ACTION LEARNING

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September, 1972.

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A guide to its use for hospital
staff based on a pilot study in
co-ordination in hospitals for
the mentally handicapped

Kind Edward's Hospital Fund
London

September 1972.

Diana Cortazzi

Ali Baquer

This pilot study follows the work of Professor R.W. Revans. It is based on the belief that those best equipped to restructure the services - and thus improve the care of patients - are those who work in the services.

ACKNOWLEDGEMENTS

It may seem unorthodox for one author of a book to pay tribute to her co-author; this is an unorthodox project. Both personally and on behalf of the Research Advisory Group I would like to pay tribute to Ali Baquer who, in his role as research officer, guided and developed the project. From the beginning he accepted with vigorous determination the thesis that participants should design the study, should guide it, should be as active in it as they wished to be. Ali Baquer's own professional skills as a social scientist have been sublimated into channels not usually explored by researchers and, paradoxically, in serving the project so well, he himself appears to have played a shadowy and insubstantial role. It takes a high degree of courage and professional maturity to do this; and generosity, to encourage participants to write up the outcome of a project which owed much of its success to its research officer. All of us who became involved owe him an immeasurable degree of gratitude.

Without the support of the King's Fund in providing financial assistance and facilities for meeting and working together, the Pilot Study could not have started. In particular, we have gained a great deal from the unobtrusive presence of Janet Craig, assistant director to the King's Fund, whose contributions have always been sensitive and perceptive.

Tim Eltham, in working with us on the construction of Indices to analyse the data in the community study, has also contributed to the hospitals project in a stimulating way. David Boorer acted as editorial advisor and, working at pressure, turned our account into a manageable thesis.

Four of the participants in the community project in particular have actively contributed to our hospitals study: Joan Trigwell, a health visitor who spent six months in the hospitals interviewing and completing the questionnaires; David Williams, an area team leader who helped enormously in our early discussions and who contributed to the technique of analysing Critical Incidents; Graham Curtis Jenkins, a general practitioner, who produced a quota of incidents for analysis, and Robin Brims Young, a deputy medical officer of health who contributed stringent comments at the analysis stage.

Typing has often needed to be done urgently, and has not been confined to this final production. For this, we have to thank Rosemary Easton of St. Lawrence's Hospital who typed and retyped with good humour; and for dealing with questionnaires and reports of our various meetings: Judy O'Connor, Stella Johnson, Sarah Stenning, and Anne Woronow for their assistance at the Hospital Centre.

Finally, without the patient encouragement of Professor Revans, who has given us so much of his time with unbelievable stamina, we would not have begun to learn.

Diana Cortazzi.

St. Lawrence's Hospital,
Caterham.

September, 1972.

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PARTICIPANTS

LIST OF PARTICIPANTS OF THE RESEARCH ADVISORY GROUP (HOSPITALS)

Chairman: Dr. R. Mein, Consultant Psychologist

(Over 200 staff of the two hospitals have contributed to the design and execution of the pilot study presented here. To list them all would be impossible. Following are the names of those who attended most of the meetings held. Not all participants who have helped in starting and developing this study have been mentioned. The omissions are not intentional.)

FROM THE TWO HOSPITALS IN THE PILOT STUDY

Mr. Barrett	Laundry Manager
Mr. Barry	Tutor
Mrs. Bean	Head Occupational Therapist
Mrs. J.M. Berry	Social Worker
Miss J. Brewer	Ward Sister
Miss Brooks	Social Worker
Mr. B. Ceresale	Charge Nurse
Mr. A. Cooper	Assistant Chief Male Nurse
Mr. B. Cooper	Deputy Group Secretary
Dr. M. Cormack	Senior Registrar
Mrs. Daly	Voluntary Work Organiser
Mrs. J. Dell'erario	Nursing Officer
Mr. H. Francis	Headmaster of School
Mrs. B.J. Gaunt	Social Worker
Mr. A. Glennister	Charge Nurse
Mr. Godwood	Head Teacher
Mr. Hacket	Nursing Officer
Sister Harwood	Occupational Therapy Unit
Mr. Holliday	Farm Manager
Mr. W. Johnstone	Charge Nurse
Mr. G. Jones	Assistant Matron
Miss Leach	Playgroup Supervisor
Miss F. Levinson	Senior Psychologist
Mr. Maley	Charge Nurse
Mr. S. May	Physical Education Instructor
Mr. Mitchell	Senior Physiotherapist
Mr. A. Monks	Senior Social Worker
Mrs. P. Mooney	Supervisor, Activity Centre
Mr. S. Namdarkhan	Charge Nurse
Mr. O'Neill	Assistant Chief Male Nurse
Dr. D.M. Ricks	Consultant Psychiatrist
Mr. M. Ridler	Chief Technician
Mr. Robbins	Voluntary Work Organiser
Miss D. Roswell	Principal Psychologist
Mrs. M. Stratford	Ward Sister
Mrs. Sutton	Assistant Matron, Sheltered Workshop
Mr. Wheeler	Charge Nurse
Mr. W.J. Williams	Chief Male Nurse
Mr. B.A. Winder	Nursing Officer

OUTSIDE THE TWO HOSPITALS

Mr. S. Atkinson	Community Services Co-ordinator
Mr. A. Baquer	Research Officer
Mr. D. Boorer	Journalist
Mrs. D. Cortazzi	Principal Psychologist
Miss J. Craig	Assistant Director, King's Fund
Dr. G. Harris	Senior Registrar
Dr. W. Heaton-Ward	Consultant Psychiatrist in Charge
Rev. W.J.A. Kirkpatrick	Assistant Regional Nursing Officer
Mr. T.B. Maguire	Principal Nursing Officer
Prof. R.W. Revans	Chairman, Working Party
Mrs. S. Smith	Social Worker
Dr. M.G. Spark	General Practitioner
Dr. P. Sylvester	Consultant Psychiatrist
Miss J. Trigwell	Health Visitor
Mr. D. Williams	Area Team Leader

FOREWARD

By The Chairman of the Working Party

A year ago Ivan Ilich published his book called "Deschooling Society". His thesis, about which reasonable men may be expected to disagree with each other, is that, to save itself, Mankind must dismantle its present educational system. Traditional methods of teaching, based on institutionalised scholarship, abstract book learning, professional erudition, syllabi and timetables set by examination boards and all the other paraphernalia of the academy are, to Ilich, not merely of ambiguous value: they are positively harmful. It is an outrageous set of ideas - at first sight - and, apparently, an indictment of society that such a book could find a publisher, let alone a readership.

But there is reason to pay attention to Ilich, all the same. While we may not accept his remedy for what he sees as the ills of our educational system, we should try to understand what he sees these ills could be. These, he argues, stem from the highly authoritarian character of the teacher-pupil or professor-student relationship; this engenders in the learner so great a dependence upon being told what to do, how to do it and by what time, that he becomes incapable of learning from his own common experience. In a state of nature, the child is able to learn from his impact on what is around him; he learns to speak his own language, for example, and, even more miraculously, to walk upon his own two feet. But, in school, he becomes a prisoner within his academic cell, carrying out the drills, laid down by others, until, by the time he comes to take his degree examination, he is locked in a ten round wrestling match with each of his professors, all aware of the grips and countergrips, the throws, the locks, and the trips that each may use upon the other. For they have spent the last three years in preparation for the contest and it is well known to them that all cannot win the first prize.

In this book, Ali Baquer and Diana Cortazzi describe an educational process of a very different kind. It was one that many different persons shared. To what extent can those who work in the psychiatric hospital learn, not so much from teachers expounding their predetermined syllabus, as from their daily experiences on their wards? And when we referred to 'those who work in psychiatric hospitals', we mean not only the student nurses who (it is to be supposed) need development for their own professional protection, but also those of experience and authority who are actually in charge of the hospital

To what extent should those inpower also see themselves as learners? Is it, to pose this question, also to suggest that professors should go back to school?

Our thesis is that not only is daily experience a learning process, among children and adults alike, but that it is, or might be made, the most effective learning process of all. Provided the subjects' independance of the instructions of authority has not been totally destroyed - and this is an important but by no means inevitable provision - there is hope that, given the support of others, he may come to realise how much he may teach himself. Automomous learning is thus a precious quality and it is the aim of this book to let us into some of its secrets.

The overall lesson is easy to state:

> "Teachers' job is not to teach; it is to help others provide for themselves the conditions in which they may learn in the cause of their daily work .... "

This book offers us some ideas upon how to put this suggestion into practice. We may not therefore have to dismantle our schools after all, but we must certainly re-think our lessons.

Professor R.W. Revans

Fondation Industrie Universite
BRUSSELS.

September 1972.

COMMUNITY

FIGURE 2

'TOMMY'S WORLD'

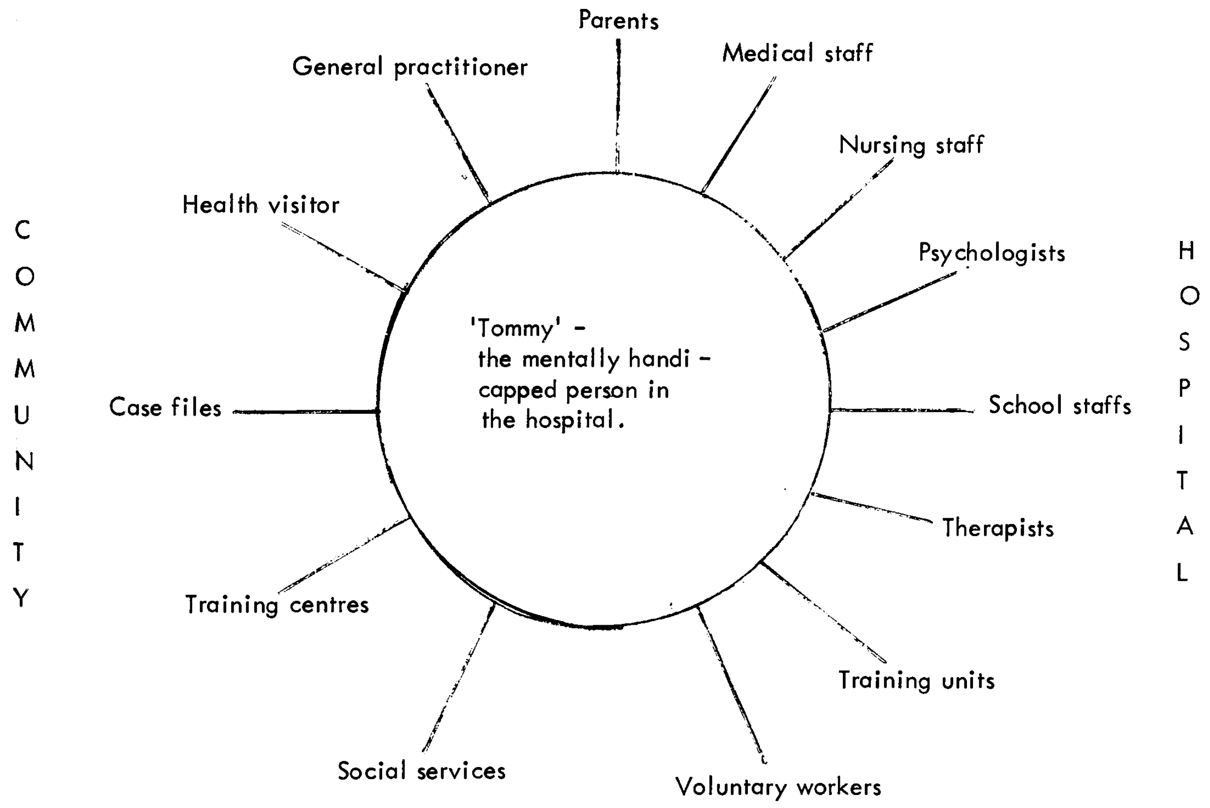

FIG2 : 'Tommy's World', showing the groups concerned with the mentally handicapped person in the hospital and the community.

BACKGROUND
TO THE
PROJECT

Brief description of origin of
community and hospital projects
on co-ordination of services

ACTION LEARNING

Background to the Project

> "There should be proper co-ordination in the application of relevant professional skills for the benefit of individual handicapped people and their families, and in the planning and administration of relevant services, whether or not these cross administrative frontiers."

(Better Services for the Mentally
Handicapped - June, 1971)

The project	A study of co-ordination of services for the mentally handicapped.
What this book is about	The hospital aspect of the project, at the pilot study stage
How it arose	In 1965 a conference at Church House discussed the Ministry of Health circular on improving the effectiveness of this hospital service for the mentally subnormal. The Hospital Centre subsequently held a series of meetings at which hospital staff described their attempts to improve the caring services. In 1968 a national conference held at the Hospital Centre agreed that patterns of co-ordination of the services for the mentally handicapped should be examined in different parts of the country. A working party was formed from volunteers attending that conference, and in 1969 a research officer was appointed by the King's Fund to conduct the project.
Where the study concentrated	Seven diverse local authorities.
The hospital pilot study	Paralled the community pilot study, and was concerned with mentally handicapped people from the same London Borough who were now living in hospital.

Chapter 1

ACTION LEARNING

The Theory

The Practice - and the Project

This chapter discusses the approach, and the attempt to find a simple operational model which hospital staff could themselves use as a basis for a study of co-ordination.

Chapter 1

ACTION LEARNING

The Theory

> "If you want a form filled in properly, ask the people who are doing the filling in what the questions should be. You'll get participation that way"

This comment from a senior nursing officer illustrates one aspect of the philosophy which guided this project - that the only people who can really take effective action to improve a service are those responsible for its daily running. Others may plan, issue edicts, print recommendations; they may suggest, urge and impress. But they cannot devise rules to cover every possible contingency nor enforce a spirit of obligation towards a client or towards colleagues who may also be concerned with that client. It is only those at the "cutting edge", those close to their clients who can contrive a dynamic and flexible contribution to his total well-being.

At an early meeting about the project, Professor Revans reiterated this theme: "It is an approach difficult to understand because we tend to say, 'Well, what are THEY doing about it?' Or we think the final answer can be found in books, or from the advice of an expert. This is an illusion. There is no solution by experts alone in this life. We must also look at our own problems when we are dealing with something as valuable as people".

It is, then, those close to the mentally handicapped who should essentially be involved in any study of that service. It is their service. Those doing the job should form a group to decide the relevant questions they wish to ask about the service they give and the people they give it to.

Because it is, above all, those actually doing a job who can discover (through their discussions with informed colleagues on the needs for common action) what facts, what tools and what help they need to do their job effectively.

We believe that involvement in such a study will lead to greater awareness and thence to active effort by those involved to improve the service they give. Hence the term "action learning".

The Practice - and the Project

To translate the theory of action learning into practice (when there is no known technique for so doing) proved in itself to be a learning experience.

To be told repeatedly by the project's advisers, "We don't know the answer to that. You're the providers. You tell us what to do", was either a spur to active investigation or a source of disbelief and misunderstanding. The frequently appealed to "They", was really "us" the participants. In other words "Do not expect strangers to do for you what you can do for yourself". This comment, made in Roman times by Quintus Ennius, could aptly have applied to participants in 1970. It seems extraordinary how long it took to realise that no procedure was to be laid down for people to follow; and how difficult it was to understand that the research "experts" were in it with them, learning too.

Because of its simple philosophy, which was yet so difficult to grasp, the project had to be firmly rooted in reality.

The study of co-ordination focussed upon "Tommy" - a convenient personalisation of the mentally handicapped. A simple model proposed that Tommy comes into hospital with certain handicaps and certain needs: there he meets a group of staff with certain skills and knowledge. The two interact. Co-ordination takes place at the points of intersection: between Tommy and a professional, and at the point where staff meets staff.*

Co-ordination is a term seldom defined. A team is formed, a conference held, a report written and sent. Co-ordination - an arranging, an organising, a systematising process - has taken place. So too, has communication - a sharing, a diffusing, a disseminating of knowledge. But labelling a group of professionals "a team" is to confuse idea with action. Holding a conference does not necessarily result in working together. Writing a report in no way ensures either the intelligent reading of it or action upon it.

