King's Fund Centre

MENTAL HANDICAP PAPERS

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Services for mentally handicapped children

London 1976

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FOREWORD

This is the record of a workshop on services for mentally handicapped children, organised jointly, in March 1976, by

Association of Professions for the Mentally Handicapped
Institute of Mental Subnormality
King Edward's Hospital Fund for London

Some thirty people, parents and professionals, have combined to write a document which clarifies their joint view of the kind of service for mentally handicapped children towards which we should be striving; and which identifies what can be done, in practical terms, during the next five years, towards the development of the desired service.

The structure of the two days was simple but effective. On the first day the members had a free interchange of views about needs, after which a number of papers were given, some describing existing services in operation, others consisting of commentaries on the existing service. That evening, syndicates identified the key areas for discussion on the following day. On the morning of the second day, each syndicate considered two questions, and their answers were argued through in plenary session during the afternoon. The results are contained in this report.

Two factors must be mentioned. Firstly, this report is a joint statement, worked out by parents and professionals together, each trying to recognise the other's problems and stresses. Secondly, all the proposals in Part IV are achievable, partially or wholly, within the next five years, and very few require additional resources of any substantial nature. Mostly they merely require a different way of working together.

We hope the report will speak for itself, and will encourage action. For action is most certainly needed.

Chris Williams

James Elliott

SERVICES FOR MENTALLY HANDICAPPED CHILDREN

A statement by
a group of parents and professionals
meeting under the auspices of
King's Fund Centre, London
Association of Professions for
the Mentally Handicapped
Institute of Mental Subnormality

The King's Fund is glad to have been able to facilitate the efforts of the workshop, but wishes to make it clear that this is a discussion paper, and that the views expressed are not necessarily those of the King's Fund.

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PART I

DETERMINING THE NEEDS

1. The first session of the workshop took as its brief - determining the needs. How do parents and professionals view the current and future needs of handicapped children? How do these needs influence the current and future development of a service for handicapped children? How do professionals view the needs of parents? How do parents view the needs of professionals? And how do we together guide the planning of a service that attempts to satisfy these needs?

2. From an open forum discussion, in which the voices of parent and professional were both heard, a number of specific needs became apparent. Although they interact or overlap, they can be crystalised into a number of key topics.

On first being told

3. The birth of a handicapped child is not an event for which a family can plan. Very rarely is there any indication that other than a perfectly healthy child will be born. It is this event we anticipate and for which we make preparations both within the family and our wider circle of acquaintances. Hence the arrival of a handicapped child immediately necessitates a radical re-appraisal of our role as parents and our predictions of the future for our child. Both parents need information. Some of this information is 'hard' information: what services, special equipment, grants and aids are available? Other information is of a 'soft' nature: where to turn for help and advice on future development? Who will explain the condition and the implications of handicap? Who will be available for contact on follow-up? Where are there other parents in similar circumstances?

4. All of these needs were expressed by many of the parents and must, in part, reflect the absence of such services in their own cases. It would appear that the experiences of parents highlight a shortfall in actual and effective help and support. There are problems in giving this information and support. Some conditions are not apparent at birth and only become significant over a period of time. There is a marked shortage of personnel who have enough information and experience to supply the necessary support to satisfy these needs.

Assessment

5. Parents need to know how their child compares with other children of a similar age: they need to know his assets as well as his deficits. They need to know his likely progress and how best to help him make that progress. They need to know details of his physical condition and its long-term prognosis. They need to

know how his development will interact with the rest of the family. They need these things spelled out in words that can be understood, instead of being mystified by technical jargon. Again the problem with meeting this need appears to lie in the lack of staff with the right skills.

Co-ordination

6. Many of the parents had experienced a stream of professionals visiting them, some offering advice, some consolation and some very little. This did not engender confidence and continuity. It was felt that a 'key person' should be identified to act as 'direction indicator' or 'interpreter'. This person would be the co-ordinator of services for their child and would be the consistent person to whom they would turn in need. The absence of a unified system for long-term contact was seen as a major problem leading to disjointed delivery of service and a lack of inter-professional liaison.

Short-term versus long-term care

7. Too often the choice seems to be between long-term home care and long-term residential care. A strongly felt need was expressed for a range of services to be made available to enable a choice to be offered for a variety of residential options.

8. The range of these services should extend from night relief care,through two weeks residence for family holidays, to long-term residential care. There was a need for follow-up services to be made available following placement in long-term care. The problems highlighted concerned both the quality of care and the location in which it is provided.

Parents who fail to appreciate their own needs

9. It was felt that some parents may actually fail to appreciate their own needs, or may find them difficult to express. This may come about either through lack of information and guidance or through a tendency to withdraw and isolate from the community. There was a clear need to enable parents to share problems, information and solutions. All too often parents have had a history of adverse experiences when interacting with professionals. Non-professional parent support groups might help the isolated parent more than increased professional contact.

10. Finally, from the group discussion, emerged a number of general comments all of which set the scene for the individual contributions to follow. We heard that the service should provide for crisis prevention as opposed to crisis intervention; that parents needed to meet professionals 'on the floor'; that a child who is 'sent away' is 'lost' to the family; and that we should acknowledge the possibility that all families may eventually need long-term care for their children.

Individual contributions

11. The first speaker stressed that putting a child into long-term care is equivalent for the parent to a mourning experience at the loss of a child. The practice of providing residential or fostering care outside of the immediate community may not be the most beneficial help that can be offered. The first priority should be for the family to be enabled to keep their child at home: nevertheless, there will remain some difficult considerations. Some families will not be able to do this: all families are likely eventually to require a form of long-term care.

12. Where parents had felt they had received insufficient information at birth it had been useful to introduce them to parent self-help groups. Such a group was described operating from a local education college to act as an information resource centre and a mutual support group. Another parent emphasised the need for the right approach when telling of the birth of a handicapped child: both parents need to be present and involved from the beginning; a long time needs to be taken over the telling; the information will NOT be grasped on first telling; long-term commitment from an identified professional needs to be made available.

13. The problems of a lack of a 'good' education assessment were emphasised. Parents are not told clearly enough of their right to ask for an assessment and of their right to be present throughout. It was proposed that assessment should be a lengthy process - possibly at least two full days initially - leading to an agreed formulation of a developmental programme, both for short-term and long-term goals.

14. The home does not present a simple problem. It was stressed that there was a wide range of difficulties encountered in the home setting. Some parents find it difficult to work with some professionals and a system of voluntary welfare workers, similar to that recently initiated by NSMHC, may provide one means of coping with this difficulty. Parents as volunteers can often act as intermediaries to remove misunderstandings. No other person but the parent can appreciate fully the implications of caring for a handicapped child. It was suggested that in some cases a barrier still existed between the parent and the professional. This could well be the greatest hindrance to a fully effective service being provided by the professional for the parent.

