the services to obtain some help for this family ? Yes/No

15.3 (If yes) Whom did you ask and what about ?

Name of agency Reason for contact Date

16 What type of education/training is the child receiving, or has received ?

16.1 Do you know how this decision was taken, that he/she should have such a type of education/training ?

17 How is his/her general health ?

Sound .... Poor ....

17.1 Any defect in his/her speech ?

No defect .... Slight defect .... Severe defect .... Total disability ....
Don't know ....

17.2 What about his/her eye sight ?

No defect .... Slight defect .... Severe defect .... Total disability ....
Don't know ....

17.3 And his/her hearing ?

No defect .... Slight defect .... Severe defect .... Total disability ....
Don't know ....

12.2 If you were not under so much pressure of work, what help could you have given to this family ?

13 How old was this child when it was first suspected that he/she might be mentally handicapped ?

13.1 Who first suspected it ?

13.2 What made them suspect it ?

13.3 Who actually confirmed that this child was mentally handicapped ?

13.4 How was this confirmation done ?

13.5 How old was the child then ?

13.6 Did the family accept the handicap at that time ?

13.7 Does the family accept it now ?

14 Who is the family's general practitioner now ?

15 There are many voluntary and statutory services in the community [illegible] families. Have you or other MWOs ever been approached by any [illegible] for any help for this family ? Yes/No

15.1 (If yes) Who are these, and what sort of help was requested of the [illegible] officers ?

Name of agency Reason for contact Date

15.2 Have you or other mental welfare officers ever contacted any of the services to obtain some help for this family ? Yes/No

15.3 (If yes) Whom did you ask and what about ?

Name of agency Reason for contact Date

16 What type of education/training is the child receiving, or has received ?

16.1 Do you know how the decision was taken, that he/she should have such a type of education/training

17 How is his/her general health ?

Sound .... Poor ....

17.1 Any defect in his/her speech ?

No defect .... Slight defect .... Severe defect .... Total disability ....
Don't know ....

17.2 What about his/her eye sight ?

No defect .... Slight defect .... Severe defect .... Total disability
Don't know ....

17.3 And his/her hearing ?

No defect .... Slight defect .... Severe defect .... Total disability ....
Don't know ....

17.4 Is he/she incontinent ?

Fully continent .... Occasionally incontinent ....
Semi-incontinent .... Totally incontinent ....
Don't know ....

17.5 Can he/she go outdoors ? Yes .... No .... Don't know ....

(If yes) Goes everywhere on his/her own ....
Unable to go out for a walk on his/her own ....
Unable to use public transport without escort ....
Uses wheelchair ....
Has difficultyiin negotiating steps ....

(If no) Child too young ....
Unable to sit without support ....
Unable to walk at all ....
Uses wheelchair ....
Difficulty in negotiating steps ....
Can negotiate steps ....
Is house bound ....
Is bed ridden ....

17.6 Can he/she wash himself/herself ?

Yes .... No .... Don't know .... Inapplicable - too young ....

17.7 Can he/she dress himself/herself ?

Yes .... No .... Don't know .... Inapplicable - too young ....

17.8 Are there any problems with his/her sleep ?

Yes .... No .... Don't know ....

(If yes) Getting to sleep ....
Waking up during the night ....

17.9 Are there any problems with feeding ?

Yes .... No .... Don't know ....

(If yes) Unable to feed himself ....
Unable to drink from an ordinary cup ....
Unable to use knife and fork ....
Other (specify)

17.10 Do you know what is his/her IQ ?

Yes .... No .... Don't know ....

17.11 (If yes) What is it ? Could you tell me when he/she was tested for it and by whom ?

17.12 Has he/she got suitable friends, playmates ?

Yes .... No .... Don't know ....

(If yes) Yes - plays with other siblings ....
Yes - friends at school ....
Yes - friends in the neighbourhood ....
Yes - goes to clubs, camps ....
No - no friends at all ....

Appendix B

17.13 How is he/she classified by your department ?

Severely subnormal .... Subnormal ....
Mongol .... Hydrocephalic .... Microcephalic ....
Cerebral palsy .... Epileptic .... Any other (specify) ....

17.14 Do you know if this child was tested for phenylketonuria ?

Yes .... No .... Don't know

(If yes) Was it positive or negative ?

18 Do you think the accommodation that the family has is adequate for the needs of the handicapped person ?

19 Do you think that this case file provides you with sufficient information to help this family ?

Yes .... No ....

19.1 (If no) Why not ?

PART II

20 What do you think should be the role of a mental welfare officer in relation to families with mentally handicapped children ?

21 What help and assistance can a health visitor provide to such families ?

22 How best do you think a general practitioner can help parents with mentally handicapped children ?

23 What role can a medical officer from the local authority health department play in helping such families ?

24 In your opinion what is an adequate service that the mental health department can provide for the families with mentally handicapped children ?

25 What assistance can be offered by local voluntary organisations ?

26 Who could help the mentally handicapped adolescents in finding suitable jobs ?

27 Who should advise the parents with young subnormal children to obtain genetic counselling ?

28 Under what circumstances would you advise a family to send a handicapped person for short term care ?

29 Under what circumstances would you advise long term care ?

30 It is often said these days that a number of patients in the subnormality hospitals should live in the community. In your opinion, what types of persons could be discharged and what conditions would you like to see before they come out ?

31 In your opinion what measures could be taken to improve the coordination of services for the mentally subnormal ?

32 In your opinion, what are the services provided by the mental subnormality hospitals to the mentally handicapped ?

Appendix B

33 Name of mental welfare officer

34 Qualifications

35 Age

36 Length of service as mental welfare officer

- a in this department
- b before

37 Total caseload

	Categories	Number
a	mentally ill - short term long term	
b	mentally subnormal	
c	any other special duties	

APPENDIX C

THE LAW OF INVOLVEMENT

This appendix outlines the derivation of the law of involvement and demonstrates its very high level of statistical significance.