To start the project participants from the hospitals formed themselves into a Research Advisory Group under the chairmanship of Dr. Richard Mein, a consultant psychologist. This group later linked with the main Research Advisory Group of the local authority study (chaired by Dr. Michael Spark,

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* See Figure 4 , page for an elaboration of this model, developed and used in a special unit.

a general practitioner) at the request of both sets of participants for a practical gesture of co-ordination.

The group addressed itself to the apparently simple questions

> Who gives Tommy a service?
>
> What are Tommy's needs?
>
> Are they satisfied - and by whom?
>
> Where are the gaps in co-ordinating those services?

This, then, is the philosophy and the operational objective. It is not, as stated so often throughout the pilot study, a scientist's fact-finding exercise, but rather an exercise in communal learning from which certain facts emerged.

In practice the pilot study, on a very small sample, can only provide indications of areas for future investigation, using perhaps the questionnaires and the guidelines developed by the Research Advisory Groups. These advisory groups were all staff, professionals, people close to the mentally handicapped person.

In this chapter the philosophy behind the project and the operational model which would demonstrate action learning are described, together with some early indications of the problems engendered by the unorthodox approach of the technical advisors: "<u>You</u> tell us what to do."

Chapter 2

THE DESIGN

1 The patients' lists
2 The selection of hospitals for pilot study
3 The Research Advisory Group (Hospitals)
4 Sample of patients
5 Description of the two hospitals
6 Secondment of health visitor

This chapter describes the design of the project and some of the problems of involving people in looking at their own ability to co-ordinate.

Chapter 2

THE DESIGN

1 Research Advisory Group

A conference of the staff concerned with hospitals for the mentally handicapped in the seven research areas of the main study was called in July, 1970 at the King's Fund Hospital Centre, London. Although numbers were limited, it was hoped that as with the community study, others would join the Research Advisory Group later on. This happened.

One of the problems that had to be faced throughout, was the difficulty in persuading the Research Advisory Group that there really was no one to tell them what to do, what to ask and how to define who or what was important to them in co-ordinating. It was their tangled world under the miscroscope - and they alone held the golden thread to signpost the way through the labyrinth.

> "It looked simple at first - advice on how questionnaires should be compiled ... Now we seem to be not advice givers, but doers".
> (consultant psychologist)

The bemused and indignant: "We thought the King's Fund were doing the research!" persisted, particularly at senior levels.

(An interesting parallel has been noticed in an experiment in Southern Methodist University, Dallas, Texas, where students were presented with an opportunity to be entirely responsible for discovering for themselves projects which would benefit the community; and responsible thereafter for planning and carrying them out, in groups. As with our project, explanations were given by the faculty if sought by the students, but the students were not told what they should do, nor how they should do it.

The experiment revealed that bewilderment, anger and antagonism resulted, and that roughly one in eight of 238 students could be described as "manifest rejectors" of the freedom to choose and to act. They waited for guidance*.)

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* "Psychosocial Factors in Hospitals and Nurse Staffing", R.W. Revans, 1972. Paper presented at a conference organised by the U.S. Dept. of Health, Education and Welfare.

If we, too, had our share of manifest rejectors, we also had another curious feature: it seemed extraordinarily difficult for some to grasp that there was available adequate technical advice both from Ali Baquer, the research officer, and from Professor Revans, a former Cambridge Fellow, ready to discuss design and statistics. Both were generous with their time.

The Research Advisory Group, then, was self-directing in its own field of professional knowledge of mental handicap and it its first-hand experience of the hospital world. It ranged across the disciplines and down the hierarchy.

2 Patients Lists

The first step was to obtain a complete list of those patients from the London borough taking part in the study who were in hospital for long-term care. This proved difficult. At the time of the survey (1969-70) admissions to subnormality hospitals were not necessarily arranged by, or through the medical officer of health, so there was no central record. Nearly 300 patients from this London borough were reported to be living as in-patients in more than eight subnormality hospitals as far away as Bristol. The main hospital serving the area was twenty-two miles from the borough.

The lists of patients obtained from the local authority were sent out to those hospitals with a sizable concentration of mentally handicapped clients from this borough. Out of eight hospitals requested to bring the lists up to date, three did not answer and only one added a few extra names. The rest of the hospitals declared that, in order to identify patients from any given area, they would need to go through all their case records, and such an exercise would demand clerical help they could not afford.

Out of the 294 names of people on the list sent to these hospitals it was discovered that six had since died and six had been discharged home, one in 1939 and another in 1943. There were twenty-two patients reported by the local authority to be in various subnormality hospitals outside the eight approached. It was not possible to ascertain whether they were still in these hospitals and therefore only an approximate estimate of the number of patients in hospitals from this London borough could be obtained.

3 Selection of Hospitals for the Pilot Study

The Research Advisory Group agreed to parallel the community study and to look only at mentally handicapped persons born on or after January 1st, 1940.

Two hospitals had the largest concentration of patients under 30 years old from this borough. One had 117, (none of whom were under ten years old); the other had sixty-eight, tending to be in the younger age range (eleven of these were under ten years old.)

The two hospitals were physically very different. One was built a hundred years ago as a series of three storied blocks linked by stone corridors and bridges, and is divided by a main road. The other is a more modern villa type hospital with units scattered across the grounds, and is surrounded by farm land.

The one hospital had around 2,000 patients, the other, 1,400 at the time of interviewing. Both had endured a good deal of publicity not long before the project started, and both were being visited by the Hospital Advisory Service during the early days of this study. In addition, one had been the subject of some attention from Pauline Morris, author of "Put Away". Although this appeared at the time to have no effect on the willingness of those close to the patients to participate in the project some of the inertia experienced later among senior staff may have been partly due to a reasonable feeling of wanting to be left alone, of having had more than enough of self-examination.

Finally, both hospitals were about to unite the male and female nursing staff under one administration. It was a time of change, anxiety and uncertainty for people in both hospitals.

4 Sample of Patients

A sample was therefore drawn of those patients under 30 years old, the criteria being that they had matching (or near-matching) dates of birth with the 19 cases in the community pilot study, and that they came from this particular borough.

It should be made clear that, in order to parallel the community pilot study exactly, we wished to study a similar sized sample consisting of only those people in hospital who came originally from the same London borough. Although it was realised that this was not a fair sample of the population of the two hospitals, in the interest of comparison between the handicapped at home and the handicapped in hospital, participants finally agreed to this.

The Research Advisory Group accepted that this meant nineteen cases only, divided between two different hospitals. There would be a further division into male and female, into adults and children, into subnormal and severely subnormal.

Participants were not happy about the size of the sample. On several occasions throughout the year of the pilot study and even afterwards, they suggested expanding it - either to one particular ward or a unit. Time, however, prevented any realistic attempt to do this: nor has it been possible, as originally intended, to use the experience of the pilot study to extend the project to hospitals in the six areas concerned in the community study*.

The hospital study therefore remained confined to nineteen patients about whom a total of 103 questionnaires was completed. It has been a sufficient response to indicate fruitful areas for a more detailed study. The number of main questions asked ranged from fifty-two on the nurses' questionnaire to twenty-four on the physiotherapists'.

5 Secondment of Health Visitor

The London borough seconded a health visitor, Joan Trigwell, at the stage of filling in the questionnaires, for a period of six months full time. This secondment, which had the purpose of involving hospital and community jointly on a specific piece of work and on a person-to-person basis, it was felt might lead to greater appreciation of each other's roles in relation to the handicapped. Joan Trigwell's account of this experience, which appeared in the Nursing Times (Vol. 67, No. 36, 9th September, 1971 pp 1119-1120. "Someone is Asking Us" - 1), describes vividly the impact of the two hospitals upon a nurse whose normal job was in the community, and who had never previously been behind the walls of a hospital for the mentally handicapped.

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* See Chapter 6, Diffusion, for a discussion on subsequent extensions, outside the original study.

This chapter has described some of the problems forming a Research Advisory Group and handing over to this group of professionals the responsibility of deciding on the sample to be studied. The problems of tracing the mentally handicapped people originating from one London borough are mentioned and finally a practical co-ordinating action - that of a local authority seconding a member of its staff to a hospital full-time for six months.

Chapter 3

THE OPERATION

This section describes the mechanics of involvement in the early stages of the project.

THE OPERATION

1 How Contacts were Made

Starting with the two physicians superintendent, the research officer Ali Baquer and Diana Cortazzi (the clinical psychologist attached to the Research Advisory Group) met a cross section of hospital staff up and down the hierarchy. During these meetings Baquer and Cortazzi described the aims and methods of the project and explained that the hospital staff would be responsible for the development (though not the technical aspects) of the questionnaires; would be assessing the relevance of the information obtained and, hopefully, would help in administering the questionnaires.

With the co-operation of the two superintendants contacts were made during the first three months of the pilot study with a total of approximately 200 staff.

Each was asked what information he or she considered necessary to decide on the kind of services he thought desirable for his patients and then asked who could provide this information. Then he discussed what information he himself had, that his colleagues might need in their turn, to do their job effectively.

Thus, from the start, the setting was not only one of collecting facts on co-ordination: it was also a challenge to think deeply about attitudes and motives. It was a potential learning situation given meaning by the emphasis on a practical outcome. It was constantly stated that the designing of questionnaires - one for each profession - to which these interviews were only a preliminary, was in the hands of those close to the patient: those who had responsibility for his well-being. These same people would be filling them in and the subsequent interpretation of data would also be their responsibility. They would thus find their own answers to their own questions, and through this personal involvement would find the impetus to action.

2 Who was Contacted

In this was suggestions for their project came from a variety of staff ranging from farm and laundry managers to deputy group secretary and consultants. Among them were:

57 nurses, mainly ward sisters and charge nurses
21 administrative nurses
5 consultant psychiatrists
2 medical staff
6 psychologists
6 social workers
7 occupation and industrial unit staff
3 teachers
9 members of a physiotherapy department
1 biochemist
1 laboratory technician

Some medical, nursing, social work and psychology staff from three other hospitals were also interviewed in the course of completing the questionnaires.

It is a strange fact that at no time were student nurses suggested. Indeed, when the psychologist finally commented obliquely on this, the response was, "Well, they're not really involved with the patients, they move around too often."

This part of the project produced a high degree of involvement. The lesson to be learned is to follow this up. We have discovered that people at the grass roots want to get involved - but can only do so when there is encouragement from the top.

Part two of the paper, "Someone is Asking Us" describes these early stages of the project and the response aroused*.

3 Who Became Involved

To come to a group discussion in one's own hospital might be taken to indicate some degree of interest deeper than the initial interview (where the emphasis was on explaining "this is <u>YOUR</u> research. What do you think should go into your questionnaire - because you will be deciding the questions and answering them, and then you will be deciding the action you wish to take"). Attendance at a Research Advisory Group in London might also indicate a deeper degree of interest. To go to half or more of such meetings or local discussions might be taken as indicating a fair degree of actual participation. Active involvement implies a rather wider development than attendance at meetings.

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* Nursing Times, Vol. 67, No. 37, 16 September, 1971.

In one of the two hospitals in the pilot study the numbers were as follows: out of 42 staff initially interviewed, 27 subsequently came to at least one local discussion group or to one Research Advisory Group meeting in London. Of these, ten attended half or more meetings. Thus a quarter of those initially interviewed formed an active nucleus. They included medical and nursing staff (both ward and administrative), psychologists and an industrial therapist.

In the other hospital, out of 75 staff initially interviewed, 15 came to a further meeting. Of these only six came to half or more of such meetings: that is, one in twelve of those initially interviewed formed an active nucleus. The six "regulars" included social workers, charge nurses and the head teacher. No member of the medical staff in this hospital became at all involved.

These figures probably indicate a minimum level of participation because it was not always administratively possible for those who would have liked, to come to London. One hospital management committee restricted the number of staff attending any conference whatsoever, and so some were not given the opportunity to come, or had to take a days leave. Holidays and unavoidable commitments also prevented attendance at times.

There was some feedback of the findings concerning role perception at a later stage of the findings and this led one of the hospitals to hold a further local meeting at which it was agreed that using the same questionnaires, one unit would study a further sample of patients. This was apparently not supported at the top because it was immediately dropped.

4 Development

a Questionnaires

Hospitals provide a large number of services on one campus and the potential for different types of questionnaire was therefore far greater than in the community part of the project. The original suggestion at the first Research Advisory Group meeting of hospital staff was for thirteen, but later it seemed expedient, because time was running out, to cut this down to the following nine:

Medical staff
Nurses
Psychologists
Social Workers
Teachers
Staff in occupational and industrial units
Organisers of voluntary services
Speech and physiotherapists
Parents

The questionnaires were tested in various places - not just in the pilot study hospitals - changed at various group meetings (which were usually multi-disciplinary), and were ready for testing on the small sample of people from the London borough by the end of the year (1970). So far the project had taken six months.

That learning was already taking place showed from comments at meetings where the creative construction of questionnaires was achieved*. The completion of these instruments was carried out by a multi-disciplinary group from all levels of the hospital hierarchy with a number of staff from local authorities joining in.

There was sharp discussion at all stages of designing the questionnaires. No two disciplines appeared to be talking the same language or even, at times, about the same basic problem of co-ordination in hospitals for the mentally handicapped. One example of this was the nurse who exclaimed to a teacher,

> "Why do _you_ need to know about the parents?
> That's our job as nurses. _You_ just teach
> them to read and write!"

At the second full meeting of the Research Advisory Group, the report notes: "There's a growing acceptance that the questionnaires could be used to teach as well as to elicit information".

This seemed a key to understanding the fundamental difference between this and more formal research methods. Not only did participants learn in an operational setting; this new knowledge was being applied.

One group, for instance, after discussing who the people were who actively set out to answer Tommy's needs, invited the gardener, who was supervising the patient concerned, to their next case conference.

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* The report on a meeting of the Research Advisory Group in September, 1970 comments: "The need for this type of study was shown once again when a local authority and a hospital worker experienced bewilderment at the ramification of each others areas of responsibility and communication."

b Interviews

Since not every type of questionnaire was applicable to every mentally handicapped person (the children for instance did not attend the adult OT units, nor was everyone receiving speech training or physiotherapy) the total interviews for the nineteen patients was 103. Where possible parents, mental welfare officers and health visitors were also seen. The case records kept by the local authority were also examined.

Some of the interviews, as we had hoped, were carried out by hospital staff working together, although the majority were completed with the help of the health visitor seconded by the London borough.

c The priorities

At this stage participants asked to form a joint Research Advisory Group with the parallel community study and thus to co-ordinate hospital and local authority in a practical setting. For many in both groups it was the first opportunity for learning about each other's problems and attitudes. And so, concurrently with the interviewing in both hospital and community, the new joint group was meeting both locally and at the Hospital Centre to discuss the problem of dealing with the flood of statistics that was threatening to overwhelm both projects.

Using the basic data tables from the community pilot study together with the hospital questionnaires, mixed groups of hospital and community professionals of all disciplines - from charge nurse to deputy medical officer of health, from health visitor to paediatrician, from social worker to general practitioner - discussed priorities for analysis. Once again this meeting revealed ignorance of each other's roles, aims and problems to an extraordinary degree. And, as so often, it seemed as if hospital and local authority were dealing with totally different clients. Goodwill for co-operation warmly shone through the fog of misunderstanding: but in the setting of such a highly specific exercise, the magnitude of the gap between paper co-ordination and day-to-day action could be seen by all participants to be immense.

Working together in this way the whole operation was contrived by hospital and local authority staff. The research officer was a vital central pivot: a co-ordinator, an advisor - sometimes almost a spirit - at no time imposing any detailed research objectives on the hospital staff, but always encouraging them to define their next moves from their current discoveries.

This chapter has indicated how contacts were made among over a hundred staff in the two hospitals and describes what proportion became actively involved. The development of questionnaires and indications of the learning this stimulated, is followed by a description of some practical implications.