15. The difficulty of co-ordinating the various agencies was raised: it was argued by some that a co-ordinator was needed, who could well be on the staff of the social services department. Two further roles were claimed for such an individual: a 'direction indicator' to direct the parent to appropriate resources; and an 'interpreter' to translate professional advice into appropriate and meaningful family advice and to interpret family problems to professional advisers. But although the workshop was sympathetic to these suggestions it was felt by some that a competent and concerned professional should in all cases function in this way, without the need for any intermediary.

16. We were asked to consider again those parents who fail to appreciate their needs or who lack the initiative to discover or expose these needs. Some parents need quite simply to be told they have needs. They need information and services. It might be something as simple but essential as a washing machine or something as intangible but essential as someone to demonstrate caring on a regular basis. They need the mutual help afforded by parent support groups.

17. Such a parent support scheme was described - at Toynbee Hall in East London - where a centre for contact has been established. Here parents and professionals meet on equal terms and jointly share the problems and successes of helping the children develop. Specialist services and advice are brought in and a process of crisis prevention has begun to evolve.

18. We were asked to grapple with the problems encountered in diagnosis and assessment. Too often there is a lack of concern shown to parents over their anxieties and feelings of failure. The diagnosis and assessment is too often seen as a 'medical' procedure, forgetting that education and social services have a role to play. Many parents of handicapped children are NOT getting the services to which they are entitled - 'why is it nobody ever tells me anything about my child' is a plea, commonly heard. The need for co-ordination and follow-up was stressed and emphasis must be placed on ensuring that the parents understand the details of the assessment and advice given. Assessment must be an on-going process, not a once and for all statement. There must be a continued commitment to a family to enable the parents to help their child. It may be that in some cases the parents can prove to be better 'therapists' for their child than can the professional: they are committed, they are always 'on duty' and they do not have an ever-expanding case-load.

19. Short-term residential care and treatment may not always be the most sensible strategy to adopt when dealing with a long-term problem. There is a need for an increased domiciliary or community nurse service. There is a need for increased training for staff to enable them to fulfil this changing role in care. There is a need for greater contact between teacher and school: the taxi driver may not be the best intermediary between the school and the home! Parents need to see how they can collaborate with the school to enhance their child's development - perhaps by spending some time in the classroom setting and by the teacher spending some time in the home setting. Parents need to be supported when they ask for these facilities.

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PART II

SOME CURRENT SERVICE PROVISION

20. For this section we had specifically asked particular individuals, or groups of individuals, to detail the various services that they were providing to meet some of the needs expressed in the previous section. The selection of contributors was guided by a wish to explore innovations.

21. Out of a number of helpful contributions made, we have selected four which demonstrate innovatory features within an existing service:

Cambridge: a district service for the mentally handicapped

Hereford & Worcester: an NHS-based community service

London: a volunteer-orientated family service **

Wales: home training for pre-school children

** This service is illustrated by the reproduction, by kind permission of Kith & Kids, of the Preface, written by Dr. Albert Kushlick, from Two to One: a Kith & Kids Community Project. Inter-Action Inprint, 14 Talacre Road, London NW5 3PE, 1976. Price 60p. (post paid, UK)

THE CAMBRIDGE DISTRICT SERVICE FOR THE HANDICAPPED

G.E. Roberts

22. The Cambridge Health District serves a population of about 300,000 with Cambridge (population about 100,000) in a more or less central position. The main hospital resources are concentrated in Cambridge. They comprise Addenbrooke's Hospital - the general teaching hospital; and the Ida Darwin Hospital - 240 beds - which provides residential care and other facilities for the mentally handicapped but which for residential purposes serves a much larger population than that of the Cambridge Health District. The local authority services in the district include four special schools for ESN(S) children, two ESN(M) schools, a school for physically handicapped children, two special units placed in normal schools for children with specific language problems (with normal intelligence) and a special unit for deaf children. Many nursery schools take in handicapped children between the ages of 3 and 5 years. There is also an Opportunity Class for very young handicapped children at a local Village College (secondary school). There are three adult training centres, two in Cambridge and one in Huntingdon, which has an associated hostel. There is an adult hostel in Cambridge which belongs to and is run by the local Society for Mentally Handicapped Children.

23. The obvious need to co-ordinate all these activities has resulted in the present multi-disciplinary approach which is aimed at the provision of a comprehensive district service to the handicapped and their families 'from the cradle to the grave'. There is a long tradition in Cambridge of close co-operation between the hospital services, the local authority services (social services and education) and the voluntary organisations; thus our approach thrived in a receptive environment. This paper attempts to describe the community-based programme associated with the Ida Darwin Hospital.

The multi-disciplinary team

24. The staff of the Ida Darwin Hospital are the main source of certain professional workers who are committed to this joint hospital and community approach.

The nurses provide a community nursing service, giving practical advice to parents with their 'children' living in the community. Nurses also visit homes of short-term care residents at the Ida Darwin, before admission, to bridge the gap between the parents and the hospital. This activity is co-ordinated by a nursing officer who is in constant touch with members of the team from other disciplines.

Department of Clinical Psychology. 3 psychologists contribute to the initial and on-going assessment, give advice to parents with particular problems, run workshops for parents of young handicapped children and participate as advisers to the local toy library.

Physiotherapy Department (5 physiotherapists) In addition to their in-patient work the physiotherapists participate in out-patient assessment, give advice to parents, treat the children at Addenbrooke's, Ida Darwin, or in the homes. They also service the two ESN(S) schools in Cambridge.

Speech Therapy Department Similarly the speech therapists (1 at Addenbrooke's, 1 at Ida Darwin) contribute to the out-patient assessment and treatment programmes, and liaise with the 'community' speech therapists.

Social Work Department (4 social workers) The social workers are employed by the local authority but are exclusively committed to the district service for the mentally handicapped and their families.

Medical staff Jointly appointed to Ida Darwin and Addenbrooke's are two consultants, 1½ medical assistants, 1 senior registrar, 1 registrar and 1 clinical assistant. The consultants provide out-patient services in the general hospitals and work on a sector basis, assisted by their medical colleagues, some of whom service the special schools.

25. The Cambridge-based consultant is responsible for the clinic in Developmental Paediatrics at Addenbrooke's Hospital. This is an assessment and on-going counselling clinic staffed additionally by the physiotherapist, the psychologist, the speech therapist and the Physician in Community Child Health. Social workers

and health visitors, educational psychologists and peripatetic teachers are also involved. This clinic is not confined to mentally handicapped children. It provides a service for children with developmental delay of all kinds, including language problems, physical handicap (cerebral palsy, spina bifida, etc.) all of whom are assessed, as appropriate, by individual members of the team.

