COORDINATION OF SERVICES FOR THE MENTALLY HANDICAPPED

n account of a King's Fund research project

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COORDINATION OF SERVICES FOR THE MENTALLY HANDICAPPED

An account of a King's Fund research project

by

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Foreword by
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FOREWORD

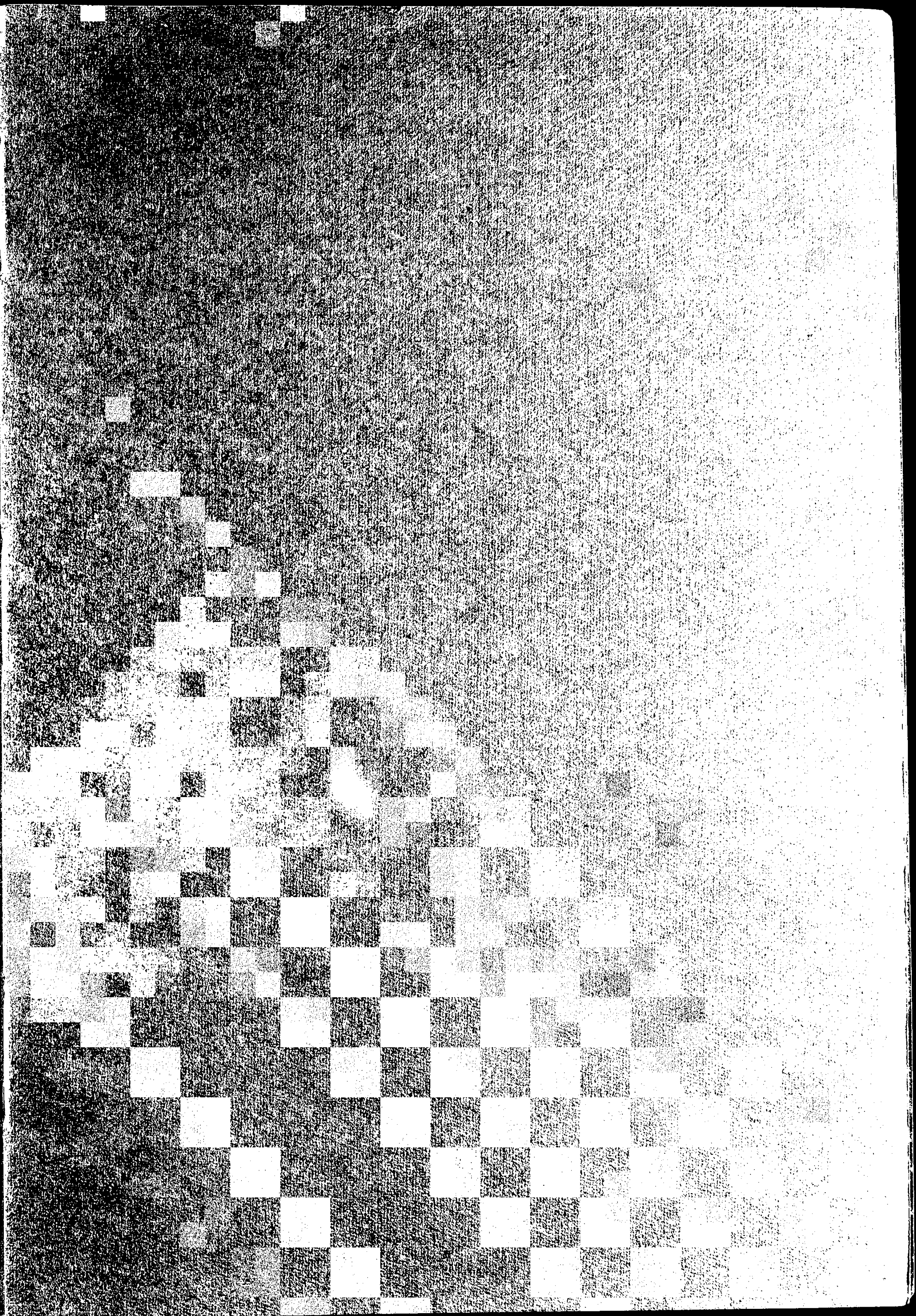
When the King's Fund agreed to support Professor Revans and his colleagues in their investigation of how care and treatment are provided for mentally handicapped children and young people, it was hoped that the results of the enquiry might possibly suggest some general guidelines for coordination of practice by the new health authorities of the reorganised National Health Service.

In the event, the structure of the study with its emphasis upon 'action learning' and research participation by those immediately concerned with the provision of the service has introduced a new and fundamentally important dimension to our original concept of the enquiry.

The material collected in the course of the study will no doubt be of considerable interest to specialists and researchers. It was, however, felt that there would be much value in having an independent description and commentary for the information of those more generally concerned with problems of management and coordination in this complex field.

We are indebted to Mr Leslie Paine for this lucid and very readable account of what the King's Fund believes to have been a valuable and productive investigation.

GAP
1974



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FOR WHOM AND ABOUT WHAT?

This account of ways and means of improving coordination of services for mentally handicapped people is written especially for members and senior managers of the various authorities – health and welfare, statutory and voluntary – concerned with helping and caring for these less fortunate members of our society. It is essentially the story (together with the various morals that may be drawn from that story) of a research project supported by King Edward's Hospital Fund for London, and carried out between 1969 and 1972 under the general direction of a working party which had Professor R W Revans as its chairman, and Mr Ali Baquer as its research officer.

Since much of what you read in these pages is of necessity based on the full report, *I Thought They Were Supposed To Be Doing That*[7], produced late in 1972 by Professor Revans, Mr Baquer and the many other participants in the study, you may wish to refer to the original and detailed material that it contains. If so you can obtain it from the King's Fund Centre.*

IMPORTANCE OF THE PROJECT

Why, however, should you be interested in the study at all? What is especially significant about it, and why is it important? Well, in one sense its importance lies simply in its existence. Somewhat like Dr Johnson coming across the woman preaching, what surprises – and I hope pleases – us about this particular piece of social research is not so much to find it done well, but to find it done at all. On the evidence of the last 25 years, the care of those suffering from mental handicap can hardly be said to have proved popular with the medical and allied professions or to have bulked large in the minds of those who administer, plan and finance our health and welfare services. Indeed, if that overworked and outworn cliché, 'cinderella', as a synonym for the neglected, is appropriate to any part of those services today, it must surely be to that which deals with the mentally handicapped.