Chapter 4

HARD DATA

1 Response Rate
2 The parents
  a differences between hospital and community parents
  b similarities between hospital and community parents
3 The mentally handicapped person
4 The nurse
  a nurse activity
  b the law of involvement
  c co-ordination
  d future investigation
5 The other professionals
6 Co-ordination between professionals and relatives
7 Role perception

This chapter records the data obtained from an analysis of the questionnaires in the pilot study. It gives some indication of the services, of the state of co-ordination between parents and hospital, between hospital and local authorities and among the professionals within the hospital. Finally comes a discussion on role perception based on information from an open-ended question.

Chapter 4

HARD DATA

The 103 hospital questionnaires on nineteen patients were completed by July 1971, a year after starting the hospitals part of the project and after six months field work.

The parents' responses were analysed by computer alongside those from the community studies. The rest of the data was analysed by hand.

1 Response Rate

Questionnaires on the nineteen patients were returned from

Files (local authority)	19
Medical staff	15
Nursing staff	18
Psychologists	12
School teachers	10
Mental welfare officers	7
Social workers	4
Occupational therapists	3
Health visitors	3
General practitioners	2
Voluntary organiser	1
Physiotherapist	1
Parents	8

The remaining parents were not in the area, or were dead. One nurse and four doctors did not return the completed questionnaires and the other professions were not concerned with any of the 19 patients in the sample.

Although the nurses' questionnaire has yielded the greatest amount of data and has been the source for the formation of various indices, it seems logical to start at the beginning, with the parents, and to follow this with some contrasting information on hospital and community children. After the discussion on the nurses' data, the nurse-parent relationship is examined, and finally a brief mention is made of the other professionals. Time has prevented any detailed assessment of the opinions of medical or teaching staff apart from the section on roles. However, the data is available.

2 The Parents

It has already been stated that of the nineteen mentally handicapped people in the pilot study sample, the parents of only eight were traced. There were two brothers in the sample so there were ten parents missing. The following observations are made with caution. They are tendencies, not facts. They are compared with the matched community group from the same London borough and with the results from the six areas in the main study*.

a Differences between hospital and community parents

The first observation is that few of the hospital parents seem to have suspected the handicap at birth or in the early weeks of their child's life. This is also the case with the community sample but is in direct contract to the main sample.

The second tendency was for hospital parents to be more readily satisfied with the advice given in the early stages. Parents of children who remain in the community seemed, on the whole, to search more vigorously for other opinions or other sources of assistance.

In answer to the question, "Who helped you most in caring for the child in the early years?", about half the parents in the main project said that nobody had helped them. In the small hospital sample, a higher proportion appeared to receive help.

It also seems that hospital families may, in proportion, show a greater tendency to have more than one mentally handicapped child in the family.

b Similarities between hospital and community parents

Other answers seem to parallel the community responses from parents. There is, with hospital parents also, a feeling of needing emotional support from the general practitioner and in ignorance of how various professions or organisations could help answer their queries, allay anxiety or relieve stress. The mother of Julia, (whose story is told in Chapter 5) says she does not see how the social worker could help her now Julia in in hospital - although the child comes home five or six times a year for two weeks each

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* The six main research areas were Hull, Gateshead, Nottingham, Oxford, East Sussex and West Suffolk. The data from the main project is discussed in: "I Thought They were Supposed to be Doing That", the report of the project "Co-ordination of Services for the Mentally Handicapped" to be published by the King Edward's Hospital Fund, London. Lithograph available - THC 72/735.

time, and causes "general upheaval and strain for the mother". The parents also visit her every week, a two-hour journey each way by public transport.

Other parents, as in the community project, do see for themselves a need for more visits from community or hospital social workers, even though their mentally handicapped child is now living away from home.

Secondly the hospital parents appeared to go first to their general practitioner for advice, as did the London borough parents and those in the main research areas.

Parents, both hospital and community, seldom appear to belong to any voluntary organisation, or to have any knowledge of how such bodies could help them or their child.

Genetic counselling, in the technical sense, was a service felt to be of prime importance by all concerned. In the community study there were twenty-eight families from a sample of 204 who had children (other than those in the sample) who also suffered from some degree of mental handicap.

18 families had one other mentally handicapped child
7 families had two other mentally handicapped children
3 families had three or more other mentally handicapped children

Information on all of these twenty-eight parents shows that NOT ONE, to their recollection, had ever received genetic counselling. Out of the total sample, only ten parents received technical genetic counselling, or at least realised that the advice they received was in fact this.

Of the eight hospital families who can provide this information

1 family had one other mentally handicapped child
1 family had two other mentally handicapped children
1 family had three or more other mentally handicapped children

NONE had genetic counselling or remembered any investigation or examination. This is, in fact, a minimal estimate based on the 8 available parents; there is at least one other family in the sample with 2 mentally handicapped children. One family had "advice" from a London hospital and two were advised to have more children by their general practitioner but did not do so.

The mother with two other mentally handicapped children had seven subsequent pregnancies (two miscarriages). She said: "No one offered any advice, otherwise we would probably not have had five more children". All, including the child in our sample, were born between 1961 and 1969.

Another family (information from general practitioner - none available from parents themselves) had no proper genetic counselling until after their second child, also multiply handicapped, was born. This general practitioner reports that the child in our sample was totally blind, severely deaf and had total disability of speech.

> "Genetic counselling took four years to arrange .... A letter from the genetic counsellor finally reached me six months after the mother had had a further termination of pregnancy which ended in a hysterectomy due to operative disaster. It subsequently turned out that she might not ever have needed the termination."

3 The Mentally Handicapped Person

It was the opinion of members of the Research Advisory Group that these were the practical factors which dictated the degree of need for services. Once the degree of need was known, this could be matched with the amount of services received and with the degree of co-ordination involved. The overall disability of the mentally handicapped person was assessed on a number of handicaps including speech, sight and hearing, epilepsy, incontinence, mobility, reading and writing. An index of disability (the D index) was constructed for both hospital and community samples. This index suggests a significant degree of difference between the two.

Of specific handicaps which seem most prominent, speech is outstanding. Both a severe degree of disability and total loss of speech characterised the children who were in the hospital study as opposed to those who were living in the community. This raises a number of questions apart from those concerning the amount of individual attention, play, nursery rhymes and conversation the hospital child is able to have. Is it possible that the mother who finally sends her child to live permanently in hospital perceives herself as receiving an intolerably small amount of affection or encouragement from a youngster who never learns to say "Mummy" or "doggie" or "Bye-bye"; who cannot indicate, in words, pleasure or pain or affection? Could this be alleviated by teaching the mother how to play and communicate with this apparently unresponsive child?

Another striking difference seems to be in incontinence. Looking either way, at total incontinence or at total continence, the hospital group are considerably more handicapped. Again, this may be either a cause or a consequence of living in hospital.

Not unexpectedly there seems to be a trend differentiating hospital from community in both the type and the number of problems mentioned by the parents as causing difficulties in the early years.

How are the needs of handicapped people seen once they reach hospital? (As with most of the above data, this has been taken from the nurses' questionnaires because of the small parental response.)

Asked about investigations on or soon after admission, the nurses' responses show that every single person had at least one investigation, usually clinical, biochemical or psychological, although others were listed.

In contrast, only eight of the eighteen reported on by the nurses were now receiving special treatment - physiotherapy, speech therapy, or psychotherapy.

Over half had visitors. Only about a third went on outings, and less than a third ever had a holiday.

In the nurses' opinion about a third of these patients could live in the community if circumstances were auspicious, although in answer to the direct question "Should he now be living outside?" they swung in the opposite direction and clearly were not in favour of this.

4 The Nurse

Eighteen questionnaires were completed by nurses and have yielded a rich store of information on how the nurse sees her patient, what knowledge she had of his family, his problems and treatment before she knew him. These questionnaires show the nurse's view of his handicaps and of his training. There are a number of indications of co-ordination, both as the nurse sees it and as she would like it to be.

Within the limitations of a small sample we can now look at some of the answers to those questions raised by the nurses themselves, questions considered of prime importance both to care and to co-ordination, by nurses and by other professions involved in the Research Advisory Groups.

a Nurse activity

An index of nurse activity has been devised*. This includes, firstly, items concerned directly with the patient such as feeding, washing and dressing; taking him for walks or on outings; involving him in evening activities in the ward. Secondly, are items concerned with co-ordinating activities: case conferences and other discussions; visits to school or training units where the patient spends his day; seeing parents, asking for reports, passing on information.

This Index suggests some interesting points. First, a general statement: in order to give fairly and equally to each person according to his needs and disability, the nurse must give different degrees of attention to different patients. So, to be fair the nurse will seem to be unfair. Tommy, with a high Disability Index may need a vastly higher percentage of the nurse's time than Johnny with a more moderate degree of handicap. In other words, to provide equality in the nurse-patient care, of a standard that will not vary, the involvement of a nurse with a given patient does have to differ significantly. And in our sample it does so with a range of care which varies at a statistically significant level of 5%. There is evidence of deliberate concentration of nursing attention on some patients rather than on others. This is as it should be, if we accept that the needs of the mentally handicapped vary.

There is no such bias or accent or unequal distribution of all services other than nursing which are given to the patient.

So, a hospital law can be formulated:

> the institution, by giving different degrees of attention to different patients paradoxically renders to each one approximately the same total service.

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* The analysis of the community sample was immeasurably aided by the use of indices which allowed the detailed examination of the operation of a particular variable. We therefore decided to use the same technique in the analysis of the hospital sample.

Having arrived at a general law which if simple and apparently obvious, now is seen to have statistical significance, the interest and learning lie in examining the exceptions.

The first exception is in the community. Here, services received by a mentally handicapped person are in significant proportion to the activity of the parent rather than to a trained judgement of need. In hospital, each patient is on his own. There is no parent to plead specially for her child, and the hospital distributes its benefits as equally as it can. But to do so, some nurses will need to co-ordinate with greater vigour on Tommy's behalf with their colleagues in other departments. The nurse must make a considered judgement: the parent is not faced with this particular dilemma.

A second, and more specific indication is suggested by this index of nurse activity:

the nurse who is highly active in caring is also highly active in co-ordinating. She is not, in fact, too busy with bathing and bed-making, with feeding and pushing wheelchairs, to discuss her patient with other people concerned with his care. Conversely, the nurse showing a low activity index for a particular patient tends to spend her time - so far as he is concerned - neither on caring nor on co-ordinating activities. Perhaps he does not need them. Perhaps someone else is highly active on his behalf. Until we can go back with this data to those who originally posed the questions, we cannot know. These types of behaviour were found to be fairly consistent among the nurses in the pilot study.

One question is immediately obvious, if a person with a low disability index (who is, by definition, only mildly handicapped) is really receiving little activity from his nurse, why is he in hospital? Because if his overall handicap is slight - by the nurse's definition - should he not either be at home, (if his parents are able to cope, with the support of the social services), or in a hospital in the community? What is this group of people getting from the hospital services that they cannot get elsewhere? And conversely, if a person with a high disability index is receiving low nursing activity - are we accepting defeat?

b The law of involvement

A second question which must remain unanswered until further research is done is, how far does the nurse in hospital parallel the parents? In the community project, the results suggested a law of involvement* which stated:

> "The heavier the disability, the greater the activity of the parent; the more active the parent, the greater the number of services the child received, the greater the co-ordination between them, and the higher the parental satisfaction".

Here we can only suggest the first part of the Law of Involvement so far as the hospital pilot study is concerned, "The greater the disability, the higher the tendency is for the nurse to be active". Is it the nurse who then stimulates the other disciplines? Who in their opinion, does the co-ordinating? Does greater activity lead to greater nurse satisfaction? These are fascinating aspects of this project which were raised by the staff themselves. Only they can answer these questions, if they are ready to undertake a deeper study than this pilot project can be.

c Co-ordination

There are other points from the nurses' questionnaire. The majority seemed satisfied with the reports they received from other departments once the child was in hospital; written communication is evidently adequate for their needs. The nurses were also, without exception, satisfied with the decision taken on the type of training or education their patient should receive while in hospital. But almost half were unaware of any case conferences about these patients. (This is referred to later in the section concerned with responses from other professionals). A question was asked concerning the involvement of the nurse with her patient in activities held away from the ward. The Research Advisory Groups had thought this to be of great importance both for the welfare of the mentally handicapped and for the job satisfaction of the nurse. Only two nurses in this sample were so involved. Overwhelmingly, the rest said they would like to be.

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* For more detailed discussion of this Law see the lithograph: "I Thought They were Supposed to be Doing That", opp. cit.

d Future investigation

These, and other less striking comments, suggest clear lines for discussion within the hospitals. On a larger scale there are specific indications for future investigations. Perhaps the most important of these, so far as co-ordination is concerned, is the question of the Law of Involvement because if this parallels the community study's findings then herein may lie one anwer to the question: "What is it that precipitates knowledge about one's patient into action on his behalf?"

In the community study's parallel publication*, those parents were discussed who appeared to be exceptions to the Law of Involvement - who had a heavily disabled child but who were relatively inactive in stirring the services on his behalf; or those who had a child with only a slight handicap but who were bewildered to receive a spate of services they did not consider at all necessary. An analysis of the first of these groups, whom we called Swimmers Against the Tide, indicated four specific cries for help, four gaps in the service they received.

(i) "No advice was given us when we needed it"
(ii) "No help was given"
(iii) "This was what we really needed at that time"
(iv) "We don't know how this person could help"

It is more than probable that there are Swimmers Against the Tide among the hospital professions. They may well be similar gaps in the service and similar cries of despair from nursing and other staff. This project suggests one method of locating them.

5 The Other Professions

Other professions submitting questionnaires were listed in the early part of this chapter. The largest groups (apart from the nurses) were medical, psychology and teaching staff.

No attempt has been made to devise Indices for these professions although a future project might well do so. What has emerged is some data, requested by them, on case conferences and on the home. Almost half the

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* Ibid.

nurses were unaware of any case conference about the patient they were concerned with in this project. Two-thirds of the medical staff and a similar proportion of psychologists were also in this position. School staff, like the nurses, were equally divided. This is not to say that there were no case conferences; we know only that there was no record available to these staff.

Without taking these facts back to the Research Advisory Group - and lack of time has prevented this - further comment cannot be made, beyond the statement that where there has been such a conference, medical and nursing staff were always present. Psychologists sometimes, social workers occasionally and teachers rarely participated.

The data from these professions on the home circumstances of their patients follows in the next section.

6 Co-ordination between Professionals and with Relatives

Indications are that the nurse may be the key figure in co-ordination, although further investigation is needed to establish this satisfactorily.

There is, for example, a clear tendency for the nurse who has no contact with the parents of a particular patient, also to have poor contact with the social worker and little with the psychologist on that particular patient's behalf.

So far as parents are concerned half the nurses in our sample never meet either parents or relatives, and all but one feel they need to do so. None of the psychologists met the parents and all but two thought it would be beneficial. The same applied to school staff. Only one of the medical staff had seen the parents since the patient came into hospital and most would have like to.

Since the greater proportion of these professionals were concerned to meet the relatives in order to do their job more effectively, the question whether or not this is one of the stimulators of nurse activity vis-a-vis her colleagues, should concern us deeply.

Recorded information about the home circumstances was available to only one-third of the nurses in the pilot study, though almost half of the teachers had seen such a report. Again, overwhelmingly, the nurses felt they needed to know more of the home background to do their job effectively.