Co-ordination

26. The hospital and community-based activity is co-ordinated:

(a) at the clinic in Developmental Paediatrics

(b) by case conferences at the local schools or at the GP health centres

(c) by regular meetings of the personnel involved from the health, social service and education authorities

(d) informal meetings, as most of the professionals work together for most of the time. Any member of the team can convene a meeting at any time to discuss any problem.

27. Once a child has been referred to the clinic by the family doctor or consultant colleague the child's family is then in contact with an identifiable team to any member of which they can turn for help. Regular contact with families in the community also ensures that crises are averted as information is fed back to the appropriate member of the team who may be required to take action.

28. The community service is backed up when necessary by short or long term residential placement either in hospital (Ida Darwin) or in hostels (social services) or in residential schools (education department). Evidence is however accumulating which suggests that by investing the available professional time in the community in the way described, the need for 'permanent' residential care is significantly reduced.

29. Apart from the involvement of the hospital-based personnel in the community as described, the physical facilities of the Ida Darwin Hospital are made available to the surrounding community. The Occupational Therapy Department and staff therein provide evening classes for adult mentally handicapped persons living in the community. Amongst the activities are further education, training in self-care, art, cookery and woodwork. This helps improve the quality of life for handicapped people living in the community, and also enables parents to have an evening break.

30. The dental service at the Ida Darwin also provides special facilities for the mentally handicapped living in the local community when general practitioner dental services have difficulty in providing for the special needs of the handicapped.

31. In some circumstances when adult mentally handicapped persons are not suited to the adult provision in the community, arrangements are made for them to attend the Ida Darwin Occupational Therapy Department, which has a broad-based brief to encourage self-care and to provide further education and training in order to improve upon the quality of life in the handicapped.

32. The hospital school, now run by the local Education Authority, also provides a number of day places for children who, by agreement with all concerned, are best placed at this school rather than one of the local special schools.

33. Whilst acknowledging that the provision of such a service in Cambridge has been facilitated by a tradition of co-operation it seems important to mention that what has been achieved has been accomplished by the use and 'redeployment' of existing staff and resources and not by the appointment of special staff to undertake this work. In addition to the benefit to the handicapped there is also benefit to staff who find themselves with greater job satisfaction than that which would be gained if they worked exclusively in their own departments, cut off from the other disciplines. And job satisfaction makes for better recruitment and therefore a better service.

AN NHS-BASED COMMUNITY SERVICE

Angus Capie
Laurence Tennant
John Hattersley

Introduction

34. Traditionally within the National Health Service, the majority of efforts directed at helping the mentally handicapped have been confined to the immediate hospital situation. In the last ten years, increased emphasis on work in the community and fuller participation of parents in treatment/education programmes in the United States has been shown to be beneficial in a variety of areas. O'Dell for example, reviews over 80 projects where parents were taught in highly structured ways more effective methods of helping them cope with retarded children.

35. The rationale for working with mentally handicapped people in the community can be summarised thus:

1. In order to help mentally handicapped children acquire new skills and behaviour, changes are required in their learning environment. The environment must be structured precisely to let appropriate learning occur.
2. Institutions have been repeatedly shown to be inefficient environments for teaching the new skills necessary to maintain people in the community.

3. The Government's paper Better Services for the Mentally Handicapped (1972) states that "about 80% of severely handicapped children and 40% of severely handicapped adults - and a higher proportion of the more mildly handicapped - live at home. Their families need advice and many forms of help, most of which at present are rarely available". (P.4, para 20) As there are many more mentally handicapped people living in the community than in hospitals, it is desirable to help develop their skills. This may also help institutions by keeping some mentally handicapped people out of hospital and also, by gradually reducing numbers, enable hospital staff to work more effectively.

4. Parents have a right to be closely involved in helping children, and since we are concerned with teaching new behaviour by structuring the environment, it is clear that the home environment is a crucial one for retarded children.

Behavioural teaching programmes

36. Initial programmes began with staff seeing children at out-patient clinics, arranging regular visits to the children's homes and setting clearly defined targets for parents to teach before the next visit. This approach is useful but has disadvantages. Visits tend to become crisis intervention situations. It is difficult in the normal busy household to teach behavioural principles that will enable parents to work out effective strategies in the absence of the advisor. Home visits are time-consuming and their cost-effectiveness is open to question in areas with widely scattered populations.

37. As help for the parents, specifically aimed at enabling them to change behaviour and teach new skills, was in demand, it was decided to run short evening training courses in behavioural teaching for small groups of parents. Results from these courses so far suggest that parents find they are of value but only some parents are able to maintain programmes after the course finishes. Such courses - which are closely allied to developmental psychology - may be more effective if the children concerned are at a similar developmental level. One way of possibly assisting parents more, is to run courses for teachers in special schools who will then be able to support parents more effectively and see that integrated home-school programmes are maintained.

38. A complementary, longer term approach is feasible and is currently being researched: two main factors have directed our attention to this longer term approach. Firstly, in our view, the single most important fact about handicapped persons is that they acquire new skills more slowly than others do - they are slow learners. Secondly, the behavioural approach indicates that the individual's environment is crucial to the acquisition and maintenance of new skills. This environment includes all of the people who deal regularly with the child, especially the parents and the teachers.

39. We would like to describe briefly a clinical/research project which aims to help the family and the community to manage and teach the handicapped person. With the close co-operation of a local day special school servicing some fifty children, we have established groups of five or six parents who meet once a month in a room provided by the school. The meetings have five broad aims:

1. To discuss and advise on the management of individual children
2. To provide information and support for the parents
3. To encourage the parents' use of available facilities such as short-term care in the hospitals
4. To facilitate communication and co-operation between home and school
5. To move toward a better co-ordination of the services offered to the home

40. Parents, usually the mothers, are offered transport to attend regular morning meetings during school term time. During discussions on individual children the child's regular teacher is invited to join the group. The school's headmistress and a social worker attend most meetings. With individual learning problems the parent and the teacher co-operate to improve the effectiveness of achieving decided goals. Parents are encouraged and taught to observe and record their child's behaviour with a view to deciding on possible causes and realistic goals. This 'interpretation' of the observations generally leads to an action plan decided upon by the group.

41. The psychologists' contribution aims to provide facts and guidance on which to base the action. As many psychological principles as possible are applied during this stage. Continued observation and recording by the parents ensures that the planned action can be updated. No attempt is made to teach the parents principles of psychology although it is clear that their behaviour often undergoes considerable change.