Appendix C

THE LAW OF INVOLVEMENT

The law of involvement was derived by observing the relationship between the six indices that had been used to examine in more detail the operation of the services. These six indices were:

disability of the handicapped person (D)
parental activity (A)
activity of the mental welfare officer (M)
interservice coordination (C)
services received by the handicapped and family (S)
satisfaction or fulfilment of parents (F)

An analysis of the six quantities, D, A, M, C, S and F measured as they vary across the 204 handicapped persons in the community sample, showed them to be significantly and positively related. We called this relationship the Law of Involvement. The demonstration of this relationship is as follows.

Suppose we take our sample of 204 parental interviews (or of questionnaires filled in by mental welfare officers; or of searches made of the official files; or of any other of the channels through which we tried to discover what is going on and from which our measures are constructed) and arrange this sample in rank order of some measure, such as D, disability, or F, parental fulfilment.

We then divide the sample into four approximately equal parts, each of about 51 cases; those with the highest values of the measure form the upper quartile, those with the next highest the upper median, and so forth. We can then work out the average values of the other measures in each of the four sets into which we have cut up our 204 cases. As an illustration of this analysis, we show in Table C-1, the results after so dividing them into four parts according to the criterion of A, parental activity.

TABLE C-1

Measure of involvement	Lower quartile of A	Lower median of A	Upper median of A	Upper quartile of A
A	7.1	14.9	20.2	29.1
D	14.5	15.6	17.4	21.0
M	13.0	13.7	14.2	16.6
C	12.6	13.9	14.6	19.8
S	18.6	19.4	20.4	22.0
F	21.7	23.9	21.4	25.3

Appendix C

Table C-1: showing, the average values (using questionnaire scales) of six measures of involvement throughout four parts of sample of 204 cases; division according to magnitude of A, parental activity.

We observe from Table 1 that the average values of the other five measures, across the four groups into which the sample is divided in accordance with values of A, also tend to rise. The one partial exception is in F, the estimate of parental support, satisfaction or fulfilment. If we turn the entries of Table 1 into rank orders by rows we find Table C-2.

TABLE C-2

Measure of involvement	Lower quartile of A	Lower median of A	Upper median of A	Upper quartile of A
A	1	2	3	4
D	1	2	3	4
M	1	2	3	4
C	1	2	3	4
S	1	2	3	4
F	2	3	1	4

Table C-2: showing, the figures of Table C-1 converted to rank order by rows.

The agreement displayed by the ranks of the six measures in Table C-2 could not occur by random sampling once in ten thousand trials. The coefficient of concordance is 0.83, $X^2 = 15.0$, $p = 0.005$ %. The agreement is not random; it has been caused by forces at work in the services.

If we now quarter our sample by another criterion, say, D, the disability that first sets the processes of involvement to work, we find the law appearing once more, as in Table C-3.

TABLE C-3

Measure of involvement	Lower quartile of D	Lower median of D	Upper median of D	Upper quartile of D
D	1	2	3	4
A	1	2½	2½	4
M	2	1	3	4
C	2	1	3	4
S	1	4	2	3
F	1	2	4	3

Appendix C

Table C-3: showing, after dividing sample of 204 cases according to measures of D, disability, rank orders of other measures.

The coefficient of concordance of Table C-3, while below that of Table C-3 is still highly significant. We may then demonstrate the emergence of this law of involvement by treating our data according to all the measures or dimensions in this way. In each such exercise the concordance is highly significant.

The simplest statistical demonstration of this Law is by the variance analysis of an array of six columns, one to represent each measure, and 204 rows, one to represent each case, as, for example, in Table IV. The result is set out in Table C-4.

TABLE C-4

Source of variation	Sum of squares	Degrees of freedom	Estimate of variance	F
Between cases	1935.7	203	9.535	2.90
Between measures	26.9	5	5.380	1.64
Residuals	3337.1	1015	3.288	-

Table C-4: variance analysis of six observable measures, D, A, M, C, S, F, among 204 mentally handicapped patients and their families.

The value of F, of 2.90, is so great that it could not occur by chance once in a million times: there is an overwhelmingly significant tendency for the six chosen measures of the dimensions of care, as they are observed in or about each given individual and his family, to be consistent, namely, to be large, moderate or small throughout in each particular case.

APPENDIX D

CASE HISTORIES

METHOD OF CONSTRUCTING CASE HISTORIES AND THREE EXAMPLES

This section demonstrates another approach to the qualitative analysis of the data, based on collated information from the comments on the questionnaires completed by all those concerned with an individual case - including the parents. Three examples of completed case histories are given.

Appendix D

We describe here a method which complements the statistical analysis, concentrating on the verbatim responses of the providers and consumers of the services concerned with a given case. To highlight the gaps between challenge and response, the presence or absence of coordination, the accounts of each person concerned with a particular case have been woven into a biographical story of the mentally handicapped individual's life.

> Our AIM has been to establish in a clear, simple narrative form all the available facts about each mentally handicapped person's life from birth up to the date of the survey; paying particular regard to the services offered to the child or young person and his family and to the coordination between the various statutory and voluntary bodies and the workers involved.

This biographical approach, connecting up the opinions independently expressed by four or five different people - each one giving care and support to the handicapped individual, adds depth to the current style of case history normally written by each profession, separately and independently.