FIGURE 3

NUMBER OF DIFFERENT ROLES

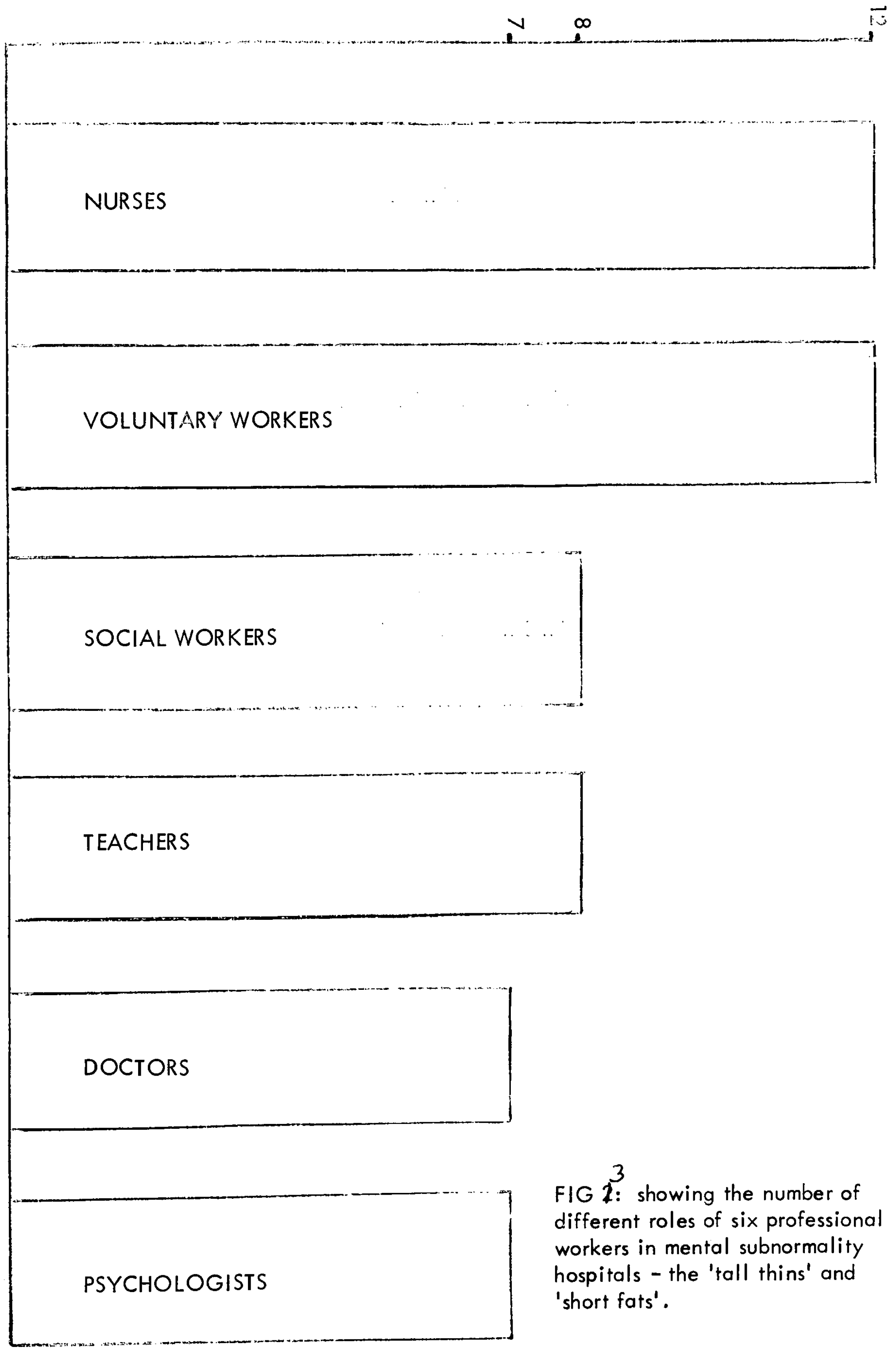

FIG 3: showing the number of different roles of six professional workers in mental subnormality hospitals – the 'tall thins' and 'short fats'.

7 Role Perceptions

Another preliminary analysis was made of the way in which the role of each profession was perceived by the staff filling in this section of the questionnaire - 42 in all. This was a separate section from the main questionnaire and was administered, not only to those concerned with the 19 people in the sample, but also to representatives of all professions in both hospitals and in three hospitals outside the pilot study area.

Figure 3 indicates the variety of ways in which the role of each profession was seen.

Two of the professions, according to the responses, have what might be described as "Tall Thin" roles, while two others look to be "Short Fat" roles.

The "Tall Thins" - psychologists and medical staff - are perceived as having very specific and perhaps stereotyped roles with which most of those responding were in agreement. Psychologists were seen as doing intelligence tests and assessing patients' abilities; medical staff were generally perceived as dealing with physical or mental illness.

Nurses, on the other hand, among the "Short Fat" roles, were perceived variously as doing basic nursing in the ward, as educators, as parent substitutes. All very different. They were seen additionally as co-ordinators of information, as providers of leisure activities and recreation, as advisors to parents. Voluntary workers also have a widespread role; uncles and aunts, letter-writers, providers of entertainment and outings, teachers of specific skills or hobbies, and as assistants in social training.

As far as the nurses are concerned it is plainly not a question of "What is the role of the nurse?" but rather: "Which of her many roles is this particular nurse playing at this particular moment?" It may not be at all obvious to the other professionals. Further how is the nurse herself to be certain from one moment to the next which role she is seen as playing? In a kaleidoscopic blind man's buff she might not even know herself where she stands at a given moment of co-ordination.

The potential for confusion is limitless.

In the community study there was a strong tendency for each profession to see itself as serving in a technical role, whereas the other professionals saw it in a co-ordinating role. In other words, everyone sees himself as using the technical skills of his profession, but is perceived by others as co-ordinator. Perhaps something of the same misunderstanding is evident in the hospital study, although it needs verifying. For, if the apparent tendency for the nurse to act as a co-ordinator (see page) is accurate, it may seem strange that only one-third of the nurses in our sample see themselves in this role.

Moveover, though seen by others in a sufficiently bewildering variety of roles to make them a "Short Fat" category, over half the nurses in our sample see themselves in only one role.

Discussion on such points as these which have emerged from the pilot study suggests some further implications which may be summarised in the following table, where the cause of confusion over role may lie within a given individual himself, or in the perception of colleagues in his own or other professions.

CAUSES	EFFECTS
Ignorance of role	Under-use of skills boredom and apathy isolation overlap and wastage
Misinterpretation of role	Misuse of skills under-use of skills and resentment
Limitation of role by the attitude of others	Isolation withdrawal and apathy resentment rebellion
Lack of communication on change of role	Confusion under-use of skills resentment

Each of these contingencies has in fact been found in a critical incident (See Chapter 5).

The question of roles - the part each of us plays while giving a service to our clients - is a central factor in co-ordination. One has only to study the following verbatim comments on roles to realise the need for further action learning in this sphere. They were made at a meeting at one of the hospitals in the pilot study:

> "Senior people know the roles of everyone!" (charge nurse)
> "They don't know their own roles half the time" (unit supervisor)
> "It's hard to familiarise oneself with everyone's role" (senior registrar)
> "You've got to get your role accepted by others" (senior psychologist)
> "It's people's interpretation of your role" (nursing officer)
> "You may have more than one role" (senior registrar)
> "People have to be satisfied that others are aware of their role" (senior psychologist)
> "I'm uncertain whether your role in the hospital allows you to do this" (ward sister)

In these days of Salmon, of personnel officers, of job descriptions, it should be clear beyond any doubt - on paper at least - what is the role of any given discipline and of any echelon within the hierarchy. Something more is evidently needed to translate paper knowledge into co-ordinative action.

Another possibility is that the "Tall Thins" (the doctors and psychologists) may find it difficult effectively to break out of the traditional, stereotyped roles assigned to them by other professionals, and since neither can work in isolation, may be frustrated by being so confined. At the very least there is the possibility that neither profession is being used effectively in the setting of mental handicap, where physical medicine and intelligence testing are relatively minor needs in comparison with the breadth of service both professions have to offer.

Associated with this picture of how the professionals see each other's roles is a factor which may perhaps also add its quota to the question of confused communication and co-ordination. If an individual is firmly labelled and pigeon-holed in a specific, narrow role then information not seen as belonging to this particular role is unlikely to come his way. Such broader information might stimulate the development of new and creative ideas about his work, or give him a fresh outlook on his patients. It remains, however, in other hands, just because it is not seen by others as in any way relevant to him.

The impression arising from comments made at meetings and discussion groups where roles have been a topic has been always of the difficulty of looking at the services received by the patients and at the need for co-ordination, from the viewpoint of another discipline or another level in the hierarchy.

It was clear throughout the pilot study that neither hospital nor community staff were at all knowledgeable about the work, the attitudes, the value even, of each others' professions. "Why do you need to know this?" was a common question, even between staff in the same hospital.

Data discussed in this chapter is on a small sample: it may indicate tendencies only. Taken in conjunction with comparable data from the main community study it suggests a number of areas for further investigation. For a brief account of some attempts to do this, see Chapter 6.

Chapter 5

DESCRIPTIVE METHODS

1	Case Histories	Julia Jean
2	Critical Incidents	

This chapter illustrates two ways in which gaps in co-ordination may be studied in a practical and constructive way.

Chapter 5

DESCRIPTIVE METHODS

1 Case Histories - taken from the pilot hospital study (names have been altered)

The hard data provides indications of a number of gaps in co-ordination. To complement the statistical analysis and to provide a further stimulus for action learning, two other methods were adopted. The first of these is a "spider's web" type of case history, so called because, with Tommy at the centre, a web of perceptions of his needs and of the services he receives, spun by those concerned with him, whether parent or community or hospital staff, is woven into one account.

Information and comments are taken from the questionnaires of parent, general practitioner, health visitor, mental welfare officer, ward doctor, nurse, psychologist, teacher: whichever has been concerned with Tommy. At times they conflict. This provides another illustration perhaps of how gaps in the service can arise through differing perceptions. It is not suggested that anyone's view is 'right' or 'wrong' - parents and staff may interpret events differently. The warning is clear.

Julia

Julia was born in 1962, the elder of two children. Her father works for a manufacturing firm. Her mother, who is hard of hearing, felt that something was wrong when, by 9 months old, Julia was not sitting up. She had been slow as a young baby and frequently sick. The family doctor always came promptly "whenever we asked for him, at any time".

Mrs. Jenkins saw the clinic doctor who "gave plenty of advice, but did not help", and in the early years leaned on "the welfare people". The health visitor, Mrs. Jenkins remembers, "only seemed to ask questions". Their records show that they had known the family since Julia was born - they suspected the handicap at eleven months. This was because she was not sitting up, and made constant purposeless movements.

A paediatrician confirmed cerebral palsy at the age of one year. Mrs. Jenkins was very dissatisfied because no advice was given to the family. But by 18 months Julia was seeing another specialist in a different hospital. She went every week, a diagnosis was made in detail, and the parents were satisfied with the way they were told of the problems. This hospital was named by them as their main source of help and understanding during the first three years of Julia's life.

Later, when the mental welfare officer visited the family, he felt they needed a great deal of support in coming to terms with the fact that their child was mentally handicapped and he would have liked to spend more time with them. Julia's mother appreciated the way he tried to help by listening to her problems.

The mental welfare officer also saw that there would be major problems after the birth of the second child, two years later. Julia, he felt, would become more demanding, while her brother would not receive adequate attention because of this. Meanwhile, his department contacted five different agencies when Julia was five years old, trying to find someone who would have her for a short while so that her mother could have a break, and trying also to get a wheelchair because Julia could not walk. Nor could she talk, feed herself, wash or dress herself.

Mrs. Jenkins was not at all appreciative of the medical officer of health's services. She contacted him on her own initiative hoping to get Julia into a junior training centre, and the mental welfare officer agreed that this would help both Julia and her family. But the medical officer of health "maintained that she was nothing more than a vegetable", and Julia was not given a place. Mrs. Jenkins thought he should have taken the family circumstances into account. She would also have liked a baby sitting service.

Finally when she was six years old and after two brief spells in hospitals, Julia was admitted permanently to a hospital for the mentally handicapped because her parents could no longer cope. They waited six months for a place.

In this hospital the ward doctor says that Julia was very aggressive, causing parental stress, and he added epilepsy to the diagnoses. He had information from the family doctor and from the mental welfare officer. The ward sister did not have this information. She would have liked it.

Julia's parents were seen by the ward doctor when they first brought her to the hospital, but not since - although he says he would like to meet them and feels it would help them as well as himself. Mrs. Jenkins, who visits every week, could see the doctor if she wanted to, she says, but she feels it wouldn't help. "We never seem to get a clear picture of progress, and he gives no hope".

During that first year in hospital Julia was sent to a neurologist and also to a speech therapist. She had her tonsils out and was referred to an orthopaedic surgeon - she had a deformity of the right foot. Neither Mrs. Jenkins nor the ward sister mentions these events.

Julia also has a speech defect: "severe" according to the doctor, "total" disability according to her parents, health visitor and ward sister. The psychologist alone suggests high-tone deafness as a disability. Mrs. Jenkins is not happy with the speech therapy service nor with the physiotherapy that Julia receives. She says she has no opportunity for discussion with either of these departments.

The psychologist assessed Julia's abilities. Both medical and nursing staff saw his report. He too would have liked to see the parents. He also regretted not discussing his report with other staff, but "was not asked."

Julia is a problem in the ward, needing constant and full nursing care. Occasionally she has tantrums and is inclined to put everything into her mouth.

Someone is needed, additional to the ward staff, to help with the exercises and in teaching her to walk (she is now eight years old). The doctor thinks a voluntary worker could be useful here. He himself spends time talking to Julia - who does not yet speak - and encourages her to walk. He visits the playgroup she attends and tries to play with her, and feels it is good for her to be in a different environment for part of the time. The ward sister says that Julia is in the ward for five days a week. She herself likes this because "we can help her with her walking exercises, which she needs most at this time."

Every Sunday Mrs. Jenkins spends four hours travelling to and from the hospital by bus. It costs her 90p. Julia also goes home five or six times a year for a holiday. The mental welfare officer feels that the family has no need of his services now that Julia is in hospital.

Mrs. Jenkins would have Julia home every weekend if the hospital would take her as a weekly boarder but both doctor and nursing staff think she could not really live at home; the former because she is severely subnormal; the latter because of the constant nursing care she needs.

There has not been a case conference about Julia. The doctor thinks it would be of no benefit. The nurse says, "There never seems to be time!"

Jean

Jean was 20 years old at the time of the project; one of twins in a family of four children. Her father is an office manager and her mother does shift work of some kind.

Jean went to primary school and had a normal education until the age of 15. She was slow to read - and this made her mother wonder - but her twin sister always covered up for her. Mrs. Johnson talked to Jean's teacher, who said there was nothing wrong. "But", said Mrs. Johnson, "the school must have realised that she was very slow". She knew there were special schools in the borough that might have helped Jean, "but the school never did anything about it". The mental welfare officer states that a diagnosis of subnormality was confirmed by the school medical officer when Jean was 15, and her I.Q. was then found to be 62. He does not know who first suspected subnormality. He himself first met her when she was 16, shortly before admission to an adult training centre. Nobody else mentions this.

Mrs. Johnson felt that the mental welfare officer only saw the family when Jean was in trouble and he would bring her back home. "She continually disappeared," she said, "and would be found by the police living with coloured men".

At this stage the general practitioner appears on the scene (although he talks about 1954 - when Jean was six - he presumably means 1964, when she was sixteen). He says the handicap of mild subnormality was first suspected then, because she went with "any male or coloured man". He says he has not been able to offer any specific help.

Mrs. Johnson feels that Jean is "not mental, she's backward - she'll go with anyone". Jean was admitted to a hospital for the mentally handicapped shen she was 16, and has had three brief spells away from hospital since then, the longest for eight months. She was admitted to the hospital without any delay, because of unstable and promiscuous behaviour. Both the ward doctor and the nurse had reports from the mental welfare officer, and, in addition, the doctor had information from the medical officer of health.

Neither the doctor nor the ward sister had seen the parents. The doctor was "not specially keen" to meet them but the nurse would have liked the opportunity to get to know them, feeling that this might help in solving Jean's problems. She thinks it might have helped the parents too. Nor has she seen a report on the home - again, she would have liked this. The hospital social worker has seen the parents and found it helped her to understand the background problem, though she is doubtful whether it helped the parents as the family, "is not really interested".