42. In conclusion we must emphasise that this approach is in an early stage of development. Although the initial response from parents is encouraging, we have no clear data on long-term effectiveness. Future developments will be aimed at reaching the families of handicapped children much earlier. It is also our intention to reduce the reliance of parents upon extensive input of professional time by helping them to help their children and each other.

TWO-TO-ONE

Preface by Dr. Albert Kushlick

43. This modestly written handbook arising from the activities of Kith & Kids, is a major contribution to the development and research of services for mentally handicapped people. It is directed at other parents and some professionals who work with handicapped people. I believe, however, that those planners, managers, professionals and researchers who fail to read it will probably remain off-target in their activities with the handicapped for a very long time.

44. This paper describes the development and implementation of the Two-to-One project organised by Kith and Kids in the summer of 1975. Because of the modesty and joyousness of the style, the reader may fail to notice that it is, in fact, a very detailed description and evaluation of a complex cycle of joint activities between parents of handicapped children, volunteers and professionals. It involves planning, setting up, running and evaluating an intensive summer school training course for handicapped children. It includes a clear description of the steps taken to recruit, train and allocate two volunteers to implement a precisely stated individual programme, worked out jointly by the professionals and the parents for each of the 17 handicapped children participating. Each programme was monitored daily by the professionals and the programmes were adjusted where this was considered necessary. Parents were provided with daily progress reports.

45. At the end of two weeks, each parent, following a personal discussion with the professionals, was given a teaching plan to implement with their child to continue to solve the educational problems identified earlier by the parent.

46. The paper has been produced because it is intended that other parents and professionals might begin doing the same things elsewhere. Kith and Kids also intend new developments (they intend to begin organising more than one such event annually). They seek the collaboration of teachers of handicapped children to extend the participation of parents and volunteers working with behavioural psychologists into the school classrooms. This would promote what I assume to be the main aim of Kith and Kids, that is, joint goal setting and joint working to attain these goals in all activities throughout the day, within the child's ordinary environment. Also, with the encouragement of Kith and Kids, some local authorities are to run classes, as part of adult education, for the handicapped person after he or she has reached the age of 16, with volunteers working on a one-to-one basis with the handicapped.

47. Suggestions that parents should participate in the process of educating or treating their children are often attacked by professionals as unrealistic or seriously misguided - how could parents possibly have the balanced judgement of an "uninvolved" professional? How could they pretend to have the skills of specially

trained professionals? Similarly, other people without ever trying, offer complex, untested, pessimistic speculations on why parent/professional collaboration cannot take place.

48. Not only does this handbook present a thoroughly documented series of steps on how such participation has been successfully implemented; it presents also a model of educational goal setting and attaining, including some of the most sophisticated technological advances that have been made in the last ten years. As many professionals planning, managing and delivering services are, at present, still unaware of these advances, it is most important that they should read this handbook.

49. Moreover, the description warrants much more than brief reading through. To make use of it the reader will do well to study it in detail. The parents of Kith and Kids and their professional advisers have not just dashed into print after a two-week flash-in-the-pan exercise last summer. Nor should the warmth of the description lead anyone to undervalue its serious contribution.

50. Their Two-to-One venture of summer 1975 was their fourth: the first was launched in 1972 and they have organised a summer school every year since then. Thus, this was the fourth in a series of complex cycles of planning, setting up, running and evaluating - each of these steps is described in detail.

51. Impressive examples are: the planning before the event of individual teaching programmes by the professionals, with each parent, on page 17; on pages 37-39 of Appendix B is a detailed programme designed for one of the children; on page 20 they describe the pre-training of the volunteers, on pages 20-25 the daily programme, monitoring and adjustment of individual programmes is presented; on page 26 they present a description of the way in which each parent is briefed on the results of the training during the two weeks' course, and on how the parents can continue to build on the joint success of children, parents, professionals and volunteers.

52. It is my opinion that in the section of evaluation, the organisers have modestly under-estimated their achievements. The data presented of new skills acquired by children over the two week period appears to show limited progress because the techniques employed for recording progress are still undeveloped.

53. The handbook refers modestly to the fact that children, parents, volunteers and professionals probably enjoyed the experience. There are now well-developed measures of the level to which children and staff were actively and interestedly engaged in planned or unplanned activities at any point throughout a whole day. There is also accumulating evidence that these measures are extremely sensitive indices of the effectiveness of programmes. Only very well organised programmes manage, at all times of the day, to 'engage' more than 50% of children

in planned or even unplanned activities. In most programmes, there are times of the day when 80% or 90% of children are literally doing nothing, or waiting while the next activity is being planned, if they are not behaving disruptively. Similarly, there are very few programmes where staff and other adult helpers do not sit about talking to one another, uninvolved in arranging materials for the children.

54. Over the whole of the period during which I was privileged to attend the Two-to-One venture, engagement levels at any time seldom appeared under 70% - at times they reached virtually 100% in planned activities involving children and staff. It is fortunate for all of us that the organisers have made video-tapes as well as provided us with a written description.

55. From both sources we will be able to derive immensely valuable assistance in attempting to replicate such developments elsewhere. The parents, the professionals and their voluntary helpers have given us a useful start. No doubt they will be as generous in sharing more of their experiences in the detailed material they must have collected over the years.

56. For those of us who will be starting to try things themselves, I believe we would be wise to note that the Kith and Kids members started with very limited objectives, and that it took them five years to get to where they are. True, they didn't have the help and guidance which they are giving to us. Despite this, and despite the development of new teaching aids over the last five years, we must heed the Kith and Kids experience and begin with very small numbers of children, parents and a small number of interested professionals. That, in itself, is an important lesson - it means that we can all try something in a very small way. As each small project is described in detail by those people who have organised it, we are gaining if subsequent groups of parents and professionals can use these descriptions as manuals on how to set up their own activities. We are greatly indebted to the Kith and Kids for pioneering this exciting development.

57. Not only have they dispelled the myth that parents are too involved to assist in the objective goal setting and assessment of their own children, but they have shown that parents can identify their own problems, the problems of their non-handicapped children and the problems of the handicapped child, with a unique precision. Indeed, without the help of the parents in identifying these problems, any professionals must have to guess what the important problems are, and it is likely that in choosing to work on some things rather than others, they may be solving their own problems and creating others for parents and other members of the family. The second myth that has been dispelled is that parents cannot work together with professionals as equals in the solution of complex problems because they cannot understand the professional approach. Kith and Kids have shown that parents can select and hire professionals, both to train themselves and to work with them in the training of their children. Parents are able to make this selection as long as there are professionals who are sufficiently competent and skilled that they can declare their own goals in a way comprehensible to other people.