This is not to say that concern for these disadvantaged people is not growing. It is – especially since the passing of the Mental Health Act 1959[4], the publicity given some years ago to conditions in some long-

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stay hospitals, and the inception of the Hospital Advisory Service. But changes in the attitudes of mind of those who run our caring services occur slowly, and are made yet slower by the difficulty of reallocating scarce resources. Even this research study, generated presumably by people with a particular interest in the subject, seems to have had a lineage of meetings and conferences reminiscent of the First Book of Chronicles, and a gestation period more than twice as long as that of the Indian elephant.

Its more manifest origins appear to lie in two circulars issued by the then Ministry of Health in 1964 and 1965 on improving the effectiveness of hospital care of the mentally ill and handicapped.[5,6] For those circulars were followed by a series of gatherings to discuss them and their implications; the first organised in December 1965 by the Royal College of Nursing with Professor Revans in the chair, and those subsequently by Janet Craig at the King's Fund Centre. These latter meetings led directly to a national conference on mental handicap in 1968 which in its turn produced the special working party which fathered the research project that the King's Fund finally adopted a year later.

Gradual though the emergence of the project may have been, the Fund's decision to support a three-year investigation into coordination of services for the mentally handicapped, is notable for three reasons. First, because its reflects a clear, albeit overdue, awakening of the public conscience to this aspect of care. Second, because it provides a sort of Job's comfort in the implication that despite relative neglect there are sufficient services involved, in sufficient variety, to warrant a study of their coordination. Third, because, by showing a substantial interest in the subject, the Fund demonstrated to us all that at least in the eyes of one of Britain's most eminent philanthropic health care organisations, looking after mentally handicapped people properly is something which merits national attention.

Significance of the Research Philosophy

The importance of the project does not rest there, however. There is a fourth reason why it has, or should have, a special interest for you and this concerns not its subject but the philosophy of participation upon which its research methods are based. The bulk of the research work was done *by* the people in the field *for* the people in the field rather than *on* them by outside experts. The researchers, in fact, were also the researched, subjecting themselves to a form of collective self-appraisal and self-criticism which some may see as having obvious affinities to the so-called 'management fundamentals' way of tackling organisational problems, and to the interprofessional, multidisciplinary approach to care and treatment which has been developing in a number of health institutions for many years.

This belief, that the best people to find out what was wrong with the coordination of services and to make things better were those most closely involved with their provision and receipt, was clearly adumbrated at the national conference in 1968 and in the meetings which led up to it. To use Mr Baquer's words, what was felt to be required was an *'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.'*

This close 'worker participation' in the research investigation was seen by Professor Revans and his working party as offering a double benefit. In addition to getting the research work done it also provided the workers involved with an excellent opportunity of learning by doing – of improving coordination by having to practise it during the investigation. As the professor himself says in his foreword to the full report:

> *'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.'*

Or to put it Mr Baquer's way:

> *'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 of 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.'*

But in addition to allowing the providers of services to learn by doing the research, and to improve coordination by coordinating themselves in the very act of investigation, the enquiry brought into the foreground of the research picture those at the *receiving* as well as at the giving end of care.

The directing working party saw that the clients – the patients, the parents and families, the consumers, call them what you will – had not merely the moral right to a say in the sort of care they received but were capable, through genuine involvement, of assisting to coordinate and improve that care. This 'Law of Involvement' (as Professor Revans and his colleagues describe it) suggests *'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.'*

The project is therefore equally noteworthy on two separate counts. It has intrinsic value because of the attention it both pays and draws to one of the most under-privileged and least glamorous of our caring services. It has also a particular methodological interest because the self-evaluating style of research it introduces can, if successfully used, so obviously produce its own reward of better coordination – and therefore better quality – of services.

Before going on to show just how much better, however, it is worthwhile pausing for a page or two in order to explain just how the research was actually carried out.

HOW THE RESEARCH WAS DONE

Those who conceived the research were agreed from the outset that the aim of the project they had in mind was neither to attempt to produce generalisations about services for the mentally handicapped, locally or nationally, nor to discover and demonstrate the inevitable variations in the forms of care that exist. Essentially, the scheme they wished to undertake was designed to allow the exploration of the many different methods – formal and informal – by which services are coordinated.

To this end they saw that while it would be unrealistically ambitious to attempt to discover all that was going on throughout the country, a comparison of what was actually happening in half a dozen or so local authorities and their appropriate hospitals, would give them the opportunity of identifying the strong and weak points of the services in which they were interested. They therefore selected seven reasonably representative local authority areas in different parts of the country in which to make their comparative studies.

The areas chosen were Nottingham (a 'regional capital'), Kingston-upon-Hull (a large industrial borough), Oxford (a 'traditional city' with a university and a cathedral), two counties – one rural and the other affluent and developing – West Suffolk and East Sussex, what they called a 'mirror city' – that is, one dominated by the influence of a world famous neighbour – for which they chose Gateshead, and a London borough – Hounslow – selected as a check area, so that research methods might be tried out there.

In each of these areas close contact was made with all authorities having any responsibility for providing services to the mentally handicapped. These included, apart from the local authorities themselves, regional hospital boards and hospital management committees, executive councils and local medical committees. Representatives of those actually involved in providing the services in each of the seven areas were then invited to join in the research project. Those who responded varied in seniority from junior front-line workers to senior administrators, and belonged to nearly all the professions concerned with this type of care.

These representatives met for the first time in London in October 1969, elected a general practitioner as their chairman, and formed themselves into an advisory group for the research. Nine months later (in July 1970) representatives of the hospital services involved also met together as a separate group with a psychologist as their chairman. In due course the two groups merged into one and, although their members then exceeded 100, continued to meet either in toto or in subgroups so as to discuss the research project, review its progress and take decisions on its further development.

From the beginning it was this gathering of providers who decided what the aims of the research were to be, what form it should take, and how it should be done, as well as undertaking the actual research work themselves. At the original meeting of the group, for example, the research team, in accordance with the philosophy of participation already agreed, instead of offering hypotheses for the project asked the providers to suggest questions that they would like answered in order to understand better the coordination of their own services. This caused much initial surprise and a certain amount of difficulty. As the writers of the full report of the scheme admit, putting their theory of involvement into practice was not easy – *'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 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 services.'*

Nevertheless, in due course the vision of involvement was converted into action and the participating group set about deciding what questions they must ask, and of whom, in order to gather in the raw material of their research. The sort of general information they felt to be necessary in respect of each mentally handicapped person in the seven chosen areas was how and when handicap first came to be suspected; what action followed; how providers differed in their views of the handicapped person's needs; and how they saw their individual roles, both towards the handicapped person and towards each other.