The social worker did not get a report when Jean came into hospital but she was able to see the case file and has since received verbal reports from both mental welfare officer and ward sister.

Once in hospital Jean had the usual investigations including a psychological assessment asked for by the nurse. She has no physical handicaps of any kind. All concerned find these records adequate; but the nurse misses a home report to complete her knowledge and the social worker states that she gets all her information by word of mouth, on request. She never gets a written report.

Jean can read and write. The social worker says her writing is childish and repetitive, the doctor says she can only copy. She has been in a wide variety of hospital training departments including adult education. In the evenings she goes to hospital dances or plays table tennis or bingo in the ward. She has a holiday once a year with other people from the hospital and goes out of the hospital alone to the shops.

When she was 18 the mental welfare officer was asked by a moral welfare agency to find a mother and baby home. The ward doctor is the only other person to mention this pregnancy. Two years later there was another pregnancy which was terminated and Jean was sterilised.

There has been a case conference, perhaps two: it is not clear. The consultant and ward doctor, the nurse and social worker were there. An assistant matron, a community social worker and a hostel warden appear in some accounts. Jean was considered for hostel care and action was taken. But again her behaviour disturbed the other residents and she came back to hospital. She now has a daily job locally and has formed a friendship with a married woman at work.

Jean's present handicap is seen from various angles. Her mother says, succinctly, "Sex". The doctor, "poor personal hygiene and promiscuity". He adds that Jean is not a problem in the ward but is at home. The nurse lists subnormality, behaviour and sex problems, but social worker and psychologist both seem to feel there is more to it than this. The social worker thinks the parents have been very rejecting and unrealistic in their expectation of Jean. Jean, she states "would like more contact with them", but the family is not interested. Mrs. Johnson, who finds that her husband gets very upset when Jean has been home, and "suffers from heart trouble", feels that she does help her daughter "by being there when she wants me". Jean doesn't come home at all now, "it's not allowed at present, but she is always welcome when permission is given". The social worker comments on Jean's great need for love and attention, "she tends to look for this in men". The psychologist thinks her main problem is "managing her feelings of inferiority and rejection by her parents".

She should not live in the community, states the doctor, "she is totally irresponsible. Needs supervision for hygiene". Jean is now 22, and nurse and social worker agree that with sheltered hostel care, she could manage. The mental welfare officer is equally optimistic, "I still think she is hostel material".

This section describes two "spider's web" case histories concentrating on the verbatim responses of those concerned with a given person in hospital. It is intended to highlight the gaps between needs and services, between the challenge provided by the disability and the response, the presence or absence of co-ordination.

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 style of case history normally written by each profession separately and independently.

It presents possibilities as a learning device for students: once the various questionnaires are available, scanning a complete set of four to six on each individual person takes an average of around one hour. This method can be developed further to illustrate diagrammatically what is happening at each stage of entry upon the scene of a given profession*.

2 Critical Incident Analysis

The whole theme of this project has been that people learn when they are emotionally involved; when they are learning about THEIR world. The parallel theme is that people learn best discovering for themselves - and by doing.

Critical Incident Analysis is taking the familiar and looking at it in an unfamiliar way.

Events and episodes from people's own wards or departments: tragic, trivial, perhaps even amusing incidents which form the highlights of teatime gossip .... these are the ingredients for study. Trivial or serious, the incidents reveal in a brief, illuminating flash, a moment for concern. A moment when a mentally handicapped person is getting, directly or indirectly, a raw deal.

> Nigel, strongly recommended for school, never got there. The report (duly initialled by the medical officer) was found by accident in his case notes a year later - by a ward sister who said, "It's none of my business to interfere", and left it there.

By analysing this incident, (familiar in essence to many departments), in a group concerned to understand the bones of co-ordination, two types of gap may be discerned.

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* Footnote: Information available from the authors.

The first sort of gap is the more obvious, overt gap in communication. The school, for instance, cannot have had a list of all children in the hospital or they might have enquired about Nigel. The psychologist cannot have sent copies of his report to the school - or they would, again, have made enquiries. The doctor must have forgotten to communicate and so must the nurse who filed the report. Fine. People have discovered a number of holes in the intricate web of communications and can take steps to repair them. By regulations, memos, or by regular discussions and conferences perhaps.

People in a group which is deeply involved just because this is a familiar incident to them, because they know Nigel and are angry, may discover the far more fundamental gaps in co-ordination: the covert, hidden gaps of attitude and emotion, of pride, of apathy, of ignorance.

The ward sister's, "It's none of my business!" is one such fundamental gap. Apathy. Born perhaps of frustration, or of anger turned inwards; of lack of job satisfaction, or problems at home. Only the ward sister herself can explain it. But the rest of those in her world can, with absolute certainty, regard that phrase as a danger signal and can take action.

In emotions lie the mainsprings of action. In discerning where emotions have taken a wrong turn people may find a way of creating a positive attitude which could provide one answer to the question, "How do I, working here-and-now, provide for tomorrow when Tommy-without-me will need support and training?"

They can perhaps begin to answer too, the senior registrar who said "This place is teeming with memos ... but co-ordination isn't good at all". If this doctor were to analyse some of the incidents in <u>her</u> world, she might well find some such covert gaps in the service.

The analysis of critical incidents is a structured exercise that is described in the King's Fund Booklet, "The Use of Critical Incidents and the Gaps they Cause, as a Teaching and Training Device". (THC 72/378)

Another use of this technique is as a teaching device for students. It can also be a valuable tool for team-building. Looking in depth at an incident familiar to group is "learning by doing", and in such a setting, discussion on roles and attitudes has a visible and urgent purpose.

This chapter illustrates two different methods of extending the numerical analysis, the "hard data", in a personalised way. People may forget that Julia is a "High Disability - Low Services Received". They are unlikely to forget the emotions they feel as they analyse such stories.

Chapter 6

DIFFUSION

This chapter outlines some projects which have developed in other hospitals not concerned in the pilot study, and discusses the question of diffusion.

Chapter 6

DIFFUSION

One of the strengths of a project lies in its capacity for attracting other groups to try out similar studies.

In the main community project the method has spread to many areas, both in this country and abroad. The hospital pilot study - although incomplete in itself - has already stimulated six different projects elsewhere.

Since so much depends on the decision of the people concerned at the "cutting edge" of the service - those who form themselves into an advisory group - the pattern of each project is different. One such offshoot had no need to go beyond the stage of developing questionnaires, others are currently at various stages.

There appear to be certain features necessary to the establishment of this kind of project.

First, the project is likely to be successful in proportion to the need perceived by the group concerned. It cannot successfully be imposed from above unless this felt need to explore some practical situation already exists.

Second, if the need exists to answer some specific question and if other methods have been tried and have failed, the motivation may be greater.

Third, in addition to need and motivation, is opportunity. The nursing officer described here, when asked to do a survey by his regional board was already interested in the method and had applied some of the principles of involvement, but this was his first opportunity to try a full-scale project. In another example, the question of parents' interest in the hospital was already in the air, the method had already appealed to the consultant, when a different social worker was attached to his unit and a new registrar arrived - both providing opportunity for a study.

Fourth, if there is a belief in teamwork among senior members of a project and if action-learning is perceived as an instrument conducive to team-building, a project is more likely to thrive.

Fifth, is the essential use of feed-back as a team-building instrument.

Below are given six examples of projects which started with the specific aim of using participative research.

1 An Incontinence Problem

This was suggested by a nursing officer in a Metropolitan Regional Hospital Board. Day and night staff were in conflict over incontinent patients, so the nursing officer stimulated the day staff to design a questionnaire to assess the facts hoping, by using this "learning by doing" method, to get some action. Some time later he took the draft questionnaire to the night staff for their approval. "There's no need for the questionnaire", they said, "there's no problem now. We all sat down with the suggested questions and discussed them together and we've settled our differences."

In this instance the questionnaire had spotlighted a topic, brought two conflicting groups together with a very specific objective - and in such a way that blame was laid at nobody's door - and forced the two groups to look at their own and each other's problems and attitudes.

2 Dependency Ratio Survey

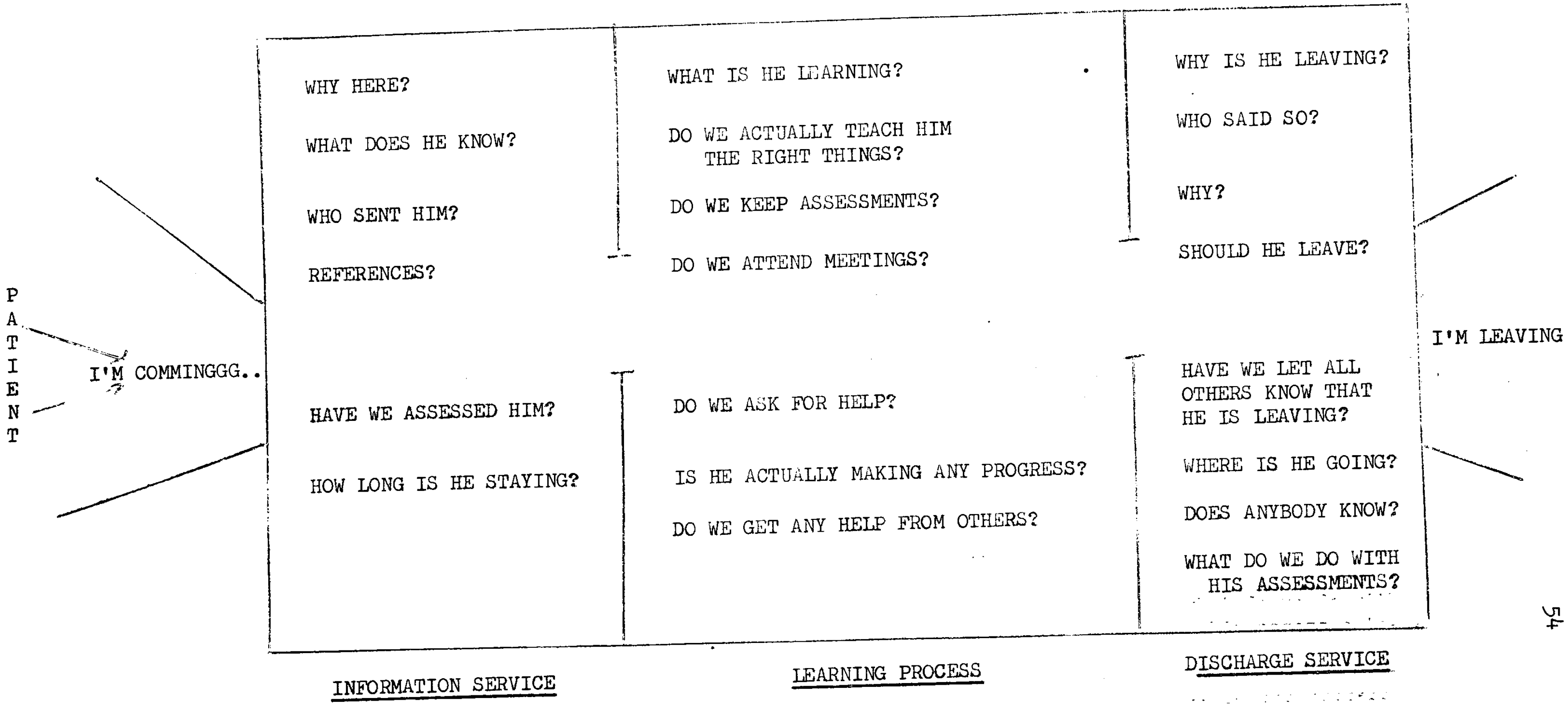
This was requested by another Metropolitan RHB nursing officer. The study of 23 wards in two hospitals was initiated by a nursing officer who was looking further than a factual survey, to consequent action. After discussion with the research officer (Ali Baquer) he convened a group of nurses who

decided what questions they wished to ask
designed the questionnaire
modified it after a trial
administered it
decided how they wished to analyse the results
fed the results back to other nurses for discussion

Their recommendations were accepted by the Regional Hospital Board who have now set up a working party to look at other hospitals in the region.

3 Social Training Unit

A study was initiated by a psychologist and carried out by a university student using the action-learning method aimed at assessing communication between five different disciplines concerned with adults in a social training unit. It is an example of how diffusion was achieved and how it helped the development of this project which has in fact revealed a number of gaps and which has resulted in two forms of questionnaire, but which (like the pilot study) has not yet achieved the feed-back stage. The student has finished



WHY HERE?

WHAT DOES HE KNOW?

WHO SENT HIM?

REFERENCES?

HAVE WE ASSESSED HIM?

HOW LONG IS HE STAYING?

WHAT IS HE LEARNING?

DO WE ACTUALLY TEACH HIM THE RIGHT THINGS?

DO WE KEEP ASSESSMENTS?

DO WE ATTEND MEETINGS?

DO WE ASK FOR HELP?

IS HE ACTUALLY MAKING ANY PROGRESS?

DO WE GET ANY HELP FROM OTHERS?

WHY IS HE LEAVING?

WHO SAID SO?

WHY?

SHOULD HE LEAVE?

HAVE WE LET ALL OTHERS KNOW THAT HE IS LEAVING?

WHERE IS HE GOING?

DOES ANYBODY KNOW?

WHAT DO WE DO WITH HIS ASSESSMENTS?

Fig 4.

Model developed by staff in a Social Training Unit.

FIGURE 5

A SIMPLE CHART OF AREAS OF KNOWLEDGE

	Ward staff	Doctors	Teachers	STU staff	Psychol-ogists
When joined STU			Yes		
How long in STU					
Sent by whom					
Why sent to STU					
Any advice given ?	No	No	No	No	No
Any advice requested ?	Yes				
Meetings attended	No	No	No	No	No
Does he/she go home ?	Yes	Yes	Yes	Yes	Yes
Does he/she receive any visits ?	No	No	No	No	No
Any speech defects ?	No	No	No	Yes	No
Any sight defect ?	No	Yes	Yes	No	Yes
Keeps clean/washes	Yes	Yes	Yes	Yes	Yes
Any problems in dressing ?	No	No	No	No	No
Writes own name	Yes		Yes		Yes
Reads own name	Yes		No	Yes	Yes
Writes a few words/sentences	No		No	No	Yes
Tells the time	Yes	Yes	Yes	Yes	
Understands concept of measurement	Yes	Yes	Yes	Yes	
Associates time with action	Yes	Yes	Yes	Yes	
Problems with money	No		No		No
Any other problems	Yes		No	Yes	Yes
Can he/she be employed ?	Yes	Yes	Yes	Yes	Yes

FIG 5 showing areas of knowledge about a mentally handicapped person for five professional groups.

Interpretative note: a blank space means 'don't know'.

his stint but the team-building has not been completed. This project underlines once again the necessity for feed-back to be seen as an essential part of the learning process.

Figure 4 shows the very simple form of questionnaire the unit staff found acceptable for their needs. This was discussed at a meeting of all five disciplines. Figure 5 illustrates an individual chart after a more detailed questionnaire had been presented and filled in for each of six adults in the unit by the five different disciplines concerned. Even in such a small study the gaps in knowledge and communication are obvious, as are a number of disagreements. As both student and unit staff concluded, "The way the staff defined their roles, and the degree of communication between them, was chaotic. But what made it more chaotic was the assumption that any reference to non-communication was sheer fantasy."

4 Critical Incidents

A group of nurses from a London teaching hospital, already involved in an attitudes study, agreed to try the structured analysis of critical incidents as a way of uncovering basic problems in nursing attitudes. They started to explore two incidents that had occurred fairly recently in their own units. At an early stage it became apparent that the question of attitudes to relatives urgently required further study. This happened when a ward sister told her story, a nursing officer wrote it down as it developed and a charge nurse from a different unit constructed a delightful diagram to interpret the incident. The other incident, written and illustrated in a similar way, revealed to the group a complete absence of the patient at all points of the analysis. It gave them in addition a very precise picture of the state of communications that led to the incident, and of the unexpected isolation of one particular unit.