> Our METHOD implies an examination of all the questionnaires relevant to the case to establish all the facts, viewpoints and attitudes under the various headings given below; bearing in mind that not all the headings and questions are applicable in all cases.
>
> a There are likely to be cases in which the parents perception of the situation and that of the professional staff does not agree and this should be made clear, and
>
> b Personnel changes may mean that the parents' comments on the role of the GP, HV, MWO etc refer to workers other than those who completed the associated questionnaires and this may account for discrepancies in attitudes.

On an average, 40 minutes were spent to scan a complete set of four to six questionnaires on each individual case.

Appendix D

METHOD FOR CONSTRUCTING CASE HISTORY

			Information to be looked for	Source
1			Personal data	The parents
	a		Date of birth or age at time of survey	
	b	i)	Occupation of parents	
		ii)	Are they caring for their own child; if not, who is	
	c	i)	Number of siblings	
		ii)	Handicapped child's place in the family	
2			Birth - first year of life	Parents Health Dept Records GP HV
	a	i)	Mother's obstetric history if relevant	
		ii)	Whether the pregnancy and birth were normal	
	b	i)	Whether the handicap was detected at birth	
		ii)	If not at birth, at what age was it suspected	
	c	i)	What were the symptoms which led to this suspicion	
		ii)	Who first noticed them (midwife, parent or relative, GP, HV etc)	
	d	i)	What action was taken (referral, hospital, admission etc)	
		ii)	Who took this action	
		iii)	The result of the action or the diagnosis if recorded	
		iv)	The manner and time at which the parents were informed of the diagnosis	
		v)	The parents acceptance of the diagnosis and satisfaction with the action taken	
3			Pre-school years	Parents Health Dept Records GP HV
	a	i)	Age at which handicap was suspected if after the first year	
		ii)	Reason for the suspicion, action taken (referral hospital admission etc) diagnosis, manner in which the parents were informed of this and parents' satisfaction as listed in section 2	
	b	i)	Any additional or different diagnosis made after the first year of life	
		ii)	Age of referral to the Health Department	
	c	i)	Any special problems faced while the child was aged 0-5	
		ii)	Any help received in dealing with these problems	

Appendix D

Information to be looked for	Source
d i) Do parents see the GP filling a useful role in respect of their child's handicap ii) What role does their GP think he should play in relation to handicapped children and to this child in particular * e i) Was the health visitor a support to the family in the pre-school years ii) What support does the health visitor feel she should offer in relation to handicapped children and to this child in particular * f i) Were the parents offered genetic counselling and by whom ii) Does the family GP feel that genetic counselling is his responsibility g i) Did the parents request and/or receive any help from the infant welfare clinic doctor ii) Did the parents request and/or receive any help from a local authority medical officer h i) Was the child sent to a nursery or pre-school special care unit ii) Who arranged it and was there any delay in obtaining a place once this had been thought necessary i i) Were the parents' satisfied with the help and services received in the child's pre-school years ii) Were any other services thought necessary but not available	Parents Health Dept Records GP HV
4 School years a Any information listed but not found in the under five years' history (age at which handicap was suspected, action taken, diagnosis, manner in which the parents were informed, parents' satisfaction etc). b i) Reason why the handicap was not suspected earlier ii) Who suspected the handicap (school teacher, school medical officer, parent etc) iii) Age of referral by education to Health Department or other action taken c Any tests or investigations and their results, eg IQ tests, hearing tests etc d i) The schools which the child attended with dates ii) Were these ordinary or ESN schools or training centres iii) Reasons for changes from one school to another e i) How were parents informed of the various education and training decisions made ii) How did the parents accept these decisions	Parents Mental Health Dept Records GP HV MWO Junior Training School

Appendix D

		Information to be looked for	Source
	iii)	Parents' satisfaction with the various types of schooling or training. Did they think sufficient help was available	Parents Mental Health Dept Records GP HV MWO Junior Training School
f	i)	The junior training school's estimate of the child's competence	
	ii)	Did the school have sufficient information about the child. Was there sufficient information passed on when the child transferred from one type of education to another	
	iii)	Were case conferences held concerning the child; were reports of progress made to other workers and parents	
	iv)	Were there services seen by the school as necessary but not available	
g	i)	Was the child ever taken into short or long-term residential care	
	ii)	Reasons for being taken into long-term care	
h	i)	Problems created by the child's handicap in the home situation	
	ii)	Any help requested or received in dealing with these problems	
i	i)	Help received from the HV and GP at this stage of the child's life	
	ii)	Were the records and reports passed on to the HV and GP at this stage adequate to enable them to offer the necessary help	
j	i)	Do the parents see the MWO as having a useful role in respect of their handicapped child	
	ii)	What role does the MWO think he should play in relation to handicapped children and to this child in particular	
	iii)	Are his records adequate to allow him to do this	
k	i)	Do the parents receive any help from relatives or friends in caring for their handicapped child	
	ii)	Are the parents in contact with any of the voluntary organisations concerned with their child's handicap and do they find them helpful	
	iii)	Are the parents in contact with the parents of other mentally handicapped children and do they find this helpful	
l	i)	Are the parents satisfied with the total pattern of help and services received during the child's school years	
	ii)	Were any other services thought necessary but not available	

5 Adult years

a	i)	Age of referral to Health Department and reason for this referral if not already covered in previous sections	