Summarised thus it sounds a relatively simple task, but in practice it was soon seen to be a very formidable one indeed. As the group started to think in more detail about the questionnaires they must send out, they also realised the vast quantity of information that these would bring in. A glance at the two sample questionnaires included as Appendix B to the full report of the study will show you how right they were. The form addressed to the parents of handicapped people covers nine pages and runs to more than 160 questions. That sent to mental welfare officers, although shorter, still has five pages containing some 74 questions. Clearly, if all the givers of care and services were to be similarly catechised about every handicapped individual in the seven test areas, the number of replies received could run into millions, making the job of analysing them overwhelmingly difficult.

A statistically significant random sample was therefore agreed upon, consisting of five per cent of all the handicapped people in the seven districts, under the age of 30. This allowed the researchers to bring the problem of data analysis within bounds while still ensuring that the findings of the study remained valid.

It was then decided that, for every handicapped person included in the sample, six separate questionnaires should be compiled for completion; by the parents, the patient's general practitioner, the mental welfare officer and health visitor, the staff of training centres, and the keepers of the official case records. Before embarking on such wholesale distribution, however, the advisory group organised two trial runs as pilot schemes – one in the check area of Hounslow on patients living in the community, and the other in two hospitals (serving the test areas) on patients who had been admitted. These two preliminary investigations were seen as complementary – two sides of the same coin in fact – the latter aiming in particular to demonstrate the links between hospital and community care. Unfortunately, shortage of both time and money forced the researchers to depart from their original intention of extending both preliminary investigations to cover the whole of the seven selected local authority districts. While the Hounslow community study was replicated in the other six test areas, therefore, the hospital study never got further than the pilot stage. Nevertheless, details of this investigation and a note of many of the lessons learned when mounting it were included in a separate report, *Action Learning*[1].

As for the Hounslow study this, when completed, gave the advisory group the opportunity of amending and improving their six questionnaires before extending their research enquiry to the other six areas. The random sampling technique of five per cent of mentally handicapped people was again used throughout the extended survey – the handicapped persons included in the sample having five characteristics in common.

1 They suffered from mental handicap as defined by the Mental Health Act of 1959.[4]
2 They lived within the geographical areas of the seven selected local authorities.
3 They were domiciled in the community, that is, at home, with relations or foster parents, in a hostel, or elsewhere, and spent most of their time outside hospital.
4 They were known to the mental health department of the local authority.
5 They were born between January 1940 and December 1969 and could therefore reasonably be expected to have received the benefit of those services made available since the 1959 Mental Health Act had been passed.

The five per cent sample yielded a total of 212 persons and, since it was drawn from the total population of mentally handicapped people of all ages in the seven areas, represented something nearer ten per cent of those who were under 30. Questionnaires in respect of each of these 212 were prepared and presented to the six groups of respondents mentioned earlier, either by means of interviews conducted by research staff or by despatching of forms for direct completion by the providers of services.

Parents and keepers of the official case files were approached first and understandably these two groups produced the best responses – in each case not far short of 100 per cent. General practitioners did not reply in quite such large numbers. Some gave pressure of work as the reason for not doing so; a few refused to divulge what they considered to be confidential information between doctor and patient; others failed to answer, presumably through lack of interest. Even so, more GPs replied than some of the other professionals, that is, the mental welfare officers, staff of training centres and health visitors. There were, however, special reasons for the fewer answers received from these groups. Questionnaires sent to them were divided into two parts – the first part being concerned with factual information about the handicapped person and with the professional's experience of the case – the second part calling for opinions on the roles of the various agencies involved in providing services. Since mental welfare officers and training centre staffs were frequently concerned with more than one person in the sample, it was not necessary for them to complete part two of the enquiry in every instance. Since health visitors in most areas supervised patients only until they reached the age of five, it was not possible to contact more than a small number who had enough personal knowledge of mentally handicapped people to be able to complete part one of their form. In spite of this the health visitors were sufficiently interested in the study to fill up part two of the questionnaire in 97 cases.

The subdivision by areas of the 212 persons included in the five per cent sample, and the actual numbers of respondents to each of the six questionnaires issued are given in Tables 1 and 2. Preliminary analysis of the replies received (as listed in Table 2) was undertaken by computer and a sample count of all the answers given to each question was made. This enabled the researchers first to draw a profile of the dominant characteristics of the mentally handicapped people included in the sample. Then, with further analysis of the information obtained, they were able to produce the main findings of the study relating both to coordination and provision of services. Let us, therefore, now look at the results of those analyses, under three headings – the profile of the sample; the pattern of coordination; and factors affecting coordination.

TABLE 1 NUMBERS IN SAMPLE

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

TABLE 2 RESPONSE TO QUESTIONNAIRES

	Part 1	Part 2 (where applicable)	
Case files			211
Parents			204
General practitioners			147
Mental welfare officers	169	44	
Health visitors	33	97	
Training school staff	94	61	

RESEARCH FINDINGS

PROFILE OF THE SAMPLE

To list the main characteristics of the 212 mentally handicapped people included in the research study may at first sight appear to be an interesting but not necessarily important exercise. But this is not so. For 'the profile of the sample' (to use the research team's terminology) provides highly relevant and valuable information, since the sample, if truly representative of the total population of mentally handicapped people in the test areas, as it should be, must give a good indication, from the patient's point of view, both of the variety of services required and the degree of their coordination that is necessary.

The investigation revealed, inter alia, that there were more mentally handicapped males than females in the population; that the majority of children studied suffered from multiple handicaps and some (13 per cent or more) came from families with other handicapped members. Such families, however, although belonging to no particular social class and being similar in average size to the national average, often had older parents (and sometimes only one) and suffered greater strains than normal. In addition it was found that a fair number of mentally handicapped children were unlikely to be so diagnosed before they started school; but once assessed, generally speaking, they obtained valuable help from junior and, in due course adult training centres. Mentally handicapped people also appear to be living longer and therefore need more care; but the getting and holding of jobs is difficult. Finally, the birth of a handicapped child seemed to be less of a discouragement to parents having further children than might be thought but there was a desperate need for genetic counselling.

Further details of these major characteristics are given under ten subheadings.