This hospital group then explored both incidents over several meetings at a deeper level to discover their own answers to the questions they are beginning to ask as they look at themselves in this very personal and practical setting. It is not an easy task, but the group is highly motivated and has the backing of senior staff. They recently demonstrated the technique to a group of tutors from other hospitals.

As a direct result of learning this critical incident technique, one of the nursing officers in the group used it to investigate an incident which was threatening to blow up into an inquiry. By involving all concerned in studying the ramifications of the incident in a positive way, the emotional temperature was cooled and the sequence of events clarified. One of the other nurses in this group is now using the technique to build a ward team.

5 Hospital and Community Parents

Conducted by a social worker and a consultant, and based on a hospital and one of its catchment areas, this project is being initiated to follow up the possibility suggested by this pilot study that there may be differences between the two groups of parents which could affect future policy. Two matched groups of children will be studied, using the questionnaires already designed.

6 Study of a Ward in depth

This project is planned to study, in depth, the experiences of adult patients in one ward. From the questionnaire used in the pilot study those questions which appear relevant to the indices of disability, service received and nurse activity, will be used. This project is part of a re-planning of training and assessment facilities. Every person on day and night shifts, including student nurses and domestic staff will fill in a questionnaire.

Each one of these six "diffusion" projects has deliberately set out to achieve team-building or improved co-ordination. They are all of fairly recent origin.

This chapter describes in outline six projects which have developed as a consequence of the pilot study, but in different hospitals and in other regions. A very simple form of questionnaire and a basic type of chart are illustrated as examples of a minimum of paper work.

Chapter 7

GUIDELINES

This chapter gives brief details to assist those interested in starting an action-learning project for themselves without technical assistance.

Chapter 7

GUIDELINES

1 What to study

This can be either an area of national concern (eg fire arrangements, violent patients) or of local concern (eg how often are patients visited, what are the provisions for young adults). It may be of joint concern to hospital and local authority or of concern to one particular ward or department.

It will, essentially, be an examination of Tommy's world, and will - as suggested by Figure 2 - centre on Tommy himself and the services he receives. The group to be formed in the first instance to study a problem will depend largely on which area is of concern and to whom. (Fig 2 Page)

The actual topic will be a group decision and the group will decide whom to involve. If an exercise is done such as that described in Chapter 3, the final list of participants is likely to be very different to the small, initial group, but it will be a comprehensive picture of those who give a service to Tommy.

2 Use of questionnaires

While not essential, the use of questionnaires has the following advantages

- an accessible and convenient record which is simpler than analysing a series of discussions
- simple comparisons can be made
- a specific indication of gaps in the services either to an individual or to groups of people, of the strengths and weaknesses of the total service across the hospital and of co-ordination can be given
- it provides a reference point for future comparisons
- it indicates areas for future study
- it focuses the attention of the group

3 Where to start?

(i) Form an advisory group that is as broad as possible from all levels within each discipline. It may well be the farm manager or the hall porter who has the most penetrating observation to make on communication.

(ii) After agreeing the topic, the group then decides what information is needed.

(iii) Check the topics and Appendix A which have already provided a wealth of information in the pilot study. These were all suggested by those on the job as being likely to produce answers to <u>their</u> questions on co-ordination.

(iv) Look at questionnaires that have already been designed and consider adapting them. (See Appendix B)

(v) The advisory group then decides on all sets of questionnaires to be used - a joint exercise which in itself produces a learning situation

4 The sample

<u>First</u>: are you selecting
a a ward (45 patients)
b all who go to the playgroup (could be 100)
c all patients under 30 years old (could be 300)
d all who are not visited (could be 1000)

It will depend upon the purpose of your study which size of group you will be surveying, and to this extent, the sample will select itself. (eg a whole ward or a whole unit).

<u>Second</u>: consider your resources - and the enthusiasm you can engender. Can you use students or voluntary helpers for any part of your project? By this stage, you should have tried out one or two questionnaires and will have some idea of the time each takes. Ours varied from ½ hour to 1 hour - but much depends on whether you are using this purely as a fact-finding survey, as an action-learning exercise to develop a team, or even (as a community social worker did) as a therapeutic interview.

If each questionnaire takes an hour to complete, is the group willing to give an hour a week each to work with the nurse or social worker or doctor on this, or could you use a case conference to do a complete set on one person? It will be a group decision.

<u>Third</u>: as a very rough guide our sample (which had to parallel that taken in the London borough pilot study) was 19. This was large enough to produce the developments outlined in this book and to give us a very good idea

of the areas we would now like to study in depth. It was large enough to convince those concerned with diffusion projects of the value of action-learning.

It was NOT large enough to make definite statements about nurse activity or services received: these can only be suggested as trends. In the main community study, where 30-40 mentally handicapped persons were sampled in each of the research areas, firm statements could be made. Again, it depends on the purpose of the project.

<u>Fourth</u>: if you decide to study a large patient area, such as all under 30 years old, it may be necessary to take 5% or 10% of the total number

IF THIS IS NECESSARY, THE SELECTION MUST BE RANDOM

Random - that is, not decided by personal choice: "Joan might be an interesting one to do, let's put her in", or: "No, we don't want Jean, she's not what we're looking for; she's different/spoilt/too difficult".

One way to get a truly RANDOM sample is to list all the names alphabetically and take every 5th, 10th or 20th name to make up your sample of 30 or 40.

For example: if you have 320 people under thirty years old, and you want to study only 40 of them ....

you will need to take $\frac{320}{40} = 8$

so you take every 8th name on your alphabetical list.

Provided the group to be studied has been selected in some random way such as this, the results are likely to be valid, as was shown in the main community study*.

5 Filling in the questionnaires

Again, it is a matter for the group to decide whether,

a each individual does his own
b a student is employed
c two different people in the same profession help each other
d two different disciplines fill in each other's questionnaire
e as with the community pilot study where a health visitor was seconded by the local authority, someone from the community or from another hospital is seconded

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* See the King's Fund Lithograph: "I Thought They were Supposed to be Doing That", c1972., [illegible]

In actual fact the richness of the action-learning project is at its best in c and d, where fresh light on each other's role perceptions is found and common problems can be discussed in the very practical setting of the focus on Tommy and his friends. It is sometimes expedient to use outside help but much is lost.

6 Analysing the information

At the time of suggesting topics and again when the questions are being decided, the group should be considering WHY they are looking at this particular problem and WHY they wish these particular questions to be included. During the interviewing period, the group should also be considering priorities for analysis - since, inevitably, there will be more information than the group can handle.

Once priorities are decided a few of the group list the relevant numbers of those questions which should give this information (see Appendix A for examples).

It is then a matter of drawing up a simple check list, which can form a general chart as in Appendix B, or perhaps an individual chart as in Figure 5.

By arranging the total figures in order of size (e.g. the total services received .... See Appendix B) and taking the highest and the lowest groups, it is possible to match, for example, the disability index for Tommy against the services he is receiving. If both are high, there is no gap; if his disability is high, but services received are low the group should discuss where the gap is.

.7 Interpreting and assessing the information

Although formidable at first sight to those petrified by columns of figures, it is a fascinating and rewarding exercise to study the charts. The group will be able to see what is happening to Tommy, across the chart, and to get a full picture of his world, his needs and the services he receives. It is equally fascinating to follow one area of service (eg nurse sees home report) down the columns to get a picture of the strengths and weaknesses of that service.

The group can, for example, look at those with high disability and see whether the services received and nurse activity are also high. Or discuss the evident gap if Tommy, with a high disability index and high nurse activity index, has a very low services received index. And why is his nurse satisfaction index (which it would be possible to construct) so low, if nurse activity is high?

Look for the inconsistencies. Here are the questions the group needs to answer. And they can only be answered by the group who posed them.

8 Feedback

This is not the place to discuss who should co-ordinate a group in such a project, who should keep notes of meetings (detailed notes are essential for all stages) or who should support participants when the going gets tough - which it will. It is essential to have approval at a high level, but active organising can be done by whichever members the group feel are most suitable.

Feedback is absolutely essential at every stage. It is more likely to happen if a small central team within the main advisory group can be formed to take an active part in this practical exercise in communicating and co-ordinating.

Feedback need not involve formal meetings - though one or two will help to improve the team-building aspect of the project. Individuals can be briefed informally on the 'phone, lunch times shared, or a brief newsletter circulated.

Without feedback there will be less action as an outcome of the project.

> In this chapter an outline has been given of some of the stages of organising and developing an action-learning project, from a practical point of view.

Chapter 8

BENEFITS OF METHOD

Benefits of this method of looking at a topic where co-ordination, co-operation and communication are vital are listed.

Chapter 8

BENEFITS OF METHOD

It may well be easier, or even quicker, to employ a researcher to do a purely scientific survey; there are other ways of encouraging co-ordination. Our method, as an action-learning process, does have certain advantages.

In the first place useful and important data can be collected by this method. Because it is those staff actually providing the service who are instigating and planning, asking and assessing, a great deal of pertinent and challenging information becomes available which can readily be used.

This method provides a TOTAL picture of what is actually happening at the point where client and professional meet in a situation where a service is needed, is given, is co-ordinated.

It is a dynamic moving film rather than a flat picture, because interaction is seen (or not seen) at every stage of the questionnaire. There is a total view of Tommy's needs as perceived by all those who have contact with him and of the intention to make available such services as may satisfy those needs: it is a picture of the actual situation from everybody's angle. In this way each profession's contribution is seen and the gaps in services or in co-ordination are located in a meaningful and operational way. The mosaics from each questionnaire centred on Tommy complete the picture of his normal day, against the setting of his life history.

It is also a total picture of Tommy's world. We can trace the service he is given as an individual. It may be, for instance, that he has a high degree of disability but is receiving a low proportion of services; or, with the "energetic irrelevance" found in the community study, he may have only moderate disability but a high degree of activity on his behalf - with little constructive outcome. Like the snowflakes imprisoned in the child's toy, whirling frantically in many directions to no purpose save to create a bewildering smoke-screen for the beholder: the energy is there but is useless.

A further feature of action-learning is that each person concerned in the project knows what is happening, and in such a way that it becomes his concern, "his" project, and so it becomes important to him to act upon his knowledge.

Educating in a common context such as looking at Tommy's needs, involves a mixed group from the start and because the whole group ultimately decides on each disciplines' questionnaire, this is a realistic method of team-building.

It is teaching people not only to look critically at their own job, but enlightening them on the contribution as seen by other members of the team - sometimes an uncomfortable experience.

Furthermore, it teaches them just how the others are fitting into the team and what they are doing for Tommy. It might be thought that the contribution of the social worker or the psychologist or the industrial unit is obvious. In fact, as many comments made in the course of this pilot study show, this is far from being so.

A practical advantage is that this method does not require a disruption of routine. It may suggest ways of improving it. All the stages mentioned of devising, filling in, analysing and assessing the questionnaires may be done as a form of case conference if it is not convenient to have a special meeting or a working lunch.

Finally there are the advantages of unexpected discoveries: in the case of our pilot study, for instance, the material for discussion and action on roles and the techniques of critical incident analysis. Other advantages might well come from different projects.

We do not suggest that this is the only way of studying co-ordination. Case conferences, discussions, study days and liaison meetings all have potential. It is by no means common, however, for action or learning to result. On the whole these forms of discussion deal either with a particular person or a particular problem at one moment of time and in such a setting we rarely ask ourselves such searching questions as, "How do I see to it that Tommy-without-me is cared for with as great (or even greater) solicitude than I have shown?" "How do I ensure that all my vast store of knowledge about Tommy is not only noted down, but is not left to gather dust on the files?"

This is, we suggest, one method of learning in such a way that we are moved to active discovery: about Tommy, about our colleagues, about co-ordination. And about ourselves.

Some of the benefits of action-learning that we are beginning to discover range from the joint collection of challenging and meaningful data to team-building; from creative thinking to knowledge of some of the deeper mainsprings of co-ordination. A few are listed in this chapter.

Chapter 9

CONCLUSIONS AND SUMMARY

This chapter summarises the progress made in defining Tommy's real needs. It also highlights the many questions which still need, urgently, to be answered.

Chapter 9

CONCLUSIONS AND SUMMARY

Conclusions

We set out in practical terms to develop techniques of involvement which would demonstrate that a multi-disciplinary group could define in practical terms the subtleties of co-ordination in relation to the needs of their clients and their colleagues. Our thesis was that those most closely involved with the mentally handicapped, the providers of the services, could themselves achieve this study since they were closest to the problems. Involvement in such a concrete study would be "learning by doing."

Put simply, before studying co-ordination, four aspects of the service to the mentally handicapped had to be defined

1 Who gives Tommy a service?
2 What are Tommy's needs?
3 Are they satisfied - and by whom?
4 Where are the gaps in co-ordinating these services?

1 Who gives Tommy a Service?

(Partially determined, of course, by where Tommy is). It was not easy for some participants to grasp the apparently simple idea that it was their opinion, as knowledgeable providers of a service, which counted. Some, with the utmost determination, were impelled to search for "facts". Nonetheless, participants did agree in identifying a total of 16 different disciplines or training departments which they ultimately, if reluctantly, cut down to nine types of questionnaire in the interests of managability.

2 What are Tommy's needs?

Individually and in groups, participants from hospital and community services were able to define some of these to their satisfaction and at various levels and at a later stage to refine the questions to keep them in line with the target of co-ordination. Nine sets of questionnaires were developed to measure - among other things - these needs.

3 Are they satisfied - and by whom?

Here the Research Advisory Groups defined questions which produced a preliminary assessment of the activity undertaken on behalf of Tommy. As a pilot study, it was not originally intended to develop specific measurements, but this has been attempted and indices have been constructed to measure this activity and to relate it to the client's needs. There is now sufficient information to form the basis for further studies on a larger scale. There are, to judge by the completed community study, some interesting possibilities for future consideration.

4 Where are the gaps in co-ordinating?

Again, the development of indices is not complete. However, it is already possible to measure some of the gaps in co-ordination between the needs and the services provided and an index of co-ordination appears to be a practical possibility. Further, by using all types of questionnaire to spotlight one mentally handicapped person, a "spider's web" case history can be constructed in more personalised form. Finally, starting with one overt gap in order to study deeper, covert gaps in behaviour, the use of critical incidents has been developed.

Tommy's real needs are now more clearly seen. Not only are they physical and educational (in the widest sense) but co-ordinating needs exist as well. Of what use to Nigel, sitting in the ward day after day, is a report stating his urgent need for schooling, lying unseen in his case file? Of what use to a patient with a high disability index is a low amount of service received? And behind the needs of the mentally handicapped for care and training are other needs for information. Here again co-ordination is seen to be basic to the satisfaction of a need. A nurse feels she has to know about her patient's home. The social worker has been there and talked to the parents. Neither is aware of the other's need for knowledge - or at least, neither takes action. There are clearly other, deeper factors than a simple lack of communication and indeed, the critical incidents technique indicates the desirability of studying basic human emotions and the satisfactions and pinpricks of working in an institution, before issuing bland edicts on co-ordination, co-operation, communication - all of which can so easily become comfortable paths to inertia.

Action-learning is not an easy way of discovering apparently simple facts. It is challenging and, like any exploration of the unknown, provokes its share of tension and anxiety. It is an exercise in self-knowledge in the setting of one's job and self-knowledge is sometimes painful.

The pilot study has shown that two different hospitals can come together and that different disciplines at different levels (hospital and community combined), can define and crystallise their problems. A cross-section of staff acting as a group can clarify which are the problems most closely concerned with co-ordination and measure them. The pilot study also showed that active diffusion of the methodology and developments from it are possible and practicable. If it has failed it is in the lack of impetus to follow through the full cycle of involvement deciding on the needs of Tommy and on the skills of the staff, designing questionnaires around these, filling-in the questionnaires, assessing the results and deciding upon future action. The pilot study stopped short before the final stages of action learning could be organised.