58. The final myth dispelled is that parents select unrealistic goals for their handicapped children. It may be that parental goals have always been realistic and that only recently have there been professionals with the skills to respond to these very realistic requests.

59. The final major corrective in the handbook is the role of the medical practitioner in the direct day-to-day programmes of handicapped children. No doubt all of these children have their own general practitioner - indeed, many of them with serious organic difficulties were also attending specialist paediatric departments where competent doctors undertake the complex diagnostic tests required to inform specific treatment which must be carried out in a wide range of settings. However, these skills do not inform the solving of day-to-day problems of the child or his parents. Nor do they inform the monitoring, supervising or co-ordinating of programmes to solve these problems. It is significant that the one medical practitioner who undertook a direct role in the day-to-day aspects of the project participated as a volunteer. He carried out educational programmes with the children and was, like other volunteers, supervised and monitored by the educational consultants with skills of joint programme design and implementation with parents and other staff. Like all other volunteers, he was also supported by the parents of the handicapped child. Medical practitioners of any speciality who acquire new skills in the educational techniques of precision teaching are very likely to make a helpful contribution to the day-to-day care of the handicapped. They will also require skills of collaborating with parents and other professionals, identifying those soluble problems which are important to the parents and the clients, and of jointly planning and implementing ways of solving these problems. The Kith and Kids venture presents a useful model on which to begin building.

HOME TRAINING FOR PRE-SCHOOL CHILDREN

Sue Revill

60. There are gaps in the range of services provided to the mentally handicapped and there is lack of co-ordination of those services which do exist. The first problem could be at least partially solved, and the second problem entirely solved, by efficient co-ordination of the existing services.

61. Many problems appear to derive from the fact that plans are formulated in terms of buildings or places rather than in terms of specific programmes of care, treatment and training. Families often face a great deal of uncertainty concerning the future of their handicapped members, particularly at crucial career stages when it is necessary to find a place in a school or workshop.

62. The joint prescription of both short-term and long-term individual programmes for each client by all agencies involved, would help to give clients more benefit from existing services. It would also identify specifically the areas in

which services are inadequate. Such individual planning must take place from the moment a developmental problem is recognised. It is important that the prescribed programme be regularly reviewed and, if necessary, revised.

63. For each mentally handicapped child known to the services there should be a continually updated record of current training and treatment goals agreed with the parents. There should also be a statement of longer-term goals relating to the provision of education, training, work and residential arrangements. The programme for each individual should be decided and reviewed at regular meetings attended by the relevant personnel from each agency, together with the parents. One person should be responsible for co-ordinating the services in each case.

64. Our research unit is working with service colleagues to develop services of this nature for the mentally handicapped in Wales. A long-term aim of the unit is to develop a comprehensive service: the initial phase will consist of the research and development of possible components of such a service. The first such component being studied is the home-training of pre-school mentally handicapped children, using the Portage Model. This is a scheme which has been developed and used successfully for a number of years in the USA. It directly involves parents in the education of their own children. It is based on the following premises:

1. Parents care about their children and want them to attain their maximum potential, however great or limited that potential may be.
2. All parents can learn to be more effective teachers of their own children.
3. Even the most severely handicapped children can be helped by individually-programmed training.

65. The advantages in this home-based precision training model include the following:

1. Learning is occurring in the parents' and child's natural environment.
2. There is direct and constant access to behaviour as it occurs naturally.
3. If instruction occurs in the home there is more opportunity for full family participation in the teaching process.
4. Since the home adviser is working on a one-to-one basis with the parents and child, individualisation of instructional goals for both is possible.

66. The materials used in this home-training system are a check list of behaviours - cognitive, self-help, motor, language, socialisation - and a card file containing outline training instructions for each behaviour on the check list. In addition, a weekly activity chart is used, consisting of a behavioural description of the skill, directions and materials needed to carry out an activity and a recording format which monitors the child's progress.

67. The present project is being implemented through the South Glamorgan AHA, using two specialist nursery nurses, supervised by a senior clinical psychologist. When a chid is referred, contact is made with the parents through their usual health visitor or social worker. The home adviser is then introduced to those parents who are interested in the home training service. If the parents decide to use the service, a preliminary developmental assessment is made. The home adviser and parent, together complete the check list of behaviours which establishes the child's present performance in the five developmental areas. After completing the check list, the home adviser has enough information to plan with the mother, and to write up, one or two activity charts for the coming week. The parent models these activities under the home adviser's supervision and works on them during the week, recording the child's progress on the activity chart.

68. During the next visit, the home adviser is able to determine from the activity chart whether the goal for the previous week was appropriate, too difficult, or too easy. If the child has been successful, the home adviser then prescribes a further step in one of the developmental areas. However, if the child has not met the criteria for success, the home adviser then modifies the instructions using the parent's suggestions and her own observations so that the child can obtain success within the next week. Each weekly visit lasts approximately one hour.

69. This is an example of a type of service which might be offered to parents of handicapped children. The objectives of the service are limited to the training of the child, but within this limitation, goals are set in clear terms and the parents are involved as major participants in the scheme. Other problems which are not capable of solution by a home-training service will be referred to the appropriate agencies. Such a framework of clear goals and explicit tasks should greatly increase the chance of achieving a co-ordinated and effective service for mentally handicapped children.

SUMMARY OF PART II

70. During this session the quality of individual contributions was impressive. People of concern and competence have shown how, despite the constraints of the traditional model, innovations can be explored and can be a success. Each innovation calls for a blurring of professional roles and an acceptance of a wider overview of the development of handicapped individuals. It is encouraging to hear of how closely professionals can and do work with parents in a true collaborative exercise.

* * *

PART III

THE WORKSHOP IN PROGRESS

Identifying key topics

71. At the end of the first day, workshop members formed syndicates of single-discipline or cognate groups, including one for parents only. The many topics which emanated from these syndicates were considered by the directing team, who arranged them into five specific topic headings, as the basis of the group and plenary discussions on the second day. These were as follows:

1. Co-ordination of services to children, including early intervention, and continuity of contact
2. Parent as co-worker, including problems of the unmotivated parent
3. The need for the residential care of mentally handicapped children within the NHS
4. The degree to which services for mentally handicapped children can be common with those for other children
5. Practical ways of improving services to mentally handicapped children within the next five years.

On the morning of the second day, workshop members were split randomly into four multi-disciplinary syndicates, parents mixed with professionals. Each syndicate considered one of topics 1 to 4 and all considered topic 5. We now set out how they reported back, and how the workshop as a whole responded to their views in plenary session.