1 AGE AND SEX OF THE HANDICAPPED The distribution of those included in the sample, subdivided by age and sex, is shown in Table 3.

TABLE 3 NUMBERS OF MENTALLY HANDICAPPED IN 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' questionnaire

From the table it becomes clear that

a There were significantly more males than females in the sample (118 compared with 94) although this in no way biased the survey.

b The small number of those in the 0–4 age group reflects the fact that many young children with mental handicaps are not discovered until they start formal education.

c The 80 cases (two-fifths of the sample) in the two older age groups suggest that mentally handicapped people may be living longer than they were some years ago and will therefore tend to require more services for longer than in the past.

2 AGE OF THE PARENTS The majority of parents of handicapped persons were middle-aged at the time of the survey. Twelve and a half per cent of the mothers and 23 per cent of the fathers were over 60,

however – a probable problem group who will find it increasingly difficult to cope because of advancing age and reducing income.

3 AGE OF THE MOTHER AT THE BIRTH OF THE HANDICAPPED CHILD Twenty-five per cent of mothers were between 20 and 24 when their mentally handicapped child was born; 23 per cent between 35 and 39, and about a further 10 per cent over 40. The study suggests that the well documented connection between mental handicap and late child bearing may have been over-emphasised in the past.

4 PARENTS' SOCIAL CLASS No significant differences between the social classes of parents with handicapped children were discovered.

5 FAMILY SETTING Approximately 80 per cent of the handicapped children had both parents alive and living together, but 14 per cent were part of one-parent families (compared with nine per cent in the community at large). It could be, therefore, that the presence of a mentally handicapped child in the family places greater strain on the marriage and on relations with other children, which may lead to family break-up.

6 FAMILY SIZE AND POSITION OF THE HANDICAPPED PERSON IN THE FAMILY There was no significant difference between the average family size in the sample (three children) and that in the general population.

Of the mentally handicapped children studied 43 per cent were youngest born or only children, which suggests that the birth of a handicapped child acts as a positive discouragement to having further children. This investigation showed, however, that significantly more parents than expected were having further children, although less than 25 per cent of the sample (51) sought advice before doing so, and in only ten cases did such advice include genetic counselling.

7 FAMILY HISTORY Twenty-eight children (13 per cent) had siblings who were mentally handicapped, and 11 (including some of that 28) had a parent or parents similarly afflicted. None of these families appeared to have had genetic advice.

8 CLASSIFICATION OF DEGREE AND TYPE OF HANDICAP Administrative classification of the mentally handicapped (subnormal, severely subnormal, and so on) varied widely throughout the seven local authorities (from 89 per cent to 37 per cent). It has little value in practice.

9 HANDICAPS The majority of children in the sample were multiply handicapped. Only seven per cent were otherwise completely fit and healthy; 39 per cent had one other handicap; and the remaining 54 per cent had a number of additional handicaps, including three children with six or more. This incidence of multiple handicap presents the greater challenge to effective coordination of services.

Table 4 lists ability handicaps and the proportion of children suffering from them.

TABLE 4 ABILITY HANDICAPS

	Percentage of children who had problems
Writing*	82
Reading*	80
Understanding money*	75
Speech	68
Telling the time*	56
Dressing	23
Washing	23
Mobility†	16
Feeding	14

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

†Does not include children who cannot go out unescorted (45 per cent).

Source: 204 parents' questionnaires

10 EDUCATION AND EMPLOYMENT Most handicapped children had received some form of special schooling although 36 per cent had first attended a normal school for 1–2 years. Only 26 of the 120 adults in the sample were in open employment. Most had had two unskilled jobs for less than a year, which had been found for them by parents or the youth employment officer. Disablement resettlement officers did not seem to be active in this sphere.

PATTERN OF COORDINATION

In order to establish how well services were coordinated in the seven test areas, four further analyses of the research data contained in the answers to the questionnaires were necessary. One such analysis involved the computer count of answers used to produce the 'profile of the sample'. The other three were simpler and undertaken directly by the researcher-providers themselves in accordance with their philosophy that the project was a continuing exercise in self-motivation and self-directed learning.

Using some of the information provided by the computer count, six facts (or indices) about each of the 212 handicapped people in the sample were collected and given a rating (high, medium, low) so as to assess for every one of them the quality of the demand they made upon, and the response they received from, the services available; together with the amount of coordination achieved in marrying the two. By this means the central research officers were able to draw up what we might call a master index of interaction between handicapped people and services. In addition, the providers themselves

compiled narrative case histories of ten per cent of the sample

analysed the verbal comments of parents recorded by interviewers

examined constructively all the critical incidents and 'horror stories'.

The multiple approach unearthed a number of the facts of coordination which we will now consider in greater detail under six subheadings. Briefly, they demonstrate that what happens in the first five years of a handicapped child's life is crucial; gross handicap and high parental activity tend to produce the best response from providers and the best coordination of services (the 'Law of Involvement'); that the care being received by individuals must regularly be reviewed; that the medical officer of health or his representative, the mental welfare officer, is the best coordinator of services; and that a serious gap in coordination exists between the initial assessment of handicap and the provision of care.

1 WHO WAS ACTIVE IN PROVIDING SERVICES? Handicapped people are numbered among the responsibilities of many agencies but are accepted as the concern of few. It is important, therefore, to distinguish between active agents directly involved with numerous cases and those only marginally concerned with a handful. Even with

the assistance of the research data, however, the reality of the situation in each area was difficult to establish. Not only do many people have a finger in the pie of care, but their appreciation of each other's activities is extremely vague. Sixteen different individuals, for example, were found to have advised parents when handicap was first suspected in a child, although only four were concerned with 20 cases or more. And when the various professionals were asked who was most likely to confirm the child's condition, opinions varied widely. Altogether, 30 agencies or individuals were found to be directly involved in providing services in this field, with a further 16 having some more indirect connections. The 18 most active of these 46 providers, together with 16 of the most important services provided were therefore tabulated, and the results are shown in Table 5. This demonstrates clearly enough that the main thread of continuity of care runs through the mental health department of the local authority and its representative in the field – the mental welfare officer. The impact made by others such as health visitors, clinic doctors, hospitals and general practitioners, while important, is generally seen to be short-lived. It suggests, too, that the most important service coordinator is the medical officer of health, at least during the period when handicap is confirmed and education arranged. It also reminds us that since the research study is 'ante-Seebohm'[2], it is vital for the mentally handicapped that the new social service departments assume the coordinating role previously played by the medical officer of health.

