King's Fund Hospital Centre

MENTAL HANDICAP PAPERS

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STRATEGIES FOR PROFOUND MENTAL HANDICAP

London 1972

Price £0.10

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Report on a
King's Fund Seminar
February, 1972

THC Reprint No.704

BACKGROUND TO THE SEMINAR

1. At the invitation of the King's Fund, a group of professionals involved in mental handicap held a residential seminar from 8th to 10th February, 1972. The intention was to explore problems relating to the care of the profoundly handicapped, a difficult subject, posing questions which are not always capable of a ready answer, but which are sometimes obscured, or imperfectly presented, during the more public debate of mental handicap matters. The membership of the seminar was limited to fourteen people: two psychologists, three doctors, three nurses, two teachers, one architect, one designer, and two administrators.

WHO ARE THE PROFOUNDLY HANDICAPPED, AND WHERE ARE THEY?

2. It was agreed that whilst terms might differ, the core of the problem was contained in the following definition:

> those who are mentally subnormal and who
>
> (i) have a very severe physical handicap, or severe sensory defects of hearing, vision or speech
>
> or (ii) have a behaviour-disorder which is either dangerous or highly disruptive
>
> or (iii) have marked anti-social or a-social habits, and whose degree of retardation makes them almost inaccessible.

3. Later in the seminar a psychiatrist identified these three groups in different words:

(i)	crippled and frail
(ii)	very disturbed
(iii)	docile, ambulant, incontinent, with no self-help ability.

4. Some profoundly handicapped people live in the community, others in the hospital: in either case there is rarely a positive approach to their treatment. In the community they are expected to fit into special schools or special care units which are often no more than depositories. In the hospital, therapeutic resources are usually vested in the more able patients, and the profoundly handicapped are left on the wards without much structured activity.

Thus, poverty of social environment, coupled with professional ignorance, leads to total lack of progress, and to frustration and stress amongst staff. In its turn, this leads directly to conditions in which irregularities can develop.

HOW MANY PROFOUNDLY HANDICAPPED PEOPLE ARE THERE?

5. The following statistics had been collected by the Department of Health and Social Security:

Census of Mentally Handicapped Patients in Hospitals in England and Wales at the end of 1970

AGE - years	Mental Category			Percentage Severe Subnormality
	Subnormality and Severe Subnormality	Severe Subnormality	Subnormality	
All Ages	64,173	47,294	16,879	74
Under 2	44	43	1	98
2 - 4	407	371	36	91
5 - 9	2,310	2,171	139	94
10 - 14	3,583	3,253	330	91
15 - 19	4,919	4,038	881	82
20 - 24	6,048	4,839	1,209	80
25 - 34	10,243	8,166	2,077	80
35 - 44	9,518	7,076	2,442	74
45 - 54	10,453	7,374	3,079	71
55 - 64	9,552	6,081	3,471	64
65 +	7,096	3,882	3,214	55

The White Paper (Better Services for the Mentally Handicapped) states that among mentally handicapped children, one in five have defects of hearing, and one in 20 are blind. Among adults, one in five have defects of hearing or vision, and one in three have speech defects.

WHAT ARE THE CHARACTERISTICS OF A GOOD SERVICE TO THE PROFOUNDLY HANDICAPPED?

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6. Early intervention: that is to say, early assessment is not enough; executive action has to follow; decisions are not self-executive. The first five years are more critical than all the subsequent years put together. Included in the tactics of early intervention might be:

identification

total assessment by a multi-disciplinary team, followed by concerted and agreed action

special regional units for certain physical or sensory handicaps

follow-up assessment

on-going counselling for the family.

7. A quality of environment which is not geared down to past performance, but which will stimulate and teach the profoundly handicapped. Such an environment, whether in hospital or hostel, would be as near the normal as the limits of practical and reasonable possibility permit, and it would be arranged in such a way as to allow small groups of people to have different living spaces, and a different range of activities, for each group. It is not so much special buildings, or special concepts of care, which give a hospital its reason for existence, for the same quality of environment or care ought to obtain wherever the profoundly handicapped may live. What ought to distinguish a hospital is its concentration of special skills.

8. The seminar was divided as to the wisdom of concentrating profoundly handicapped people together, as against a process of dilution which would mean that several small groups of less handicapped people might each absorb one profoundly handicapped person. There was complete agreement that the frail and passive ought to be separated from, and protected from, the strong and disruptive. Each required a very different atmosphere: one needed stimulation of activity, the other a diversion of existing activity into other courses. The Sheffield proposals offer a 24-bed unit in three separate sections: one for the physically frail; one for the passive; and one for the hyperactive. This type of unit was supported by the seminar, provided that there would be complete flexibility as to who should be in each group; different mixes might be appropriate on different occasions; behaviour patterns might change significantly, according to the influence of different groups. But the principle of separating the frail from the aggressive was re-inforced. The seminar was aware of the dangers of a doctrinaire policy: the untrained often have to face the results of the dogmatism of the experts.