Appendix D

		Information to be looked for	Source
	ii)	Any assessment or investigations of the young person made at this time and their results (eg IQ tests)	Parents Mental Health Dept Records GP HV (possibly) MWO Adult training centre or industrial unit
b	i)	Is the young person in employment, unemployed or attending an industrial or training centre	
	ii)	Who helped the young person to find employment if applicable (MWO, training centre staff, DRO etc)	
c	i)	Capabilities and degree of handicap of the young person (defects of sight, speech and hearing, ability to read and write, ability to go out unescorted etc)	
	ii)	Is the young person considered suitable for open employment if this were available	
	iii)	Any differences in this assessment as made by the parents, the GP, the MWO and the adult training centre or industrial unit	
	iv)	Are the parents satisfied with their child's employment or training situation	
d	i)	Has the young person spent any time in short or long-term residential care or lived in a hostel after the age of 16	
	ii)	Reasons for this (eg court order, death of parents etc)	
e	i)	Personal problems faced by the mentally handicapped person as an adult (eg sex life, friendship opportunities etc)	
	ii)	Any help requested or received in dealing with these problems.	
f	i)	Help received from the GP and MWO at this stage of the handicapped person's life	
	ii)	How do the GP and MWO see their roles in helping the mentally handicapped adult and this young person in particular	
	iii)	Are there any barriers to the offering and receipt of this help	
g	i)	Any other information relevant to the situation of the mentally handicapped young person at the time of the survey, the plans for his future etc	
	ii)	Are the parents satisfied with the total pattern of help and services made available to their child after the age of 16	
	iii)	Are any other services thought to be necessary but not available	
	iv)	What role the local voluntary organisations have played to help the child and his family	

Appendix D

THREE CASE HISTORIES

David is the third child in a family of five. His father is a labourer. He was born in 1965 and found to have 'pyloric stenosis'. An operation to correct this was performed when he was seven months' old. The hospital suspected, during David's first year, that he was mentally handicapped as well, but nothing was said about this to his parents. When David was about one year old, his mother suspected that something was wrong because he could not sit up, grasp or feed properly. She consulted her general practitioner and was referred to the paediatrician at the local children's hospital. He was unwilling to make a definite diagnosis and David was not confirmed as mentally handicapped until tests were done when he was four years' old. His parents were told by letter that he would require special education. His mother said that she was very unhappy at having been informed of his condition in this way, because she had been asking the consultant paediatrician himself about this for years and had received no answer one way or the other.

David presented every type of problem in his early years. He had difficulty with sleeping, feeding, toilet training, mobility etc. The parents felt that the only real help that they received at this stage came from the children's hospital. David was found to have an IQ of 24 when he was nearly five years' old. He was unable to talk and had severe limb disabilities. His condition was being investigated by the paediatrician for biochemical or chromosomal disorders, querying gargoylism.

The mental welfare officer visited the family for the first time after the project had started and recommended that David should be admitted into the special care unit of the junior training centre. At first this appeared to be impossible because of the long waiting list, but his parents wrote to and telephoned the mental health department, backed by the health visitor. The school medical officer visited David at home. He was admitted to the unit shortly after this visit. It was hoped that this would help David who was not toilet trained and could not walk or talk. It was also hoped that it would help his mother who was suffering from a chronic anxiety state and found it difficult to cope with David at home. At the time of the survey, the training centre staff reported that David was by then only occasionally incontinent and was able to feed himself. He was receiving speech therapy.

Appendix D

The mental welfare officer continues to visit the family from time to time and David's mother feels that it would be helpful to have more frequent visits, if the mental welfare officer had time to make them, so that she could talk over her problems. David is very aggressive. This upsets his brothers and sisters and prevents his parents having any social life. Above all, David's parents want to be rehoused and though their mental welfare officer agrees that inadequate housing is their most pressing problem they have not received any help from the housing department. This adds to the mother's already poor mental condition and the mental welfare officer says that his only real anxiety about the family is that the mother might have a breakdown.

- - - - - - - - - - - -

Yollanda is the youngest child in a family of four girls. Both her parents work away from home, Yollanda was aged 15 at the time of the survey. Her mental handicap was first suspected by her parents when she was about two years' old because she was late in walking and talking. Her mother questioned her general practitioner and was told to wait until Yollanda was older to see if there was anything wrong. No further action was taken until Yollanda reached school age. She still had problems with her language and mobility, and following a routine school medical examination she was referred to an ESN school.

At the time of the survey, Yollanda's mother revealed a very poor understanding of her child's condition and of what was being done to help her. She thought that the health visitor had to be contacted via the general practitioner and she did not know what a mental welfare officer was. She could not recall every having been visited by one. She thought that the ESN infants school which Yollanda had attended, was some sort of play centre, that the ESN junior school was similar to an ordinary school and that if Yollanda had received more individual attention while she was there, she would not have needed to go on to a junior training centre at age 11. Yollanda's mother was dissatisfied with the junior training centre, expressing the opinion that the children did not receive enough schooling or training there and that the older mentally handicapped were relied on too much to look after the younger mongols. At the time of the survey, Yollanda's mother still did not understand why her daughter was backward and was very anxious as to whether or not she would be able to get a job. She did not meet the parents of other handicapped children because she thought that they seemed to neglect their children and were not interested in them.

Appendix D

The mental welfare officer continues to visit the family from time to time and David's mother feels that it would be helpful to have more frequent visits, if the mental welfare officer had time to make them, so that she could talk over her problems. David is very aggressive. This upsets his brothers and sisters and prevents his parents having any social life. Above all, David's parents want to be rehoused and though their mental welfare officer agrees that inadequate housing is their real pressing problem [illegible] received any help from the housing department. This adds to the [illegible] mental condition and the mental welfare officer says that his only [illegible] family is that the mother might have a breakdown.