Co-ordination of services, including early intervention and continuity of contact

72. Parents have a right to be told of the diagnosis at the earliest possible moment, and fathers should be involved right from the start. The method and timing of this information is of paramount importance. As is shown in Right from the Start (1) this is often done clumsily or insensitively and could well be improved by the training of staff in the skills and nuances of imparting this information. Parents should be given a leaflet with simple facts appertaining to mental handicap, followed up by a more comprehensive guide containing detailed national and local information; the local information should be specific and should include names and telephone numbers of people or organisations offering service in the immediate locality.

73. This is not a once-only operation: it is essential to offer parents an easy opportunity to talk over the situation as frequently as they need, not only with a doctor, but also with the social worker, specially versed in work with the mentally

handicapped, who should be involved from the beginning. Some assessment and other clinics should be held outside normal working hours so as to make it more possible to involve fathers, on an on-going basis, keeping them interested in, and participating in, any programmes which are developed. Immediate notification by the doctor to the health visitor involved with the family is essential, coupled with opportunities to involve the community nurse where appropriate.

74. There are particular problems in those instances where a diagnosis cannot be made early, and much more notice should be taken of the parents' growing anxieties and queries. It should be compulsory for a developmental screening system to be set up, starting from the age of six months, operated by the health visitor but with direct access to the specialist developmental assessment clinic - for all handicaps - based on the paediatric department of the district general hospital. This clinic should include, at various times, such specialists as psychiatrist, paediatrician, specialist in community medicine, specialist social worker, nurse, psychologist, physiotherapist and speech therapist.

75. The two key team members in ensuring continuity and co-ordination of services to parents are the medical consultant and the specialist social worker; their organisational base should be the multi-disciplinary team described above: the existence of this team is fundamental to continuity and co-ordination.

76. Parents are in no doubt of the great benefit of their being able to knock on one door for help. In every district there ought to be some location to which parents may go for advice and support, or to be put into touch with the right people. It might be provided at a voluntary centre, as at Toynbee Hall in East London; or at an NHS hospital, as at Rotherham; or at an adult training centre; or, ideally, by appointing a specialist social worker, though regretably there seem to be few with special knowledge and understanding of mental handicap.

77. No case can ever be closed in mental handicap, so social work support should be on a long-term basis, not a matter or crisis intervention; social workers and other visitors should not just turn up at the house: making an appointment in advance is not only a courtesy but pays a dividend. Specialist or clinic consultations should be readily available right through the life of the handicapped person so that the broadly-based team is always seen to be supporting the family, and working with local societies and parent groups. Continuity should not be restricted to the needs of children: the same principle applies to adults,and the same kind of team organisation is necessary, though some of the professional membership might be different for the adult team as opposed to the children's team.

78. As time goes on the possibilities of carefully arranged integration with other children in the education system needs to be considered: that is to say, education, health and social care, though provided by separate agencies, need to go hand in hand. Whilst the public are now showing a greater awareness and

understanding of the needs of mentally handicapped children, the process must be continued by involving volunteers, including schoolchildren, in work with the mentally handicapped.

79. The workshop considered the geographical basis of the service: that is to say, the size or type of territory most suited for one team to deliver a well co-ordinated service. There was a preference for the more locally-based district service, as opposed to the more remote area or regional service. There was a gut feeling that since relationships are the important thing, the problem really becomes this: we know who ought to be involved in giving service - at what point will the size of the area or district begin to inhibit close inter-personal relationships? In other words, how much ground could one multi-disciplinary team cover whilst still preserving personal contact with fellow workers, with parents, and with handicapped children. As an example, the Cambridge representatives developed their idea of a "shopping population" or "a district general hospital population".

Parent as co-worker

80. As the basis for all which follows, it is essential to recognise not only in word but in deed, that parents have a paramount role in all activities for the development of their handicapped child. The second essential is to enable parents to counter the effect of the immediate shock by involving them at a very early stage in the detailed task of working out with professionals what is to be done from that day forward. Many professionals now see the need to recognise the parent as a full partner, as part of the team: this line of thought is more fully developed in the King's Fund's Mental Handicap Paper No.9 - Collaboration between parents and professionals.(2)

81. Within that framework, parents need much encouragement to become more effective in a situation which is for them totally unfamiliar, unexpected and unwanted. Here, as on other occasions in the workshop, great stress is laid on the need for some social workers at any rate, to specialise in work with mentally handicapped people.

82. In undertaking their primary task, parents need access to professional help as a right. Not all parents feel that they have this right: they still feel that the service is given, if at all, as a favour. Yet it would be a pity to insist on this access to service as a matter of civic right: the line of thought should rather be that parent and professional cannot deliver a service unless each is readily available to the other.

83. Any professional person working with a mentally handicapped child, for example, teacher, therapist or nurse, should be in a position to relate directly with the parents, and to involve them directly in the way in which their child is

progressing. It is not helpful if this information can be given only indirectly from some higher point in the hierarchy. This direct contact between worker and parent is what is most likely to bring out the parent's latent qualities as co-worker. Professional workers in direct contact with parents are the ones most likely to recognise the smallest improvements or developments and to share these experiences with the parents, thus giving great encouragement. Visits by nurses or care staff to the home offers the family the great advantage of being able to exchange experiences with fellow-practitioners, rather than listening to the opinions of organisers. Parents who have a handicapped child could be key figures in encouraging new parents, if only there were a system for putting them in touch.

84. Not only is the parent needed as a co-worker, but he or she has an unrivalled opportunity to observe: this in the main is denied to professionals unless the child is in a residential situation. Given the right encouragement, the whole family, including brothers and sisters can operate as co-workers. Put another way, the parents and families may be seen as the workers, and the professionals as their advisers and supporters. In one way, parents are teachers - teaching the professionals quite a bit about this particular handicapped child; yet in another way they are students, learning from the professionals about the techniques and approaches derived from the broad, world-wide scene of mental handicap.

85. The concept which embodies the parent and the family as part of the team operation, is considered essential. There is need for some study of problems which seem to prevent parents from participating in this way, even when given the opportunity: for example, whether the unmotivated parent really exists, or whether the system has demotivated the parent; or whether some parents are labelled as unmotivated because they happen to think the professionals are wrong.

86. There could be great value in counselling sessions for fathers who appear to have opted out. Most are distressed by their lack of ability and their lack of being able to contribute anything which will lessen the sum of human suffering. That is why they sometimes appear to be totally uninvolved. Some are left out because it is difficult for them to take time off work to meet professionals, rather than having opted out. But some do most certainly opt out of the situation: they need to be helped to come to terms with the idea which seems to be in their minds that they have somehow produced, by their own fault, a flawed child: perhaps it is for these fathers first of all that the counselling sessions might be valuable.