2 COORDINATION AT THE TIME HANDICAP IS SUSPECTED The essence of coordination is communication and the diagram on page 27 plots the paths of contact between the various agencies involved when handicap is first suspected in a child. The central part played by the medical officer of health and the mental health department of the local authority again emerges clearly enough, as does the role of the general practitioner as an initial referring agent for the parents. In the majority of cases the GP can be seen to have referred his patients to the consultant specialist and the hospital paediatric services, but what is equally and disturbingly clear is how few were referred back either to the GP or to the local authority. This suggests, in fact, a major gap in coordination of services. This suggestion is substantiated by a further research finding that at least 52 per cent of all children were referred to the local authority more than two years *after* handicap was first suspected. Indeed, in 27 cases, children suspected at birth were not so referred until they were five years old or more.

TABLE 5

AGENCIES ACTIVE IN PROVIDING 16 SELECTED SERVICES

(for sample of 212 mentally handicapped children)

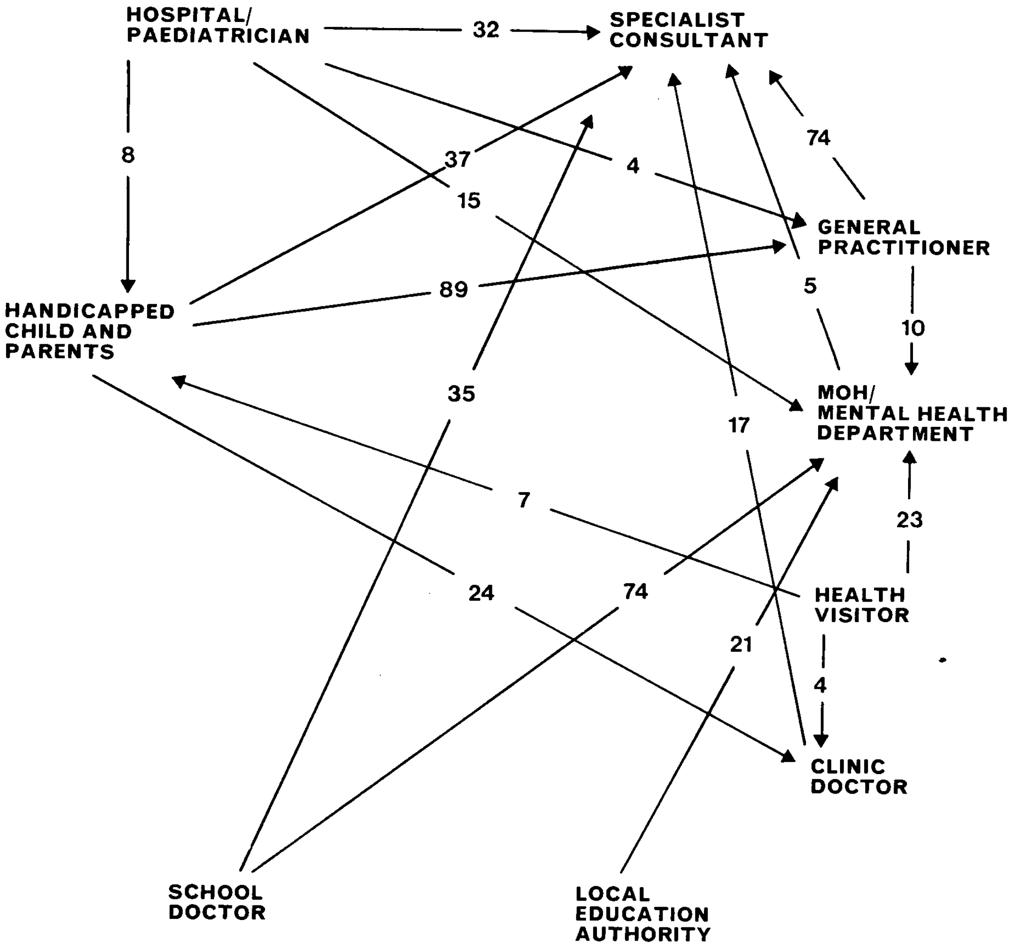
Type of Service Required (CHALLENGER)

(RESPONSE) (PROCESS)

Provider of Service	Who suspected the child's condition	Who gave advice upon suspicion of handicap	Who gave advice on having further children	Who arranged for child to see a specialist	Who notified the local authority	Who provides advice and emotional support now	Who arranged assessment of IQ	Who assessed IQ	Who confirmed the handicap	Who helped parents in the first three years	Who arranged admission to nursery	Who helped parents to accept decision on education	Who arranged admission to special school	Who arranged employment	Who arranged short term care	Provision of education/training facilities
Immediate family	●									●	●			●		
Relatives/friends/neighbours						●				●		●				
General practitioner	●		●	●		●										
Medical Officer of Health or representative		●					●	●	●			●	●		●	
Mental welfare officer						●						●			●	
Health visitor					●											
Clinic doctor		●														
JTC/ATC/ESN school staff*																●
Local education authority					●		●						●			●
Normal school staff	●															
School doctor	●			●			●		●							
Child guidance clinic/educational psychologist								●								
Hospital where the child was born			●													
General hospital—paediatrician		●		●	●											
Hospital for mentally handicapped—paediatrician		●	●	●	●				●		●					
Clinical psychologist								●								
Consultant/specialist		●														
Youth employment officer														●		

*JTC junior training course
ATC adult training course
ESN educationally subnormal

PATHS OF CONTACT BETWEEN VARIOUS AGENCIES AT THE TIME OF SUSPICION OF MENTAL HANDICAP



Notes: The links between each agency are not indicative of all contacts that occurred but only the most frequent ones.
Figures in the diagram refer to the number of handicapped people who were subjects of the particular path of contact.

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

3 ACTIVITY BY THE MENTAL WELFARE OFFICER The potential of the mental welfare officer as a focus of coordination has already been mentioned. Certainly, most families in the sample saw him and his department as being most likely to satisfy their requirements; while most mental welfare officers saw themselves and their departments as the likeliest agencies to help the handicapped. What is also true is that 76 per cent of parents (153 out of 212) reported regular, although sometimes infrequent, visits by mental welfare officers which they appreciated; and nearly half of the mental welfare officers said that, given more time, additional home visits would be their first priority.