Yollanda is the youngest child in a family of four girls. Both her parents [illegible] home. Yollanda was aged 15 at the time of the survey. Her mental handicap was suspected by her parents when she was about two years old because she [illegible] and talking. Her mother questioned her general practitioner [illegible] Yollanda was slow to see if there was anything wrong. [illegible] Yollanda reached school age. She still had problems with [illegible] and following a routine school medical examination she was [illegible]

At the time of the survey, Yollanda's mother revealed a very [illegible] situation [illegible] child's condition and of what was being done to help her. She thought that the [illegible] visitor had to be contacted via the general practitioner and [illegible] did not know who the mental welfare officer was. She could not recall every [illegible] had been visited by [illegible] thought that the ESN infants school which Yollanda had [illegible] was [illegible] centre, that the ESN junior school was similar to an ordinary school and that if Yollanda had [illegible] more individual attention while she was [illegible] she would not have needed to go [illegible] a junior training centre at age 11. Yollanda's mother was dissatisfied with the junior training centre, expressing the opinion that the children [illegible] receive enough schooling [illegible] training there and that the older mentally handicapped [illegible] after the younger mongols. At the time of the survey Yollanda's mother still did not understand why her daughter was backward [illegible] was very anxious as to whether or not she would be [illegible] to get a job. She did not meet the parents of other handicapped children because she thought that they seemed to [illegible] their children and were not interested in them.

Appendix D

Yollanda had an IQ of 49 at age 11. At the time of the survey, the training centre staff reported that she had a slight speech defect, was able to go out on her own, but was not allowed to do so, was unable to read, but could write with difficulty. They felt that she could benefit from speech therapy but this was not available at the centre. They had never been asked for a report on Yollanda but felt that such a request could benefit both staff and parents. The mental welfare officer who had just taken over the case, reported that he had not yet visited the family. He said that his case file on Yollanda was quite inadequate. The notes were out of order and incomplete and there was no identification sheet.

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Iris is an adopted child who was born in early 1960s. Her natural mother was sixteen at the time of her very premature birth. She was adopted when ten weeks' old by a factory worker and his wife and is their only child. Her adoptive mother first suspected that something might be wrong when Iris was about three months' old. She did not feed properly and looked strained, worried and worn. Iris's mother contacted her general practitioner who referred Iris to a paediatrician. Iris's mother reports that this paediatrician dismissed her at the interview and gave no advice save that the child was mentally retarded. Iris's parents were notisatisfied with this consultation and advice and changed their general practitioner. Their new general practitioner telephoned the health department when Iris was aged three and a quarter, at her mother's request, and said that he had seen the child and considered her suitable for day care at the training centre. Iris was admitted to the nursery training centre some months later. She was referred to a psychiatrist at the local university at age four. He was unable to assess Iris properly because of her over-activity but confirmed that she was retarded. Iris's mother was, by then, able to resign herself to this fact but her father found it very difficult to accept.

Iris developed very slowly and presented problems of all kinds throughout her early years. She did not begin to walk, talk or be clean until she was nearly five years' old. She cried all the time. Iris's mother does not consider that she received any help during her daughter's first three years. She found it easy to consult her general practitioner but did not find that he was familiar enough with the problems of the mentally handicapped to give any advice. She only saw a health visitor and attended an infant welfare clinic on one occasion. Iris's mother herself, had to take the initiative to approach the general practitioner and to get Iris admitted to the nursery training centre. The mental welfare

officer visited annually and his visits were helpful. Iris's parents would appreciate more frequent visits and feel that these would show that somebody cared. Iris's mother does not find contact with the parents of other mentally-handicapped children at the nursery training centre is very helpful. She comments that 'They don't speak the same language and have no outside interests.'

Iris's IQ was tested twice when she was five and found to be not ascertainable. She was transferred from the nursery training centre to the junior training centre when she was eight, but they could not cope with her aggressiveness and constant demands for individual attention, and Iris had to be sent back to the nursery. Iris is very over-active, screams and runs around throwing any article which she can get hold of. She is continually aggressive to children and adults. Iris is unable to cope with occupational training due to her extreme over-activity (described by a paediatrician in 1970 as extreme hyperkinesia). Her parents naturally find Iris very exhausting and difficult to manage and she has had to be admitted to the local subnormality hospital for a period of short-term care to give them a break. Provision has been made for further such admissions if her parents want them. When Iris is at home, her mother is unable to leave her for even a minute because she is likely to remove the fireguard etc. As a result, her parents do not have any social life together and there is a permanent atmosphere of tension due to constant anxiety at Iris's behaviour.

The mental welfare officer agrees that Iris causes great strain at home and says that, despite a good family background, disagreement over her management has divided her parents and led to marital problems. He supports Iris's mother's request for more very short-term or over-night hostels for handicapped people living at home, possibly associated with the training centres which are closed sixteen out of every twenty-four hours. He comments that he would like the local authority to give a higher priority to this; otherwise he is only able to offer Iris's family a sympathetic ear and some advice, when what they really need is more facilities to give them relief and a little free time.

APPENDIX E

CONSTRUCTION OF INDICES

Quantitative analysis of the information by the use of various indices is discussed. Two examples of how these indices were constructed are provided.

Appendix E

CONSTRUCTION OF INDICES

Indices were constructed to examine the effect, on each person in our sample, of the following factors:

1 parental activity (A)
2 disability of the handicapped person (D)
3 activity of the mental welfare officer (M)
4 interservice coordination (C)
5 services received by the handicapped and/or family (S)
6 satisfaction or fulfilment of the parents (F)

Indices were chosen as our method of measurement because they enabled us to observe the operation of each factor and the interaction between them for each of the cases in our sample.

We present in this appendix the detailed construction of two of these indices, parental activity and services received.