The need for the residential care of mentally handicapped children within the NHS

87. On this most controversial issue there were undoubtedly differences of opinion among members of the workshop. It would not be of any service to blur these differences or to paper over the cracks. This having been said, a surprising amount of unanimity emerged, and in a number of cases the differences turned out to be ones of degree or timing. But even so, whilst there was agreement that there is a small proportion of children who need specialised care or specialised treatment or

specialised programming, there were differences of opinion about the location in which that care or treatment or programming should be provided, some favouring an NHS setting and some not. This issue is returned to in the plenary discussion. Given below is a record of the discussion as the syndicate reported back and as the workshop responded.

88. The syndicate reported that there is no need whatever for residential care for mentally handicapped children to be provided within the NHS:

> some members of the workshop contended that whilst there is no need for the long-term residential care for mentally handicapped children in the NHS, there is a need for NHS specialist centres which have residential facilities, though not of a long-term or permanent nature.

89. The syndicate reported that the responsibility of caring for mentally handicapped children should be transfered to the local authority, but with strong support of specialist NHS personnel and facilities:

> this was agreed, but a number of members re-emphasised the need stated above for NHS specialist centres with shorter-term residential facilities.

90. The syndicate reported that the change in responsibility for the care of mentally handicapped children should be carried out within a period specified by the Minister:

> some members of the workshop emphasised that the timetable should be a gradual one.

91. The syndicate reported its recognition that there may be problems in the provision of suitable local authority homes for children and that for this reason there does need to be a transition period; but they also emphasise the need for a transfer of resources from the NHS to the local authority centre to permit the transfer:

> the workshop agreed that the period of transition would need very careful planning and would need the transfer of resources; they considered that the joint financing principles proposed in Health Circular (76)18 could be of great significance in freeing the log jam.(3)

92. The syndicate reported that if parents cannot manage at any period, the child should be taken into a local authority home or should be fostered, but should still be eligible to receive specialist NHS help:

> this was agreed.

93. The syndicate reported its view that the changes suggested above need not threaten nurses but on the contrary, would provide an opportunity for trained mental handicap nurses to have a role in giving a specialised back-up service in a community setting:

the rightness of trained mental handicap nurses being involved on this broader basis was agreed, but many fears were expressed about the threat to career expectations and the uncertainty of the present situation: an uncertainty which may be relieved, or could be exacerbated by the findings of the Jay Committee. Fears were expressed about the problems of the exchange of personnel, and the rigidity of the present training schemes of the GNC and CCETSW.

94. There is a need to concentrate on the quality of child care, whatever the location of the child may be: restrictive practices may exist in some residential homes, and highly liberal practices may exist in some hospitals.

95. Subject to what is said above, the main differences of opinion in the workshop were:

1. Whilst there was broad unity of support for the idea that residential care for mentally handicapped children should not be provided as part of the NHS service in any long-term sense; and whilst a need was seen for specialised provision for the "difficult" group - for example, the multiply-handicapped, the disturbed and the excessively frail - the workshop then divided. Some members believed that the care should still be provided in a non-hospital setting, though heavily serviced by NHS specialists; whilst others believed it would best be done in an NHS setting though not necessarily on a "hospital model". In spite of this division, members of the workshop with apparently opposing views, agreed that with this most difficult section of a difficult group we begin to reach a 'don't know' area in which trial and error, and a willingness to concede that we may be mistaken, are of more value than slogan and counter-slogan.

2. One group of parents said that parents do not want their children to go into hospital: that they have to accept the fact. Another group insisted that some parents do prefer hospital for the children and are not happy about decentralised or integrated settings, or about fostering placements. It was not possible to resolve this issue: if we were talking of adults it might be sensible to conclude that what suits one adult will not suit another. But here we are trying to get into the minds of children and it is difficult to say what they would prefer in the present stage of knowledge of these matters. What is certain is that if we are to go by the wishes of parents, then there does seem to remain a small group of people who definitely prefer hospital care for their children. Whether this kind of expectation will persist into the 1980s is difficult to say.

To what degree can services to mentally handicapped children be common with those available to other children

96. The reporting syndicate, and indeed the whole workshop, were obviously in sympathy with the philosophy of providing services, wherever possible, as part of the ordinary range of community services, rather than as services special to mental handicap. There was equal sympathy for the need for a massive decentralisation of specialist services. But this was a workshop, not a philosophical

symposium, and the syndicate had to grapple with questions of degree: how far can this process go without harming the cause of the mentally handicapped child? To what degree are we entitled to rob the child of service because of our own insistence on the dogma of integration?

97. Side by side with this obvious sympathy for services to be common with those available to other children, the syndicate faced the dilemma of preserving scarce specialist skills, and the risk of losing those skills in a dilution which may sound very well on ideological grounds but which might result in a return to even worse services than at present. For example, on education, it is said that many parents prefer the specialist school service as it stands at present, and that a move to an integrated school service at the present time might result in the loss of hard-won skills of a very special nature. The existence of specialist centres of one kind or another makes it more likely and more easy for professions of various disciplines involved on the mental handicap front to meet and work with one another.

98. Yet, in many cases, existing general services should be able to cover mental handicap, but there are problems. For example, it is accepted that all social work services should come from a generic social services department, but too few social workers know enough about, or are interested in, mental handicap. Similarly, not all health visitors know enough about developmental delay though it was said that recent training of health visitors represents a great improvement, an improvement which may well be paralleled on the social work training front.

99. The decentralisation of residential care is relevant to integration in that accommodating mentally handicapped children in small groups hinges directly on the degree of integration with the community actually achieved. Nothing could be worse than isolation in small groups which in some ways is even more distressing than the isolation of large groups which can to some extent develop their own social structure. Much more experimentation on how to handle integrated settings is needed.

100. Staff need training to prepare them for work in an integrated setting: how to go about the task of securing integration on a person-to-person basis rather than on the issue of physical location. For example, highly experienced mental handicap nurses, used to working with children in hospital, and working to the most modern standards of child care, might still need training and preparation if they are to undertake the same task in an ordinary children's home setting: the principle is the same but the tasks may be different. This need covers not only the running of a place so that it becomes a real family home, but equally important, developing its contacts so that it really is an ordinary working part of the local community. Local authority staff coming into this situation will have the same need for in-service training in the strategies of integration.

101. An overwhelming opinion in the workshop was that integration with ordinary community facilities and services would never really begin to take hold until local authorities take much more seriously their mandatory responsibilities.

102. Paradoxically, the tenor of the reporting group was on the need for more specialised services of certain kinds, rather than less: it was pointed out that some highly specialised services necessitate quite large catchment areas.