9. In any case, whatever the mix or the segregation, small group living, especially for the profoundly handicapped, was considered an absolute prerequisite of success. Even the group of eight was considered too large: five or six was considered to be the maximum.

Each group would always need two members of staff: if there is only one staff member he will spend his time retrieving one or other of his charges, during which time the others will be demoralised by receiving no attention, training, or encouragement. In summary, for the profoundly handicapped, no group larger than six and no staffing less than two. The seminar was reminded of Professor Tizard's dictum "the best way to help the child is to help the staff".

10. Whether activities take place in living units, wards or physiotherapy and other special departments, any therapy instituted should be completely integrated with the work of the teachers, whether they work within the walls of a school or on a peripatetic basis. The teachers should be pursuing the same objectives as the hospital or social services staff. Otherwise the rest of the caring team will be moving steadily away from custodial care, whilst the teachers move steadily towards it.

11. After all the sound and fury of public debate about the location of facilities, and the hospital versus hostel argument, it was an agreeable surprise when the seminar decided that problems of location, whilst important, are not central to the issue of profound handicap. Given the conditions described above, location then becomes not a matter of doctrinaire edict but of local choice. Although the seminar doubted whether a mental handicap unit would flourish in the climate of a district general hospital site, it was possible that in some cases it might be the best available siting choice. And whilst the seminar doubted the value of establishing new units on an isolated mental subnormality hospital site, it was not felt that there should be a panic flight from a well-placed urban site, or one which has become urban through the advent of new housing. Equally, they saw no reason why a hospital should not build a hostel in part of its catchment area, still run by the hospital system. If the village concept suited some mentally handicapped people, then several living units could be grouped in the country, whether run by hospital or social services, or even jointly.

12. Whilst proximity to home area is a relevant factor in the frequency of visiting by relatives, there was evidence that a regular parents' meeting in the hospital will attract relatives from very long distances, and that this kind of contact is more meaningful and helpful than ordinary visiting.

POINTERS TO A GOOD SERVICE

13. Firstly, a good service ought to recognise that whilst some families, given full supporting services, might be able to keep a profoundly handicapped child at home, many would find this destructive of family life, and damaging to other children. The family should have a free choice as between home and residential care.

14. On the subject of early intervention, the seminar endorsed the type of multi-disciplinary developmental advisory clinic which not only assesses, but which also ensures action by the right people. The seminar considered that the new assessment

units foreshadowed by the White Paper ought to move into this multiple role of assessment, advice and executive action.

15. It was claimed that the general practitioner giving a diagnosis of mental handicap may have only a sketchy idea of the supporting services available to the parents. Interviews of the parents of forty mongol children in Camberwell confirmed that parents were given little advice on what to do, or even whom to contact: none had been put into touch with the National Society for Mentally Handicapped Children, for example. One mother learned the diagnosis by seeing the word 'mongol' on a birth-weight card.

16. Was the at-risk register an effective instrument? Most members did not think so: a full developmental check for all children was much preferable. Why did these parents not draw on the advice and experience available from hospital staff? Hospital nurses could furnish a fund of really practical hints. Perhaps the association of living units with catchment areas, either by new building or by sectorisation of large hospitals, would help.

17. A great need is for nursery education, at least from age 2 to 5. If this does not rank as an official educational priority, education authorities and hospital boards should subsidise local voluntary groups.

18. A hospital should only exist if it offers something specific, which is unlikely to be obtainable elsewhere. Two main tasks, at which a good hospital ought to excel, are:

(i) to control behaviour, and to unlearn bad behaviour: the need here is for highly skilled staff to direct the operations of less highly skilled staff;

(ii) to maximise and reinforce existing skills and good attributes: this can be done by people without special skills, given proper direction.

19. A technique which has great possibilities for some profoundly handicapped and disturbed patients, is operant conditioning, or behaviour therapy. Many advances in this technique are being pioneered in the U.S.A.. A team of psychologists, doctors and nurses ought to go there to study their methods. There is however, no point in undertaking operant conditioning at some central clinic unless the same process is continued in the home and in the school: thus it might be better to base the work in the living unit. Psychologists present pointed out that at their respective levels, qualified nurses and also unqualified workers can make a valuable contribution, given skilled planning by a well-versed psychologist. Here is a very effective role for the nurse, given adequate familiarisation with the technique. Good nurses have instinctively used the technique for years, but formal instruction would make their efforts much more effective. In unskilled hands, operant conditioning could re-inforce bad behaviour.

20. But behaviour therapy should be only one aspect of the life of the profoundly handicapped person, though a very important one. An equally important aspect is the existence of free activity, carefully programmed hour by hour for each separate individual. A doctor was supported in his view that, for the overactive and disturbed, the combination of operant conditioning and programmed activity seemed so far to have been the only successful one.

21. There is much evidence that minor changes in the hospital regime, often involving no more than a willingness on the part of staff to change their outlook or habits, can produce some remarkable results. In some places, by planning the activities of the day, by devising methods of training, by sheer motivation and interest of nurses and others, night sedation has disappeared, incontinence has dropped dramatically, and the environment has been respected. Some hospital staff enjoy tackling the problems of the profoundly handicapped, whilst others shrug their shoulders in despair. The value of a more active approach, involving only minor changes in regime, should be demonstrated widely.