Index of services received by the handicapped and family as seen by the parents (S)

This index measures the level of services provided by statutory services and official persons, as seen by parents. The parents' questionnaire was chosen as the source of information for this index because it is the most complete source of information available. It would have been possible to extract much the same information from the file questionnaires, except that the high level of information missing on some of these questionnaires would have imparted an unacceptable degree of bias to this very important index. Short of constructing a very complex, sophisticated index which used as many sources as possible, this index will serve as a useful approximation of the objective situation. It does not include services provided by voluntary organisations, relatives, friends or neighbours. Services regarding employment were also not included because of the comparatively few handicapped adults in the sample that are employable.

a The following actions were scored one point each:

i) referral to a specialist
ii) help with problems of the handicapped during the first three years of his or her life
iii) arrangement of meetings with the MOH
iv) decision on type of education for MS
v) parents provided with explanation on type of education decided upon

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ii) help with problems of the handicapped during the first three years of his or her life
iii) arrangement of meetings with the MOH
iv) decision on type of education for MS
v) parents provided with explanation on type of education decided upon

vi) parents given a report on the educational assessment of the handicapped
vii) help with getting parents to accept the type of education decided upon
viii) help provided when parents asked on official organisation or person for help
ix) advice given on family planning
x) genetic counselling provided

b The following actions were scored on a one-to-five scale corresponding to the number of services provided; for example, one point scored for one service, two points for two services etc, up to five points for five or more services:

i) the number of helps recepved by the handicapped and family during the first three years of the child's life
ii) the number of helps received from the GP
iii) the number of helps received from the health visitor
iv) the number of helps received from the clinic doctor
v) the number of actions taken by official bodies on suspicion of subnormality
vi) the number of admissions for short-term care

c The following actions were scored on a one-to-three scale corresponding to the frequency of meetings of parents with official persons:

i) frequency of seeing MOH
ii) frequency of visits by MWO

The maximum possible score was 49 points. The range of scores was from 1 point to 22 points, with a mean score of 9.85 points and a most common score of 10 points.

Index of parental activity (A)

This index measures the level of parental activity by scoring their attempts to contact an official organisation or person regarding their mentally handicapped child or associated family problems. Membership of voluntary organisations and activity in gaining education or employment were also scored. The source for this index was the parents' questionnaire.

a The following activities were scored one point if they were performed by the parents:

i) suspicion of subnormality
ii) action taken on suspicion, eg consulted specialist, (in this category the number of actions taken by parents was scored, with up to five points for five or more actions)
iii) first referral to a specialist
iv) arrangement of meeting with MOH
v) meeting with other parents of handicapped children; membership of voluntary organisations. (This was scored on the number of voluntary organisations belonged to with a maximum of four points for membership in four or more organisations,

Appendix E

vi) degree of activity in voluntary organisations (one point for membership but inactive, two points for active membership and three points for very active)
vii) parents decided on type of education
viii) sought help for employment of the handicapped
ix) sought help from official bodies for a variety of problems (one point for each time help sought up to a maximum of three points)
x) sought advice on family planning
xi) sought genetic counselling

The maximum number of points that could be scored on this index was 21 points. The highest raw score for any one parent was 7 points, with a mean score of 3.19 and the most common score being 3 points.

APPENDIX F

INDEX OF COMPLETENESS OF CASE FILES

This appendix details the forty selected items of information which were used to assess the completeness of case files.

Appendix F

INDEX OF COMPLETENESS OF CASE FILES

Out of all the different categories of information recorded on the case files held by the local authorities, 40 items were selected as representative of the information the professional participants in this research wanted to know about. These 40 items form the basis of this index and they are listed below. Each time one of these items appeared on the case file, it was scored one point:

1. marital status of the parents
2. family composition
3. place of the handicapped in the family
4. information on siblings
5. history of the mother's pregnancy
6. mother's prenatal history
7. mother's postnatal history
8. illnesses and injuries of the handicapped
9. age of walking
10. age of suspicion of subnormality
11. reasons for suspicion of subnormality
12. the persons who suspected subnormality
13. action taken on suspicion
14. age of the handicapped upon notification to the local authority
15. reasons for notification
16. persons who notified the local authority
17. action taken on notification
18. problems of the handicapped upon notification
19. services offered to the handicapped upon notification
20. problems of the family upon notification
21. services offered to the family upon notification
22. classification of the degree of handicap
23. classification of the type of handicap
24. presence of behaviour disorders
25. assessment of IQ
26. assessment of mental age
27. attendance at nursery
28. attendance at schools and training centres
29. present school status
30. employment record
31. present employment status
32. name and address of present general practitioner
33. family history
34. admissions to institutions (eg to hospital for short-term care)
35. reasons for admission to institutions
36. problems of the handicapped at present
37. problems of the family at present
38. services offered to the handicapped and family at present
39. agencies that have contacted the mental health department
40. agencies that have been contacted by the mental health department

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The maximum possible score on this index was 40 points, a score that was reached in one case, while at the other end of the scale, the lowest score was 14 points in 3 cases. The mean score was 22 points and the most common score was 21 points.

APPENDIX G

REPORT OF CONFERENCE
21 SEPTEMBER, 1972.

An account of a meeting held at the Hospital Centre at the conclusion of the project. Some of the active participants from the research areas describe their experience of the project to representatives of local authority health and social services departments outside the areas surveyed.

Prepared by,
David Boorer
Journalist

Appendix G

PARTICIPATIVE RESEARCH - THE PROVIDERS' VIEW

A Journalist's account of the King's Fund Hospital Centre Conference 'Co-ordination of Services for the Mentally Handicapped' held on 21 September, 1972.

If enthusiam and a desire to spread the gospel by those involved in this research is any guide then the research method must be considered a success. Certainly this was the overwhelming impression gained from those who had participated in this research when they 'reported back' at the Hospital Centre Conference.