103. This makes it look as though the syndicate and the workshop as a whole were in favour of segregated services. This was not at all the case. Many examples were given of services which ought to be common to all children, for example, baby clinics, health clinics, primary care services, developmental and screening services and playgroups. Yet there still remained an underlying disparity between the great desire of every member of the workshop to move towards an integrated and decentralised kind of service, countered by a wish to preserve special skills which have been gained over the last years mainly through the advantages of working in a segregated setting of some kind.

Other activities to improve services to mentally handicapped children within the next five years

104. The workshop considers that all the improvements described in paragraphs 72-103 are capable of achievement within the next five years, given the will, even within the economic climate at present prevailing. In addition, the following activities would cost little or nothing.

1. The task of informing parents at the time of diagnosis to be regarded as a specialised and skilful task for which staff preparation is needed at all levels
2. Need for one agency to have a comprehensive record system for mentally handicapped children in the district, including those in residential care
3. More sharing of records, with some attempt being made to loosen the medico-legal knot of confidentiality
4. More sharing of information between professionals and parents rather than regarding specialist information as being the exclusive possession of the staff
5. Parents to be encouraged to attend residential settings and to share their experience with the residential care staff or nurses
6. Programmes for each individual handicapped child which specify short and long-term goals in clear terms and which are regularly reviewed between professional and parent
7. More attention to the evaluation of on-going service models

8. Writing research results clearly and making them readily available to staff
9. Schemes of collaboration between health and local authorities to be encouraged under the joint financing mechanism recently announced by the Secretary of State
10. More experiment in the techniques of operating integrated services
11. Post-graduate or post-qualification training, including staff-exchange systems, for all who become involved in services to mentally handicapped children. Social workers involved in mental handicap to receive specialised preparation
12. More informed use of voluntary workers, with proper preparation before they take up duty
13. Respite to be more readily available to parents, whether in the form of short-term beds or in the form of occasional day care
14. Staff of residential units to receive the same level of specialised back-up support as ought to be available in the family situation

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PART IV

SUMMARY: ACTION TODAY

Even after two days' work the workshop could have compiled a long list of requests and recommendations, many of them incapable of early fulfilment. A glance at the preceding pages will indicate the depth and breadth of the subject. However, this workshop has been concerned with what is possible within the next five years. And it is possible to make at least a start on these measures today. The workshop has chosen five key areas on which to offer their ideas for a better deal for mentally handicapped children. They are:

The system of delivering a co-ordinated service

Parent as co-worker

Residential care

Common services

Staff training

The system of delivering a co-ordinated service

1. Recognising the right of the father and mother to be told of the diagnosis at the earliest possible moment and the crucial importance of the method and timing of imparting this information.

2. Giving parents information about mental handicap in general; and about services which are available locally and what it is that parents can do themselves, right from the start.

3. The principle of knock on one door; that is, the establishment of some local organisation or place to which parents can turn for information and advice.

4. The development of the multi-disciplinary team as the base from which the team of professionals operate, in and out of hospital.

5. The importance of the parent being included in the team when his or her child is being discussed.

6. The team to establish a personal relationship with the handicapped person and the parents; to make an attempt at crisis prevention rather than crisis action; to provide a channel for specialist help when needed; and to ensure that the one-door principle is somehow implemented.

7. Creating an operational area for the team which is not so large as to inhibit the personal approach but not so small as to limit the availability of specialists.

8. Respite for hard-pressed parents, residential and non-residential.

9. The establishment of the assessment clinic within a paediatric department, covering developmental handicaps of all kinds.

The parent as co-worker

1. The sheer logic of involving the parent if only because his or her observations are much more continuous than those of visiting staff.

2. The unassailable right of the parent to be involved in what is decided about his or her own child.

3. Parents to be helped to discard their traditional, somewhat subservient role by being sympathetically helped to be more effective in a situation for which they are totally unprepared, and for which they have no experience on which to fall back.

4. More sharing of information amongst professionals, and between professionals and parents.

5. Programmes for each individual handicapped child which specify short and long-term goals, and are regularly reviewed between professional and parent.

6. Parents to be encouraged to develop a direct relationship with the professional staff working with or for their child rather than being restricted to official answers to questions through the official hierarchy.

7. Parents need easy access to the service team, not only so that they may raise problems and get answers, but so that they themselves may help to provide the answers for which the team is looking.

8. Efforts to be made to bring the so-called unmotivated parent into the scheme of things, and to involve fathers.

Residential care

1. There is no need for ordinary residential care for mentally handicapped children to continue to be provided by the NHS.

2. There is a need for NHS specialist centres having residential facilities, not of a long-term nature, designed for some specific treatment or intervention.

3. The responsibility of providing long-term care for mentally handicapped children should be transferred to the local authority even though strong specialist NHS support will still be needed in the non-NHS setting.

4. This transfer of responsibility to be accompanied by the transfer of resources, a process which may be helped by the new arrangements for joint financing.

5. This transfer should not be allowed to threaten the career of trained mental handicap nurses. It is hoped that the Jay Committee will see the significance of these well-qualified people being involved in the broader mental handicap service rather than in the NHS alone.

6. If parents cannot manage at any period, the hospital should not be the long-stop for residential care: this should be provided by the local authority.

7. Staff of residential units to receive the same level of specialised back-up as ought to be available in the family situation.

Common services

1. Parents and professionals to uphold consistency, and to work together to implement the elementary civic right of mentally handicapped children to open access to ordinary community services.

2. Whilst integration is the goal, accept the principle that we are at present in an intermediate stage between segregation and integration, a stage in which intrinsic quality of some services may be better achieved by specialisation.

3. The key question is: what is best for this handicapped child today? If access to a common service is best for this child today, then go hard for that objective.

4. Experiment, and then training, in the practical issues involved in establishing, and then integrating, a residential or non-residential unit in a local street.

5. As citizens, continue to urge local authorities to take more seriously their mandatory responsibilities to mentally handicapped children.

Staff training

1. An on-going programme of in-service training and education for all existing staff of all professions.

2. An obligatory introduction to mental handicap for all staff of all professions and callings, when they first enter the mental handicap service.

3. Social workers and health visitors to be given truly adequate preparation for work with mentally handicapped children and their families.

4. More effective use of volunteers, and their better preparation by being given a better understanding of the nature of mental handicap and of the strategies of today.

5. Special preparation of all staff who are about to move into a unit, residential or otherwise, in an integrated or community setting: such staff may be highly qualified in their basic professional role, but may have little experience on how to go about knitting their unit into the life of the surrounding community.

PARTICIPANTS

These are the people who helped in the discussions leading up to this report. They include at least six who were known to be parents of mentally handicapped children; in addition there were people from organisations or groups whose purpose it is to represent the needs of those children. The professional members of the workshop included nurses, doctors, therapists, social workers, teachers and psychologists.

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