But while they may appear to be the most logical people to act as coordinators of care and services for the handicapped, the study showed that in the majority of cases mental welfare officers were neither seen, nor saw themselves, as coordinators. One reason for this may be the case-load these officers carry, not only of mentally handicapped people but also, of course, of the mentally ill. On average those in the seven survey areas looked after 10–20 long-term and the same number of short-term mentally ill patients, together with 40–50 mentally handicapped people. As the full report says: *'This is a prodigious load for any social worker and the unfortunate effect on often time-consuming activities of coordination can be guessed at.'*

4 ACTIVITY BY THE MENTAL HEALTH DEPARTMENT From tabulated results published in the full report it is quite clear that the mental health departments of the seven local authorities bore the brunt of administrative organisation of the many services available to handicapped people. The majority of parents came into contact with this department at some time or other (usually when their child was either just going to school or just leaving it) over such problems as the need for admission to a training centre, the need for short-term hospital care, holidays, assessment, sheltered workshop admission or help with employment.

The actual level of coordination achieved by these departments, however, was shown by the survey to be *not* very high, and to be effective in only a minority of cases. It also seemed that once a handicapped person had been settled into a particular pattern of services, changing that pattern to suit changing needs was not easy, and a successful re-coordination of new and more appropriate services was seldom achieved. Clearly, therefore, while mental welfare departments may be foremost in coordinating services for the mentally handicapped, they have a long way to go yet before they can be said to be providing effective and regularly reviewed coordination in the majority of cases.

5 THE 'PIT OF ISOLATION' The time-lag between suspecting mental handicap in a child, confirming it by assessment and receiving supportive help from the local authority is a further point that has previously been mentioned. This period of such a child's life – usually the first five years – is a crucial one for the emotional and psychological well-being of the family, and it is of great importance that gaps in service provision at this stage should be closed. That such gaps undoubtedly exist the survey confirmed, for 37 per cent of children in the sample were suspected of handicap before they were two but not referred to the local authority until they were four. In addition, half the parents in the survey claimed that no-one at all had helped them during the first three years of their child's life. This fact, the people and agencies giving help, are set out in Table 6.

TABLE 6 PEOPLE SEEN TO HAVE HELPED THE PARENTS DURING THE FIRST THREE YEARS OF THEIR CHILD'S LIFE

Person or Agency	No of parents who received help
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	14
No reply	21

It is important to realise, of course, that of the 102 parents reporting no receipt of help in the first three years of their child's life, some were not themselves aware that handicap existed at this stage. Naturally, they did not seek help. On the other hand, handicapped children exhibit developmental problems during this early period and only 17 out of the 201 parents who commented were able to say that their children had *no* such developmental problems at all during these years.

The inevitable conclusion is, therefore, that a pit of isolation exists in the early years of a mentally handicapped child's life and that many families fall into it. The disturbing facts which emerge from Table 6 are first, that a large number of parents, for whatever reason, see themselves as in this pit, whether they are, in fact, or not; and second, that the small number of agencies apparently able to help at this time suggests that services which can be of real value to parents in these early days just don't exist.

6 CHANGES IN THE PROVISION OF SERVICES OVER THE LAST 30 YEARS Finally in this section it is interesting from the viewpoint of coordination to note the steady increase in services provided to handicapped people that has taken place over the last 30 years. Between 1940 and 1944 each child received an average of 0·86 services. By 1960–64 this had risen to 2·15, and during 1965–70 it fell slightly to 2·08. Study of the research statistics produced a similar result for services provided to the families of handicapped children.

The most dramatic increases have occurred in education and training, while the provision of short-term care has also expanded, and so has the supervision of families by mental welfare officers, and the advice given to them on educational and financial matters. General help with day-to-day care, however, has remained constant, while admissions to schools for the mentally handicapped have actually declined.

All these changes have one thing in common – they make coordination more important yet more difficult.

SOME FACTORS AFFECTING COORDINATION

From the previous section you should by now have some idea of the sort of pattern of coordination that was found to have grown up in the seven test areas over the past 30 years. In this section we are concerned with why such a pattern became established, and with some of the main factors which helped to produce it. In particular we look at how coordination is affected by the quality of the official case records; the providers' perceptions of family needs and of their own professional roles; by one particular service – genetic counselling; and finally by what has been previously referred to as the 'Law of Involvement'.

1 OFFICIAL CASE FILES Examination of the case files of those included in the survey revealed a lack of uniformity in both the quantity

and categories of information recorded. Not unexpectedly, differences were found between the records of one local authority and another, but what was less expected was the variation between files compiled by staff working in the same district. The researchers decided, therefore, to compile an index of 'case record completeness' using a list of 40 pieces of information considered to be of prime importance. As a result of this review only one file was found to contain all 40 items; three lacked as many as 26, and the majority were deficient in 12 or more.

The researchers accepted, of course, that no formal written record can possibly replace personal contact with a handicapped child or his family, but they pointed out that a good case file provides valuable past history which can contain signposts for further action as well as indications of possible problems to come. It is also a reasonable illustration of the quality not only of the care being given but of the coordination being achieved. Particularly for someone taking up for the first time the responsibility of providing a particular service, the record is inevitably the starting point from which, as the full report puts it, he or she '*must glean the essential pathology of the situation*'. The investigation's findings seem to have proved beyond reasonable doubt that these important basic documents require improvement.

2 PERCEPTION OF THE NEEDS OF THE HANDICAPPED CHILD AND HIS FAMILY No-one surely would disagree that the object of coordination of services is that they may match as closely as possible the needs of those who require them. But this essentially simple aim, difficult enough to achieve at the best of times, is obviously made more so when receivers and providers do not see eye to eye on what their requirements are. Such a lack of consensus was quite clearly demonstrated in the survey by the replies received to the questionnaires submitted to general practitioners, mental welfare officers and health visitors. Their responses produced a wide divergence of views on the sort of help that handicapped children and their parents require. The GPs, for example, thought that general medical care was the most important requirement, although this was not necessary in many cases; mental welfare officers saw education and training as the prime requisite; whereas parents rated the provision of holidays, clubs, leisure activities, and similar measures designed to integrate their children into society, as their highest needs.

Generally speaking, the investigation suggests that while the professionals believe that families want general support, the families are much more concerned about their and their handicapped child's isolation from normal social contacts. Certainly, when a comparison was made between the views of parents and those of mental welfare officers on what were the family's most pressing requirements, disagreement of some kind resulted in the majority of cases. Similarly, when the researchers took the views of three different professional groups on the actual physical handicaps from which the children in the survey were suffering, there was again disagreement, the assessments of mental welfare officers coming closest to those of the parents.