The need for such participative research was emphasised by Professor R.W. Revans, an outline of the method was given by Dr. R.G. Brims Young, deputy county medical officer of health from East Sussex, and a description of 'How we did it at Hounslow' by David Williams, area social services officer, Harrow. People in Hounslow started this research - as did many others - with no clear idea of how much participation was expected of them. But they learned and gradually more and more people, (parents, social workers, health visitors, mental welfare officers and general practitioners) were drawn into this activity. Once the group had decided to study coordination, people began devising questionnaires, administering them to one another and evaluating the results. The very process of coming together to plan the project, devise the questionnaires and interview colleagues from other professions served to bring people closer together and helped them to understand one another's roles. As David Williams said: 'At one point I was actually having a cup of tea with a health visitor - which was unheard of before.'

The exercise also produced a change in the attitudes of social workers. 'People,' said David Williams, 'stopped making excuses about personality blocks. They were having to ask themselves, "How do we get round this problem?" ' Participation also broadened horizons. 'We were beginning to understand that the people at the top are not the hard nuts we thought they were - they were equally concerned .... '

Equally important was the fact that people found that interviews with parents using the questionnaire gave them information about that family and its problems they had never had before. The project also gathered a momentum of its own. One social worker who, apparently, didn't want the project to die and who believed in participation as a means of learning, started a project of his own. He decided to look at all the mentally handicapped in the area as a learning situation and within a short time had nearly 40 people involved; parents, mental welfare officers, general practitioners, paediatricians, health

PARTICIPATIVE RESEARCH: THE PRO[illegible]

A Journalist's account of [illegible] **Conference 'Co-ordination of Services for the Mentally** [illegible] **September, 1972.**

If enthusiasm and a desire to [illegible] **by those involved in this research** [illegible] **guide then the research** [illegible] **considered a success.** Certainly [illegible] **overwhelming** impression [illegible] **who had participated in this research** [illegible] **'reported back'** at the [illegible] **Conference.**

The need for such [illegible] **which was emphasised by** [illegible] **W. Revans, in** [illegible] **outline of the method** [illegible] **Dr. R. G. Brims Young, deputy** [illegible] **medical officer of health from East Sussex,** [illegible] **description of 'How we did it at** [illegible] **Dr. David Williams, area social services** [illegible] **Harrow.** People in [illegible] **started this** [illegible] **as did many others** [illegible] **of how much participation** [illegible] **expected of** [illegible] **But they learned** and gradually [illegible] **and more people** (parents, social workers, health **visitors, mental welfare** [illegible] **general practitioners) were drawn into this** [illegible] **Once the group** had [illegible] **co-ordination, people began** [illegible] **administering the** [illegible] **evaluating the results.** The very process of coming **together to plan** [illegible] **questionnaires and interviews** [illegible] **professions served to** [illegible] **together and helped them** [illegible] **another's roles.** [illegible] **Williams** [illegible] **'At one point I was actually** [illegible] **tea with a** [illegible] **before.'**

The [illegible] **attitudes of social workers.** [illegible] **David W**[illegible] **personality blocks.** [illegible] **ask themselves** [illegible] **Participation also broadened horizons** [illegible] **people at the** [illegible] **hard nuts we** [illegible]

[illegible] **impor**[illegible] **interviews with** [illegible] **the questionnaire** [illegible] **had** [illegible] **The proj**[illegible] **didn't** [illegible] **in the** [illegible] **involv**[illegible] **parents** [illegible] **health** visitors, residential staff and teachers from a junior training school.

The increased awareness of other peoples roles described by David Williams were amplified by Marjorie Hills, a health visitor recently appointed training manager to Hounslow Health Department. She too had begun the project believing that it was merely another piece of research. She too had learned just how involved she was expected to be. She too had gained. She had experienced a deeper understanding of the roles of the mental welfare officer and other professionals; several gaps in co-ordination had been closed as a result of the project and she was now getting better feed back from her colleagues. The improved relationship between the professions had endured despite the shake up caused by Seebohm. Some of the credit for this, she believed, should go to the project. 'If someone hadn't been interested enough to do something about lack of coordination the services we have been giving would be inadequate. The project has made us aware of the weaknesses in our services. It is up to us to rectify that.'

Findings from this research project were outlined by Sid Atkinson, community services co-ordinator, Gateshead and are described in greater detail elsewhere in this book The lessons to be learned from the project were highlighted by Roy Wardell, assistant director of social services, Kingston-upon-Hull. Study of the 212 parents involved in this project revealed that over half said that nobody helped them at all during the first five years of their child's life. When questionned further only 14 per cent named professionals as being any source of help. This prompted Roy Wardell to ask, 'Do we listen to them and act or merely pose queries about the way the question was framed? What about the other 97,000 families in this country with mentally handicapped children? Have they been asked what they think? A major lesson from this project might be that we ought to find out.'

Another major lesson to be learned is that the project gave areas an opportunity to identify specific needs. In Hull, as one example, they found that families with mentally handicapped children had two main needs which could be met by the social services department. First was a need for emotional support, guidance and practical assistance during the period of isolation which frequently exists for parents in the pre-school period. Social workers were felt to be best equipped to provide this support and Hull's social services department committed itself to this.

But this alone was not enough. A social worker cannot cope single handed because other professionals are involved and, as this research project has shown, effective coordination does not always exist. 'The attitude,' said Roy Wardell, 'seemed to be that if one has an educational problem one should approach the education authorities, a housing problem the housing authorities and so on.'

To overcome this, to ensure a real coordination, Hull appointed a senior member of social work staff to ensure that services for the mentally handicapped were actually coordinated. 'This,' said Wardell, 'has the added value that such a staff member is available as a known link with other services and organisations to promote the maximum degree of effective communication.'