What we cannot yet clarify, at this stage of a small pilot study, is how the concept of learning by organised involvement becomes acceptable in some places or at some times, why it is only verbally acceptable in other places, or why it is accepted on a deeper level of learning and development in yet other parts of the hospital services.

The King's Fund provided a setting and facilities which demanded a specific outcome, as well as a more subtle understanding of role and of attitudes. The specific outcome is the nine types of questionnaire designed by those on the job functioning as a group. The data gathered in the ensuing interviews is beginning to supply stimulating answers.

A number of questions must remain unanswered. We do not know at the moment where is the centre of the patients' world in reality nor where the energy lies that promotes action on his behalf. This is important. The community data shows that the medical officer of health is regarded both by parents and by those giving a service as the central figure in initiating and co-ordinating activity on behalf of a mentally handicapped person, with the mental welfare officer playing an equally important role in stimulating, developing and co-ordinating at grass-roots levels. Who takes their place in the hospital? Community data has shown that parents need a great deal of emotional help from their general practitioner which they do not feel that they are receiving. Is this also true of the nurse, the parent-substitute in hospitals, in relation to the general practitioner substitute, the ward doctor? Who gets the satisfaction - and parallels the parent in this respect? How serious, not only for the victim, the patient, but for providing a positive stimulus to action and to learning for the staff, are inconsistencies? How serious is it, for the heavily handicapped patient to receive relatively little service, or the mildly handicapped to get a great degree of unco-ordinated activity with little satisfaction either to himself or to the providers of those services?

We do not know the answers. We urgently need to find out.

Summary

There were certain defined aims at the start of this project which were to some degree fulfilled in this unfinished pilot study. This is a summary of the main achievements described in this book

1	Design of instruments to assess needs and co-ordination	a	Nine types of questionnaire designed and tested.
		b	"Spiders web" type of case history
		c	Critical incident analysis
2	Information	a	Needs as seen by those doing the job
		b	Needs as seen by parents
		c	Activity of services
		d	Co-ordination
		e	Three sets of indices suggesting certain tendencies
		f	Some comparison of hospital-community differences.
3	Co-ordination	a	Joint hospital/Local Authority Research Advisory Group
		b	Secondment of health visitor by local authority to hospital
4	Diffusion		Six new projects in hospital not concerned in the pilot study.

> In this chapter the question engendered by this pilot study are briefly reviewed, with a note on the benefits and difficulties of action learning as a method of studying Tommy's challenge and response of the services. Finally is a listed summary of the main practical achievements of this pilot study.

APPENDIX A

Nurse Activity and Services Received

Questions and Indices

APPENDIX A

Indices

Two examples follow of questions that we used to construct indices which might assess the amount and range of activity undertaken on behalf of the mentally handicapped person. One index deals with services received before and after comming into hospital and - so far as this was possible on the pilot study questionnaires - restricts this to non-nursing activities. The other was constructed specifically as a nurse activity index, attempting to assess the amount and range of training and rehabilitation done by nursing staff on behalf of a particular patient.

It must be remembered that this is a pilot study, done with the expressed aim of developing and trying out a set of questionnaires. Therefore, had the main study taken place, some questions would have been reworded, omitted or included on everybody's questionnaire. Moreover, due to the form this particular pilot study took, the total response from some professions was small, because not everyone gave a service to each of the 19 persons in our sample.

Within these restrictions it seemed a useful exercise to construct indices and enough has been learned from this exercise to reconstruct the questionnaires. Since the nurse questionnaire happened to have the largest number of returns our four experimental indices were taken from their responses only. In a major study, of course, the services received index would probably be constructed from medical, nursing, psychology and records office questionnaires. This would, incidentally, also reveal gaps in communication. We had no time to do this.

However details of two indices are presented here, to assist anyone trying a similar project. If they provoke energetic disagreement, so much the better.

a Services received (S.R.) index

This has (within the above limitations) been constructed from these activities performed directly on behalf of the handicapped person and - although the information had to be taken from the nurse questionnaire - it is specifically concerned with NON-NURSING services.

The number of the question refers to the nurses' questionnaire, available from the Hospital Centre (see References).

4.0 Was this his first admission to a hospital?

5.6 Have you seen any report on the home circumstances? (This particular question is preferably taken from the medical questionnaire where it is given more extensive coverage)

6.0 Did he attend any of the following before coming into hospital? (List of places such as playgroup, nursery, training centre etc.)

7.0 Had he been seen by any of the following before coming in? (Mental welfare officer, psychologist, consultant/specialist)

8.0 Has he ever seen any specialist
- a in connection with his handicap
- b in some other connection (eg tonsils)

The above questions were concerned with services received before admission. The next group were concerned with services given directly by this particular hospital after admission.

9.0 Have any attempts been made to have his sight and hearing tested?

18.0 Was any investigation made on, or soon after, admission? (eg clinical, biochemical, psychological, genetical etc.?)

19.0 or 21.0 Do you know his IQ or mental age? Have you seen any psychological report on him?

28.0 Does he attend, or has he ever attended, any of the following in the hospital (playgroup, school, special unit, OT, workshop/ITU, adult education, utility department, works out etc.)?

29.0 Does he have any special treatment (eg physiotherapy)?

35.0 and 35.2 Does he usually have a holiday - arranged by the hospital?

b <u>Nurse activity (N.A.) index</u>

This has been divided into those activities mainly of a communicating, co-ordinating nature, and those assumed to be specifically concerned with training and rehabilitation. (Again, had there been a main study, this index would have been reconstructed on the basis of the pilot study experiences).

4.4 Did you ask for a report on the home?

5.0 Did you see the parents/relatives when this person first came to your ward? (or 5.5 have you seen them since?)

9.5 Who first mentioned the need for assessment of sight/hearing? (scored if nurse did)

9.7 If there was a defect, who passed this information on to other departments? (scored if nurse did)

18.3.1 If you were not satisfied with the report on various investigations made after admission, did you follow this up?

20.0 Have you at any time asked for psychological investigation of this person?

22.0 and 22.4 Have you discussed him with the psychologist or any other department?

28.1 How was the decision made to send him to one of the units/departments? (Score if nurse involved)

28.3 Do you ever visit him in any of these units/departments?

30.0 Has there ever been a case conference or other discussion on him?

39.0 Is it easy for you to discuss problems regarding this person with the family, nursing staff, medical staff etc.

These are taken to be nurse activities essentially involving co-ordination. The next section is concerned directly with training and rehabilitation.

11.0 Goes outside hospital with staff.

12.0 and

13.0 and

14.0 Has to be fed, washed, dressed; wholly or partially.

29.1.2 Are there ward activities for him, if so, who takes them? (Score if nurse does)

30.3 How did the patient benefit from the case conference/discussion? (Score if nurse took action)

31.0 Have you ever been involved with this person in any activity other than in the ward?

34.1 If he goes on outings, do you ever go with him?

36.0 Can you say what he does in the evenings? (Score if nurse actively involved in games, hobbies)

It will be seen from these two examples that the material for the indices came from various parts of the questionnaire. To some extent this may counteract any halo effect.

APPENDIX B

Extract from data chart

APPENDIX B

SERVICES RECEIVED (S.R.) INDEX

Code Number	Has been in other hospital or residential unit	Report on home circumstances	Seen before admission by mental welfare officer - etc.	Attended playgroup training centre etc. before admission	Investigations after admission	Psychological Investigation	Training activities in hospital	Special treatment - e.g. speech or physiotherapy	TOTAL	High or low services received index
1	0	1	0	0	1	1	1	0	4	L.S.R.
2	1	1	0	1	2	1	3	1	10	H.S.R.
3	0	1	1	1	2	1	1	2	9	H.S.R.
4	1	0	0	0	2	1	0	0	4	L.S.R.
5	0	0	2	1	2	1	1	Not Known	7	- - -
17	0	0	0	1	2	0	1	0	4	L.S.R.
18	0	0	0	0	7	1	0	0	6	L.S.R.

* Information taken from nurses' questionnaire

APPENDIX C

The Questions we asked parents
and nursing staff.

Copy of the

QUESTIONNAIRE FOR PARENTS

Code No. of Patient ......
Name of Hospital ......
Name of Interviewer ......
Length of Interview ......
Date of Interview ......

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 5.2 Past
(from when)
6 Place of birth of the handicapped
At Home Age At Hospital (Specify)
7 Parents Age Occupation
Father
Mother
(Other spouse if natural spouse
dead or separated or divorced)
8 Siblings (Mark the "place" of the handicapped in the family)
Sex Date of birth
8.1 (ASK about any miscarriages or still births - record order in which miscarriages occurred and ask about length of pregnancy)

PARENTS PERCEPTION OF THE HANDICAP

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

LENGTH OF PATIENT'S STAY IN HOSPITAL

10 How long has your child been in hospital?
From to
10.1 Who arranged his/her admission?
10.2 Why was the admission arranged?
10.3 How long did he/she have to be on the waiting list for long term admission?
10.4 Had he/she ever been in hospital for short-term care? Yes ... No ...
10.4.1 (If Yes) For what reason?

VISITING

10.5 How far is the hospital from your home?

a) In distance

b) In travelling time

c) How do you usually travel there?

10.6 How often are you able to see him/her in hospital?

10.6.1 When you visit, do you take him/her:

out of hospital grounds? Yes .... No ....

for a walk in the grounds? Yes .... No ....

to visitors room/cafeteria etc. Yes .... No ....

or do you remain on the ward? Yes .... No ....

10.6.2 Do you find the visiting facilities are adequate for the particular needs of you and your child?

10.6.3 (If No) Have you any suggestions about this?

11 Does he/she come home at all?

11.1 (If Yes) How often and for how long?

11.2 Do you feel satisfied with the arrangements made by the hospital when you have your child home?

11.2.1 (If No) Why not? and what would you suggest to improve this?

11.3 Do you have any particular problems when he/she comes home?

11.3.1 (If Yes) Why do you say this?

11.3.2 Who could help?

FIRST SUSPICION OF HANDICAP

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

12.1 What made you suspect it?

12.2 What did you do about it?

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

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

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

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

13.2.1 How was the assessment made? Was your child admitted to hospital for observation and investigation? or was your child assessed as an out patient?

In patient ..... Out patient .....

13.2.2 Were you satisfied with the consultation and advice given?

13.2.3 (If No) What did you do then?

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

13.2.5 (If Yes) In what way?

13.2.6 (If No) Why not?

13.3 Were you satisfied with the manner in which you were told that the child was handicapped?

13.3.1 (If No) Why not?

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

Specialist and Hospital
Referred by
Diagnosis
Age of child on diagnosis
Were you satisfied with the diagnosis?
Satisfied .... Dissatisfied .... Very Dissatisfied ....

15 Who is your own doctor?

15.1 Is he the same doctor you had at the time the child was born?

FIRST THREE YEARS OF HIS/HER LIFE

16 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 only against categories where problems faced)

Sleep pattern .... Feeding .... Drinking from Cup ....
Sitting up .... Incontinence .... Control of bladder and
bowel .... Walking .... Talking .... Hearing ....
Dressing .... Other

17 Who helped you most in respect of thecare of the child during the first three years?

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

18 Did your own doctor help you?

18.1 (If Yes) In what way do you think he helped you?

18.1.1 (If No) Did you seek his help? Yes .... No ....

18.1.2 (If Yes) What advice did he give you?

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

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

19 Do you see his/her doctor in the hospital? Yes .... No ....

19.1 (If Yes) Is this usually at your request?

19.2 Does it help you? Yes .... No ....

19.2.1 (If No) Why?

19.3 Do you feel you are able to give the doctor any help? Yes .... No ....

19.4 (If Yes) In what way do you think?

19.5 (If No) Would this help?

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 Whose help did the Health Visitor get, and what was the help?

20.2.2 How long did you have to wait to be referred?

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 Yes) Why is that?

20.3.2 (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 (If Yes) In what way do you think he/she helped you?

21.1.1 (If No) Why not?

22 Have you/your husband ever seen the Medical Officer from the Local Authority Health Department regarding the handicap of your child?

(If "no" or "never" - go the Question 22.4)

22.1 (If Yes) 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 No) Why not?

22.4 How do you think a Medical Officer from the Local authority Health Department helped you?

22.5 Was it fairly easy for you to get in touch with the Medical Officer from the local authority Health Department? Yes.. No ..

22.5.1 (If No) Why is that?

23 Were you visited by a Mental Welfare Officer?

23.1 (If Yes) How often did he call?

23.1.b (If No) Would it have helped if he had called?

23.1.1 Did you find these visits useful? Yes .... No ....

23.1.2 (If Yes) Why?

23.1.5 (If No) Why not?

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

23.3 Does he still visit you, now that your child is in hospital? Yes .... No ....

23.4 Would it help if he still visited you? Yes .... No ....

23.3.1 (If Yes) How would it help?

23.3.2 (If No) Why do you think so?

24 Do you ever have any contact with the hospital Social Worker? Yes .... No ....

24.1 (If Yes) On what occasion(s)?

24.2 How did this help you?

24.3 In what way were you able to help the Social Worker?

24.4 Where would you like to meet him/her?

24.5 (If No) Would you like this?

24.6 Where would you like to meet him/her?

24.7 Does anyone else visit you now, such as the Child Care Officer? Yes .... No ....

24.7.1 (If Yes) Who are they?

25 Have you got any friends and neighbours or relatives who used to help you in any way with regard to your handicapped child?

(If No) Go to Question 26

25.1 (If Yes) What sort of help do they give you?

Kind of Help	Given by	Friend/Neighbour/Relative

MEETING PARENTS OF OTHER HANDICAPPED

26 Do you meet other parents with handicapped children?

Yes .... No ....

26.1 (If Yes) Where do you meet them?

26.1.1 How often?

26.1.2 Does it help to meet such parents? Yes .... No ....

26.1.3 (If Yes) In what way?

26.1.4 (If No) Why do you think so?

26.2 (If does not meet such parents) Would it help to meet such parents? Yes .... No ....

26.2.1 (If Yes) In what way?

26.2.2 (If No) Why do you think so?

MEMBERSHIP OF VOLUNTARY ORGANISATIONS

27. Are you a member of any voluntary organisations? (If needed please name the organisations known in the area)
(If No) Go to Question 27.2

27.1 (If Yes) What are they?

27.1.1 How active are you in these organisations?

27.2 Do you take part in any hospital activity? Yes .... No ....

27.2.1 (If Yes) What activities and how often?

27.3 Do voluntary organisations in this area help you in any way?
Yes .... No ....

27.3.1 (If Yes) In what way?

27.3.2 (If No) Why is that?

NURSERY OR PLAYGROUP ATTENDANCE

28 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 before he lived in hospital?
Yes .... No ....

28.1 (If Yes) Which one? For how long?

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

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

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

28.3.1 Did going to this nursery help the child in any way?
Yes .... No ....

28.3.2 (If Yes) In what way?

28.3.3 (If No) Why not?

EDUCATION AND TRAINING

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

29.1 Who decided it?

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

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

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

29.1.4 (If verbally) By whom?

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

30 Please tell me about the schools and training centres the child attended before living in hospital and for how long? Were you satisfied with the training and education he/she received there?

Institution and address from until
Type of Training Were you satisfied with it?
Very Satisfied .... Satisfied .... Dissatisfied ....
Very Dissatisfied ....

PATIENT'S ACTIVITY IN THE HOSPITAL

31. Is your child attending any of the following in the hospital?

Play group/nursery .... School .... O.T. .... Workshop/ I.T.U. .... Laundry .... Farm .... Garden or other similar Departments .... Working out .... Others ....

31.1 (If he/she does not attend) Why do you think this is?

31.2 Do you think he/she should? Yes .... No ....

31.1 (If Yes) Which?

32. Do you ever get a report of any kind on his/her progress?
Yes .... No ....

32.1 (If Yes) From whom? How often? Does this satisfy you?
Yes .... No ....

32.2 (If No) Would you like to? Yes .... No ....

32.3 (If Yes) Who could you ask?

32.4 (If No) Why do you say this?