Taken together the two comparative studies show quite clearly that where perceptions of basic facts about mentally handicapped people and about the services they require differ so widely, not only must coordination of services be made much more difficult, but the actual relationship between parent and professional must inevitably be impaired.

3 PERCEPTION OF PROFESSIONAL ROLES A further factor which cannot help but affect coordination of services is how providers see their own roles and those of their colleagues. It is a statement of the obvious to say that if a group of people are concerned with the provision of specific services to help others, all so involved should understand and agree their individual tasks in pursuit of the common goal. Yet this is not always so in practice and, in an attempt to look more closely at this particular area of coordination, the views were compared of parents and some of the providers of services on whether the professionals should primarily be concerned with their own direct services or with the coordination of these and the services provided by others. The analysis of replies showed that no providers saw their coordinating function as anything like as important as their direct professional role. All, on the other hand, suggested that the key coordinators in this field were the medical officer of health, and to a lesser extent the mental welfare officer.

Clearly, this implies that professional people, and certainly the three included in this particular comparison, GPs, health visitors and mental welfare officers, are unlikely to see themselves as service coordinators even if others may expect them to be. This is particularly important for the medical officer of health and mental welfare officer who, in spite of their own feelings to the contrary, are seen as foci of coordination by most of their professional colleagues. The importance lies in the point touched on, en passant, earlier in this account that the research investigation was carried out immediately before and during the initial implementation of the Seebohm report.[2] Now that the recommendations of that report have been implemented throughout the country it is vital that the question of successors in the field of mental handicap to the medical officer of health and the mental welfare officer be answered. As the full report puts it: *'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.'*

4 LACK OF UNDERSTANDING – GENETIC COUNSELLING The fact that so many parents were given no form of genetic counselling emerged from the study which produced the profile of the sample. Using replies received from GPs the researchers were able to throw further light on the reasons for this failure. They suggest that the basic cause was a general misunderstanding of the purpose of this particular service, not only by non-medical professionals but by GPs as well. Few of the GPs questioned, for example, seemed from their replies to appreciate the real meaning of genetic counselling as a service, not only to parents and their children but also to GPs themselves, which aimed to provide accurate information on the risk of any abnormality that had already occurred in the family, recurring. Undoubtedly, the members of the caring professions in mental handicap should know what the service is and who can give it. If they don't, their lack of understanding could be a bar to the provision and coordination of proper assistance. The researchers suggest that the present situation could be improved if health visitors, mental welfare officers and other professionals concerned could be included on the distribution list of the Department of Health and Social Security's handbook on genetic counselling.[3]

5 THE 'LAW OF INVOLVEMENT' Reduced to essentials the 'Law of Involvement' is a truism. Simply stated it maintains that in general the more disabled the child, the more active the parent, and so the more engaged the mental welfare officer, the more prolific his contacts with others in the service, the higher the level of help received, and the greater the satisfaction of the family. The proposition, in fact, has much in common with the generally accepted clichés that what you get in this life depends on how strongly you pursue it, and that he who shouts loudest gets most.

This 'Law of Involvement' is, therefore, well named. It arose from the examination of what we have called the 'index of interaction' (page 24) between parents and providers, and this particular study demonstrates 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. It is not only the level of services provided that rises with the degree of disability but also the level of comfort or relief perceived by the parent. And providers must realise that parents will not always rate the quality of care they get by the same standards as do the providers.

What this particular aspect of the research investigation suggests most strongly is that parental fulfilment is closely linked with parental activity and that parental activity in its turn is at its highest when a child's disability is grossest. It also suggests that the vital factor in determining the quality of services provided was what the parents did rather than what was wrong with the child. This confirms the feelings of many who work in the field that social services in the past have been essentially passive rather than active, reacting rather than acting, responding not so much to need as to demand.

The 'Law' also implies that greater activity all round needs to be stimulated by someone other than the parents – the paediatrician, health visitor, mental welfare officer, for example. For if the level of a child's disability is not high and the parents are thus not stimulated to great activity, it does not necessarily follow that the child does not need a wide range of services. This is where coordination at the time of suspicion of handicap is vital. The researchers wisely suggest that the more people who become actively and cooperatively involved at this early stage, the better the chance there is of this cooperative activity continuing to benefit the child and his family. A prime concern of those responsible for providing services, therefore, should be to identify ways and means by which others apart from the parents can break into the circle of care at an early stage and stimulate the provision of services necessary to meet the needs of the child. A service which is apparently geared to respond only to the demands of parents is one which, in the words of the full report, *'will inevitably neglect many dark corners where the needs of disadvantaged children may be great but not so visible.'*

VALUE OF THIS FORM OF RESEARCH

The first and very practical benefit which resulted from this research study was obviously the large amount of factual information collected. The six questionnaires sent to the parents and the providers of care in respect of the 212 mentally handicapped people in the sample, produced more than 200,000 answers about services, providers and receivers. By any standards this is an extremely valuable hoard of data likely to repay detailed study for a long time to come. But as was stressed in an earlier section (page 10), the particular value of this piece of research lies as much in the way that the information was collected and used as in the actual information itself.

Participation was the essence of the exercise – participation leading to informed action. By participating the researcher-providers became more conscious of the system within which they worked, were able to see more clearly its advantages and disadvantages, and were given a greater motivation to increase the former and eradicate the latter. Perhaps the primary achievement of this research method, therefore, is the creation of an atmosphere and situation in which change and improvement in the organisation being researched is both acceptable and possible.

A strong feature of this participative style is certainly the integration it achieves. Working colleagues do not necessarily discuss regularly their problems and points of view with each other, but they did so on this occasion – posing their own questions and producing their own answers in a series of joint discussions. And not only were the many providers of services involved but also the parents of the handicapped people, and to some extent the handicapped people themselves were brought together in a spirit of objective curiosity. The providers found as a result that they became much more of a team than before – had fewer feelings of interpersonal rivalry and resentment – had a greater appreciation of the complexities of the service they were trying to give – and were more aware of their interdependence in the common task of helping handicapped people and their families.

This sort of approach gives a real meaning to the phrase 'action research' for, as the researchers themselves point out, no programme designed to stimulate action in any particular field, sophisticated or comprehensive though it may be in theory, will necessarily result in significant action by the people to whom it is addressed, unless those people are 'action oriented'. It is the aim and the value of participative research to make them so.