A 'great demand' for short term care was the second major need expressed by parents with mentally handicapped children. Hull reacted to this by accelerating the use of new buildings and was able to clear a converted children's home and use it for short term care for mentally handicapped children during the summer months. This rapid reaction to a need achieved more than simply relieving parents from strain, important though that was. It brought parents, volunteers, and professional staff together in running units and provided the social services department with, 'a wealth of information which will be of enormous value when we open our proposed residential home for mentally handicapped children.'

Hull's objectives are neither dramatic nor far fetched. People in Hull see this method of research as a means of giving mentally handicapped people and their families the same level of service as everyone else. Roy Wardell put it like this 'What I see this method of participative research as being all about is creating a situation where the mentally handicapped have available to them the same range of services as the rest of the community so that we can look forward to a time when mentally handicapped people go into hospital because they are ill and not because they are mentally handicapped. This cannot be achieved overnight but if we make certain that what is an offer now is properly coordinated and that we in the social services provide the kinds of practical services which the clients want, we will at least encourage a situation where the whole problem is known to us because we are in touch with all, or nearly all, the families concerned and not just the knowledgeable minority who have the stamina to fight for what should be so readily available.'

The idea of participation (in research or anything else for that matter) is one which frequently frightens people. It does not always, for instance, endear itself to top managers. But those who doubt its validity or who worry about its implications might have been reassured by what Mr. R. Lloyd Jones, West Suffolk's director of social services, had to say about involvement as a tool for managers. Mr. Jones believes in this principle, which, he says, 'has great potential over the whole range of services.' It has many important aspects; it is a method of collecting data which is a means of achieving positive change; it plants seeds for the achievements of those changes which research shows necessary. In this respect said Mr. Jones the research method is unique.

'Its great value is that it concentrates on achieving awareness among professionals and managers of one anothers roles.' This, in an age of specialisation with its consequent narrowness of vision, is vital.

Mr. Jones did more than philosophise about the benefits of action research. He suggested that this method is essential if social work departments are to meet the demands of the future. If the recommendations in the White Paper 'Better Services for the Mentally Handicapped' are to be met a vast amount of change must take place, and a vast increase in resources will be needed. Each director of social services must shortly submit a ten year plan based on the assumption that resources are going to increase at the rate of ten per cent a year based on current prices. How is change achieved? In Mr. Jones' eyes these things can only be achieved if people are involved and involvement is what action research is all about. 'I've never come across a method of doing this like the method developed in this project.'

It would be too much to expect that an audience of the uncommitted would blindly accept the principles of participative research despite the enthusiastic advocacy of participants. But the grinding of professional axes was surprisingly muted at this conference and the majority of questions and comments centred around matters of detail. It became clear, though, that people do not take readily to the idea of involvement as a principle and any future projects must be as carefully introduced to the participants as this one. But the audience was not generally hostile and a great number of questions seemed aimed at clearing up obscure points.

[illegible] ention (in research a [illegible] that matter) is one which [illegible] people. It does no [illegible] instance, endear itself to top [illegible] for those who doubt its valu [illegible] worry about its implications migh[t] [illegible] reassured by what Mr. R. Linv[illegible], West Suffolk's director of socia[l] [illegible] had to say about involvement [illegible] for managers. Mr. Jones felt [illegible] this principle, which, he says, [illegible] applied over the whole range of services. It has many important aspects [illegible] method of collecting data which is a means of achieving positive [illegible] it can see [illegible] for the achievement of [illegible] changes which research [illegible] necessary. In this respect said Mr. Jones the research method is unique.

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Apart from one or two people who remained unconvinced about the value of the exercise, one or two more who thought it was all too easy really and a couple who muttered, sotto voce, 'what's new about that?' the majority of the audience were interested enough to wonder what is to happen next. Many expressed their sadness at the projects demise and, for some time, discussion ranged around the possibility of setting up some form of consultancy.

Whether the conference achieved what one speaker hoped it would - the spreading of the gospel - remains to be seen. But certainly the atmosphere was friendly and equally certainly the many tributes paid to Professor Revans, Ali Baquer, Janet Craig, Dr. Michael Spark - the Chairman of the Research Advisory Group, Tim Eltham, and the others actively involved in the project were sincere - and well merited.

David Boorer.

REFERENCES

1 Ministry of Health, HM 64 (45) and HM 65 (104).

2 Whitehead JA and Cortazzi D (eds) 1968. Improving the Effectiveness of Hospitals and Services for the Mentally ill and Mentally Subnormal. King's Fund.

3 Cortazzi D. 16 September 1971. Someone is Asking Us - 2. Nursing Times, vol 6, no 37.

Hills M. 9 September 1971. Someone is Asking Us - 1. Nursing Times, vol 6, no 36.

Williams D. 9 September 1971. Helping the Mentally Handicapped. Social Work Today. Vol 2, no 11.

4 Tizard J and Grad JC. 1961. The Mentally Handicapped and their Families. Maudsley Monograph No 9.

5 Nissell M (ed) 1971. Social Trends No 2. Central Statistical Office. HMSO, page 59.

BIBLIOGRAPHY

Baquer A

December 1971. Report on Coordination of Services for the Mentally Handicapped. Multilith. THC 72/45. Ibid.

Boorer D

1972. Involvement as a Tool for Management. THC 72/500. Ibid.

Cortazzi D

1972. The Use of Critical Incidents as a Teaching and Training Device. THC 72/378. Ibid.

Revans R W

1964. Standards for Morale: Cause and Effect in Hospitals. London: Oxford University Press.

1971. Developing Effective Managers: a new approach to business education. London: Longman.

1972. Hospitals: Communications, Choice and Change. London: Tavistock Press.