33 Does he/she have any special help from the following:

Physiotherapist .... Speech Therapist .... Psychologist ....
Others (please state what)

33.1 Are you satisfied with this? Yes .... No ....

33.1.1 (If No) Why not?

34 Is he/she in any special activity group? Yes .... No ....

34.1 (If Yes) Please describe this

34.2 (If No) Do you think he/she needs any special activity?
Yes .... No ....

34.3 (If Yes) What?

OTHER DISABILITIES

35 How is his/her general health? Sound .... Poor ....

35.1 Any defect in speech? No defect .... Slight defect ....
Severe defect .... Total disability ....

35.2 What about his/her eye sight? No defect .... Slight defect ....
Severe defect .... Total disability ....

35.3 And his/her hearing? No defect .... Slight defect ....
Severe defect .... Total disability ....

35.4 Is he/she incontinent? Fully incontinent .... Occasionally incontinent .... Semi-incontinent .... Totally incontinent ....

35.5 Are there any problems with his/her sleep? Yes .... No ....

(If Yes) getting to sleep .... Waking up during night ....

35.6 Are there any problems with feeding? Yes .... No ....

(If Yes) Unable to feed himself ....
Unable to drink from an ordinary cup ....
Other - specify

35.7 Can he/she go outdoors? Yes .... No ....

(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
Had difficulty in negotiating stairs

(If No) Child too young
Unable to sit without support
Unable to walk at all
Uses wheelchair
Difficulty in negotiating steps
Is ward bound
Is bed ridden

35.8 Can he/she wash himself/herself?

Yes .... No .... Inapplicable - too young ....

35.9 Can he/she dress himself/herself?

Yes .... No .... Inapplicable - too young ....

35.10 Can he/she read?

Yes - no problem .... Yes - with some difficulty ....
No - can't read .... Inapplicable - too young ....

35.11 Can he/she write?

Yes - no problem .... Yes - with some difficulty ....
No - can't read .... Inapplicable - too young ....

15.12 Can he/she tell the time?

Yes .... No .... Inapplicable - too young ....

35.13 Can he/she understand money?

Yes - no problem .... Yes - has some difficulty ....
No - doesn't understand money .... Inapplicable - too young ....

35.14 Has he/she got suitable friends, playmates? Yes .... No ....

35.15 (If the handicapped is an adolescent or adult) Are there any problems regarding his/her sex life?

Yes .... No .... Inapplicable - too young ....

35.16 Are there any other problems that he/she faces now which we have not talked about so far? Yes .... No ....

35.16.1 (If Yes) What are they?

PRESENT PROBLEMS OF THE FAMILY

36 What problems do you and other members of your family face now because of him/her?

36.1 (If problems mentioned) Have you asked for any help from any authorities or services with regard to problems faced by him/her, or by your family?

Yes .... No .... go to Question 37.

36.1.1 What were the problems for which you needed help?

36.1.2 Whom did you ask?

36.1.3 What happened?

GENETIC COUNSELLING

37 After the birth of this son/daughter, did you get any advice on having more children?

Yes .... No .... go to Question 38.

37.1 Did you ask for advice, or was it given to you?

37.1.1 Advice asked for Whom did you ask?
37.1.2 What advice was given?

37.1.3 Advice given Who gave it to you?
37.1.4 What advice was given?

37.2 Was any investigation or examination done to find out if you should have more children? Yes .... No ....

37.2.1 (If Yes) What sort of investigation was it? Who arranged it and who did it?

OTHER GENERAL QUESTIONS

38 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?

39. Is it easy for you to discuss the problems concerning your child with the following in the hospital?

1. Easy 2. Fairly easy 3. Not at all easy 4. No need for discussion 5. No opportunity for discussion

Family/Relations Nursing Staff Medical Staff School Staff
Social Worker O.T. Department Laundry, farm garden or other
Industrial Unit Staff Speech Therapist Physiotherapist
Psychologist Physician Superintendant Other

40 In what way do you think <u>you</u> are able to help you child nowadays?

41 Who do you think, in this hospital, has played the major part in helping him/her with his handicap(s)?

42 Under what circumstances do you think your child might be able to live outside the hospital?

43 What help do you think subnormality hospitals offer the mentally handicapped?

43.1 And their families?

Copy of the

QUESTIONNAIRE FOR NURSING STAFF

Code No. of Patient
Name of Hospital
Name of Local Authority
Name of Interviewer
Length of Interview
Date of Interview

PART I

1 Name of the patient
1.1 Date of Birth 1.2 Sex
2 When did this patient first come to your ward for long term stay?
2.1 How old was he/she then?
3 How was it decided that he/she should live on this ward?
3.1 Were you and your staff happy with this decision? Yes .... No ....
3.2 (If No) Why do you say that?
4 Has he/she been on other wards? Yes .... No ....
4.1 (If Yes) How many and for how long?
5 Was this his/her first admission to a hospital? Yes .... No ....
5.1 (If Yes) Where had he/she been living previously?
5.2 Were you sent any kind of information/report? Yes .... No ....
5.3 (If Yes) By whom?
5.4 (If No) Did you ask for it? What happened?
6 (If No) When was he/she previously admitted?
6.1 To which Hospital?
6.2 Short-term/long-term care?
6.3 Have you any report from previous admission(s)? Yes .... No ....
6.4 (If Yes) Is it, in your opinion adequate for your needs?
6.5 (If No) What more information would you have liked to have?
7 Did you see the parents/relatives when this patient first came to your ward? Yes .... No ....
7.1 (If Yes) In what way did you find this helpful?
7.2 Do you think it helped the parents/relatives? Yes .... No ....
7.3 Have you seen them since admission? Yes .... No ....
7.3.1 (If Yes) How frequently?

8 (If No) Would you have liked to meet them at the time of his/her admission? Yes .... No ....

8.1 Why?

8.2 Have you seen them since admission? Yes .... No ....

8.3 (If Yes) How frequently?

8.4 (If No) Do you think it might have helped the parents/relatives? Yes .... No ....

9 Have you seen any report on the home circumstances?
Yes .... No ....

9.1 (If Yes) Whose report was it?

9.2 (If No) Would you have liked one?

10 Did he/she to your knowledge attend any of the following before coming into hospital?

Play group/nursery .... School/Junior Training Centre ....
O.T./Workshop/Adult Training Centre .... Adult Education ....
Rehabilitation Unit .... Outside Employment ....
Other (specify) ....

11 Had the patient, to your knowledge, been seen by any of the following, before coming into hospital?

Mental Welfare officer/social worker ....
Psychologist (Educational/Clinical) ....
Consultant/Specialist (please specify) ....

12 Has the patient to your knowledge, ever seen any specialist

(a) In connection with his handicap?

Yes .... No .... Don't know ....

Specialist and Hospital	Referred by	Diagnosis	Age on referral

(b) In some other connection (e.g. tonsils)?

Yes .... No .... Don't know ....

Specialist and Hospital	Referred by	Diagnosis	Age on referral

13 Have any attempts been made to have his/her eyes tested?
(If Yes) By whom? ..... No .... Don't know ....

13.1 And hearing?
(If Yes) By whom? ..... No .... Don't know ....

13.2 Was this routine? Yes .... No ....

13.3 (If Yes) Is this repeated regularly? Yes .... No ....

13.4 (If No) Who first mentioned the need for this assessment?

13.5 Was the result communicated to this person?
Yes .... No ....

14 If there was a defect in sight/hearing, who was this information passed on to?

Parents/relatives ....
His/her own G.P. ....
School ....
O.T./Workshops ....
Social Worker ....
Voluntary Organiser ....
Medical Staff ....
Other Nursing Staff ....
Speech Therapist ....
Recreation Officer ....
Psychologist ....
Other (Please State Whom) ....

14.1 Who passed this information? (specify)

15 If there was a defect in sight/hearing, has this patient joined any special club connected with this?

Yes .... No .... Inapplicable - give reasons ....

16 Is he/she a multiply-handicapped person? Yes .... No ....

16.1	(If Yes)	Speech	No defect Severe defect	Slight defect Total disability
16.2		Sight	No defect Severe defect	Slight defect Total disability
16.3		Hearing	No defect Severe defect	Slight defect Total disability
16.4		Movement	No defect Severe defect	Slight defect Total disability

16.5 If there is any defect at all in any of the above, do you think it is part of a syndrome?

16.6 Does he/she suffer from epilepsy?

16.7 Does he/she suffer from any additional physical handicap not mentioned above? Yes .... No ....

16.7.1 (If Yes) Please specify:

16.8 Is there any sign of minimal brain damage?

16.9 Is he/she incontinent?

Fully continent(clean and dry both day and night)
Occasionally incontinent (wet or dirty day or night)
Frequently incontinent (wet and dirty day and night)
Totally incontinent

17 Is he/she mobile?

(If Yes) Goes outside the hospital alone
Goes outside the hospital with staff
Goes in hospital grounds alone
Goes in hospital grounds with staff

(If No) Too young
Unable to sit without support
Unable to stand
Uses walking aid
Uses wheelchair on his/her own
Is pushed in wheelchair

18 Are there any problems with his/her feeding? Yes .... No ....

(If Yes) Has to be fed
Unable to drink from an ordinary cup
Unable to use knife and fork
Slow feeder
Other problems (specify)

18.1 Is there ever any opportunity to teach him/her? Yes ... No ...

18.2 (If No) Who could do this?

19 Can he/she wash reasonably well without help?

Yes .... Yes, partially .... No .... Inapplicable ....

19.1 Is there ever any opportunity to teach him/her?

19.2 (If No) Who could do this?

20 Can he/she dress him/herself?

Yes .... Yes partially .... No .... Inapplicable ....

20.1 Is there every any opportunity to teach him/her?

20.2 (If No) Who could do this?

21 What do you think is the diagnosis?

22 Why do you think he/she was admitted?

23 What do you think is the main problem in managing him/her?

24 In what way do you think you can help this patient?

25 Was any investigation made on, or soon after admission?

Yes .... No ....

25.1 Was this investigation

Clinical .... Biochemical .... Genetical ....
Psychological .... Other (Please specify)

25.2 Did you see a report? Yes .... No ....

25.3 (If Yes) Were you satisfied?

25.4 (If No) Did you follow it up?

25.5 (If No) Do you think this might have benefitted the patient?

25.6 Why do you say that?

26 Have you facilities available for such investigation?

Yes .... No ....

27 Do you know his/her I.Q./Mental Age? Yes .... No ....

27.1 (If Yes) What is it? When was the assessment made and by whom? I.Q./M.A.

27.2 (If No) Should you know it?

28 Have you asked at any time for psychological investigation of this patient? Yes .... No ....

28.1 (If Yes) What was the result?

29 Have you seen any psychological report on him/her? Yes .. No ..

29.1 (If Yes) Was it adequate for your needs?

29.2 (If No) Why not?

29.3 (If psychological report seen) Did you agree with the findings?

30 Have you or any member of your staff discussed this patient with the psychologist? Yes .... No ....

30.1 (If Yes) Was it helpful to you?

30.2 Do you think the discussion in any way helped the psychologist?

Yes .... No ....

30.3 (If No) Why not?

31 Have you discussed him/her with any other department? Yes .... No ...

Please state which.

32 Can this patient read and write?

Read:	Write:
Yes, no problem	Yes, no problem
Yes, with some difficulty	Yes, with some difficulty
No - can't read	No - can't write
Inapplicable, too young	Inapplicable - too young
Don't know	Don't know

33 Are there any behaviour problems? Yes .... No ....

33.1 (If Yes) Please describe them?

34 Are there any problems regarding his sex life?

Yes .... No .... Inapplicable - too young ....

34.1 (If Yes) Please describe them?

35 Is he/she classified as:

E.S.N. .... Subnormal .... Severely subnormal ....

36 In your opinion, is he/she institutionalised? Yes .... No ....

36.1 (If Yes) What do you think could be done about this?

37 Does this patient attend or has he/she ever attended any of the following in the hospital?

1. Attends now 2. Has attended in past

Play Group School Special Unit O.T. Workshop/Ind.
Unit Adult Education Utility Department Works out
Other (please state)

37.1 How was the decision made to send him/her to this?

37.2 Were you happy about it?

37.3 Do you ever visit him/her in any of the above departments?

38 Does he remain on the ward? Yes .... No ....

38.1 (If Yes) How do you feel about this?

39 Does he/she have any special treatment? (e.g. physiotherapy, speech therapy, psychotherapy etc?) Please say what:

40 Are there any ward activities for him/her? Yes .... No ....

40.1 (If Yes) What are they?

40.2 Who takes them?

40.3 (If No) Who do you think could help in this?

41 Has there ever been a case conference or other discussion on this patient? Yes .... No ....

41.1 (If Yes) On what occasion?

41.2 Who else was present?

41.3 How did the patient benefit by such discussions?

41.4 (If No) Why do you think this was?

42 Have you ever been involved with this patient in any activity other than on the ward? Yes .... No ....

42.1 (If Yes) What kind of activity?

42.2 Did it add to your knowledge of this patient?

42.3 (If No) Would you have liked this?

43 Is this patient, generally speaking, isolated? Yes.... No ....

43.1 (If Yes) Why do you think this is?

43.2 (If No) Does he/she relate to:

Staff .... Patients .... Voluntary Worker ....
One particular person (Please specify)

44 Does he/she ever have a visit? Yes .... No ....

(If Yes) How often?

44.1 Often .... Occasionally .... Once a year ....

44.2 Who visits him/her?

Parents/relatives/Voluntary Worker/Other (specify)

44.3 (If No) What could you do to help in this?

45 What outings does he/she go on?

45.1 Do you ever go with him/her? Yes .... No ....

46 Does he/she usually have a holiday? Yes .... No ....

46.1 (If Yes) With parents/relatives

46.2 (If has a holiday) Arranged by the hospital? Yes .... No ....

46.3 (If No) Why not?

47 Can you say what this patient does in the evenings?

47.1 Are you happy about this? Yes .... No ....

47.2 (If No) Why not?

48 Under what circumstances do you think this patient could live outside the hospital?

48.1 Who should be involved in deciding this?

49 Do you think he/she should now be living in the community?

Yes .... No ....

49.1 (If No) Why not?

50 Who do you think in this hospital has played the major part in helping this patient with his/her handicap(s)?

51 Is it easy for you to discuss the problems regarding this patient with the following

1.Easy 2.Fairly easy 3.Not at all easy 4.No need for discussion 5.No opportunity for discussion

Family .... Nursing Staff .... Medical Staff ....
Psychologist .... Social Worker .... O.T. Dept ....
Industrial Unit Staff .... Speech Therapist ....
Physiotherapist .... Voluntary Workers ....
Other (specify) ....

51.1 Can you explain why you did not find it at all easy to discuss the problems, if you have put any ticks in column 3?

52 Do you think the records you have available to you provide you with sufficient information to help this patient? Yes .... No ....

52.1 (If No) What further information would you like to have, and who can provide it?

53. What reports from other departments in the hospital for nursing staff need to have on this patient in order to give best service and why?

Reports	Reasons

53.1 Please specify which one you get now?

54 In what particular way do you think <u>you</u> have helped this patient?

PART II

55 What do you think should be the role of the nurse in a subnormality hospital?

56 What should be the role of the ward doctor?

57 How do you see the role of the psychologist?

58 What about the school?

59 And the Social Worker?

60 How about the voluntary worker?

61 Is there anyone else in the hospital you think has an important role to play in the patients' lives? How do you see it?

62 Do you ever give lectures/talks in the community, on any aspect of subnormality?

63 What services do you think the subnormality hospital could provide to the community?

64 What community services do you think the hospital can benefit from?

65 Do subnormality hospitals serve any useful purpose?
Yes .... No ....

65.1 (If Yes) What purpose?

65.2 (If No) Why not?

66 Name of nurse

67 Age

68 Sex

69 Qualifications

70 Grade

71 Length of service in: N.H.S.
Subnormality
This Hospital
Other jobs

72 Number of nursing staff in this hospital

73 Number of patients on your ward

January, 1971.

The Hospital Centre.

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