APPLYING THE METHODS ELSEWHERE

With the aim of helping those interested in assessing the effectiveness of existing services and in making realistic plans to meet future needs, the researchers laid down a number of guidelines on the application of the participative research methods which they used in their project. Before summarising these, it is relevant to note some of the qualifying comments that they make about their system.

To start with they stress that they are not claiming to have developed a magic formula to overcome all problems of service delivery. They have not produced a blueprint to be rigidly applied everywhere, but rather a set of suggestions which can be used with some confidence by others, and which, if adapted as required, should create research tools based on the involvement of staff at all levels, that will allow information to be collected and analysed to the benefit of all concerned. They emphasise that participative research is based on the belief that people learn in action, and that they grow and develop in an organisation if they try to solve their own problems. It is essential, therefore, if you intend to venture into this field of investigation, that those in authority and responsible for the administration of the services being investigated be fully cooperative and convinced of the value of what is being done, and that the complete involvement of all the staff concerned be encouraged and nurtured.

The guidelines briefly outlined below are extracted from Chapter 12 of the full report in which they can be read in greater detail. They show that there appear to be five distinct and interdependent stages to be gone through before the project can be completed; and that these successive and often overlapping stages of development involve a wide variety of diverse skills.

STAGE A: RESEARCH DESIGN

All concerned in running the service to be investigated must recognise and accept a genuine need for the research investigation; and an individual or group of people from within the service should preferably initiate the study. A directing research advisory group should be constituted, made up of voluntary members drawn from staff at all levels of seniority, and assisted by a technical research adviser – possibly provided by the research section of the authority, if it has one, or by a nearby college or university. This technical adviser, however, should follow the decisions of the advisory group rather than leading it in defining the course or scope of the research programme.

The group must be responsible for its own organisation; must decide the scope of the programme and the methods by which it is to be carried out. It must differentiate at an early stage in the information to be collected between what is crucial and what is only marginally relevant. It may be better to start with a broad idea rather than a well defined but misplaced hypothesis. Time must be allowed for the advisory group to win the confidence of all those participating in the study and, in particular, to overcome such standard reactions as apathy, that the research is a waste of time, that the existing system needs no alteration, and that answers to problems are already known.

STAGE B: FIELDWORK

At this stage of the research programme it becomes a 'learning by doing' exercise. Participants must undertake the fieldwork and should be encouraged to apply the agreed research instruments (questionnaires, interviewing, and so on) themselves. They should meet regularly and discuss problems which arise so as to determine the pace of the work and ensure the inclusion of other staff who gradually become involved in the investigation as it proceeds. Those responsible for running the service being investigated should encourage the involvement of as many staff as possible, even to the extent of assisting them with outside help if necessary. It is important to have a timetable both for the whole project and for the data collection process but this must not be too rigid.

STAGE C: ANALYSIS AND INTERPRETATION OF DATA

Those who designed the programme should decide how the data should be processed, although, since the amount of information collected will almost certainly be large, skilled help with analysis will be necessary. How that analysis is undertaken, and in what order of priority, should be decided by the advisory group; but all participants should be involved in interpreting the data.

STAGE D: FEEDBACK

Broad diffusion of what has been learned from the investigation is important. This can be achieved by means of meetings of participants and by the writing of articles and reports which should have a wide circulation. As many as possible of those who can benefit by the receipt of such information should be involved in meetings and should be encouraged to comment on draft reports and articles. At this juncture the research group changes to an action group which should be capable of dealing with the practical problems it has brought to light. It is important to allow sufficient time for participants to adjust to this change and to achieve a sense of close integration in the taking of necessary action.

STAGE E: FINAL OUTCOME AND DIFFUSION

The final report of the investigation should be produced by the advisory group and should include as far as possible the views and recommendations of all who attended feedback meetings or who commented on reports and articles in draft. Such a collectively written report is more difficult and takes longer to produce than one written by a single author, but it has the advantage of controlling individual bias. The involvement of many participants in the research helps to ensure wide diffusion of what has been learned among those directly concerned in the field of study and in allied fields, but it is important that the lessons are spread as far as possible through written papers, lectures and talks. As with any research study, the findings made and resultant action should be dispassionately evaluated, but the success of the programme can best be judged by the impact it produces on those who participated in it.

SUMMARY AND CONCLUSION

This investigation into coordination of services for the mentally handicapped is of particular interest for two basic reasons. First, because it is concerned with one of the least favoured or fashionable areas of our health and social services. Second, because of its research methodology – the self-evaluating, learning by doing style of investigation which is called 'participative research' and which involves those who provide the services, supported by skilled research advice, in planning the research programme, in collecting the data, in analysing them, and taking the resultant action.

Undertaken in the areas of seven local authorities in England, and with a pilot investigation in two hospitals, the project was based on a random sample of 212 mentally handicapped people living in the community and under the age of 30, for each of whom six detailed questionnaires were completed by the providers of services and by parents.

The study revealed a number of disturbing facts about the sample population, such as that many mentally handicapped children had elderly parents or only one parent, and similarly afflicted siblings; that the majority of the sample had multiple handicaps; that suspicion of handicap was often not confirmed before school age, and that, regrettably, genetic counselling was little in evidence.

The pattern of service coordination discovered in the test areas demonstrated, inter alia, that what happens in the first five years of a handicapped child's life is crucial, and that there was a serious gap in the provision and coordination of services at this stage. It was also shown that, while the number of services available to the mentally handicapped has increased significantly over the last 30 years, and while the number of people involved with the child and the family is large, the influence of many is marginal or short-lived. The mental health section of the medical officer of health's department, and its officer in the field, the mental welfare officer, provide the main thread of continuity of care and are the key coordinators of services. Since the investigation was undertaken immediately before and during the initial implementation of the recommendations of the Seebohm report[2], it is of the greatest importance that the new local authority social services departments and the generic social workers who work in them assume the coordinating roles of the old mental health departments and their mental welfare officers.

Some of the more important factors affecting coordination, or the lack of it, were found to be the absence of uniformity in and completeness of official case records; the inability of providers and parents to see eye to eye on the requirements of the mentally handicapped and their families; the differing perceptions that providers of services have of their own roles and those of their colleagues; the failure of *any* providers to see themselves as coordinators. The operation of the so-called 'Law of Involvement', which suggests that parental activity rather than professional initiative or a child's actual needs, is the vital factor in determining the quality of service received – gross handicap inspiring high parental activity and so, good service provision, and vice versa.

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