22. Even in conditions of overcrowding and understaffing, it is possible, by better use of resources, to provide off-ward activities for small groups of patients during the day. For example, wards vacated by the more able patients who go to occupational therapy could be used during the day for the concentrated training of small groups of the profoundly handicapped. In most hospitals, despite alleged lack of space, it is usually possible to find room somewhere.

23. Staff are unlikely to go to the undoubted trouble of changing established practices unless there is a clear overall strategy in which they can see their efforts fitting in with those of other professions. It follows, particularly in such a difficult area as profound handicap, that the strategy for the profoundly handicapped has to be worked out by a team on which the various professions are represented. Even this is not enough: most of the work of implementing change falls on nurses - when it goes wrong they face the results. So it is important that wards or living units should be involved in working out the change in regime, before it happens. The importance of commitment to improvement cannot be overestimated: without this commitment to a new strategy, increased staffing will be largely valueless.

24. Whilst the seminar recognised the importance of the team approach in grappling with the problems of profound handicap, there was little support for the idea of a hybrid training. Instead, each discipline ought to unite its professional excellence with that offered by the others. Professional co-ordination should be the aim, not professional hybridisation.

25. The best hope of integrating the efforts of the hospital and the school lies with the hospital workers establishing a good personal relationship with the head of the school, for it is he who is personally responsible for the quality of education. Whilst many hospitals are emerging from a period of authoritarianism and bureaucracy, many

education authorities seem to be somewhat rigid in their attitudes to special education. In the past, less than half of hospital children went to the hospital school; now, teachers will be involved, in school and in living unit, with a profundity of handicap which is outside their previous experience. Much educational work should be undertaken long before the statutory age of 5, and long after the statutory age of 16. If there is not an active further education programme, profoundly handicapped adolescents will vegetate and regress. If special care units lack objectives and a purposeful programme, they will remain as baby-sitting organisations. In fact, does the school or the special care unit know what to do? Expectation is not self-fulfilling. In a videotape, the seminar had seen the collective series of skills needed to train a little girl to eat at table: all these skills would be needed as much in the school as in the living unit. This cross-over of experience might be obtained if one roof covered the teachers, the physiotherapists, occupational therapists, and the music therapists, and if they all spent half of their time in the living units with the nurses.

OBSTACLES TO A GOOD SERVICE TO THE PROFOUNDLY HANDICAPPED

26. There was a strong feeling that the bureaucratic system (using the word in its organisational, not pejorative sense) is not sufficiently aware of the strategy and objectives of the professional field workers and thus makes administrative decisions which appear intrinsically sound but which militate against the strategy, rather than help it forward. There is a contradiction between aims and means. This concern applies with equal force to administrative decisions at national, regional and local level. An example was given of a hospital which decided it would serve the mentally handicapped better if staff abandoned formal uniform and wore their own clothing: but recognition of this in cash terms was given reluctantly, and was hedged about with petty provisos. In the words of one member, the management of the mental handicap service is underprofessionalised: local administrators are sometimes pre-occupied with laid-down administrative procedures: whereas their expert contribution ought to be firstly to learn about the reasoning lying behind the mental handicap strategy, and then to devise a managerial system, possibly by means of a clinical services committee or a professional executive, whose prime aim is to facilitate the work of the multi-disciplinary professional team. When an administrator works in this way he is indeed a professional, a working member of a professional team. The same degree of involvement ought to be seen amongst administrators who make important decisions at regional and national level: in some places this understanding and involvement exists in plenty: in other places it can be painfully absent.

27. The key to the situation is for members and administrative officials to be ready to learn about the strategies for mental handicap, and then to look for the best managerial methods to implement those strategies. This would mean a complete integration of clinical and organisational objectives. The professional caring team could improve matters greatly by positively communicating the basic ideas of their strategies, in non-technical terms, to members and administrators. The fault is not all on one side.

28. Another block to progress is the continued existence of what one member called professional straitjackets: the isolation of one profession from another, or the attempt at professional one-upmanship. The phrase 'team effort' may be trite, yet it conveys the reality that to achieve a good result with mental handicap, and particularly profound handicap, a number of professions need to contribute on an equal footing. This applies equally whether the object is to develop a strategy for a whole hospital or for one particular handicapped person. At the living-unit level, this free association of different professionals is essential; at the whole-hospital level, some interdisciplinary cabinet or professional executive is needed to control priorities and resources.

29. A hospital which finds progress blocked by a fairly senior member of staff who cannot or will not make a progressive contribution, will be helped by the existence of this multidisciplinary management group, which will tend to isolate, and to work around, the non-contributor.

30. The basic proposition that handicaps can be socially manipulated by the social group does not necessarily hold in cases of profound handicap. Thus, the main change-agent is not the living group of handicapped people, but the staff themselves. This being so, another severe obstacle to advance can be the absence of job-satisfaction. This can be particularly forceful when staff find themselves caring for profoundly handicapped and severely disturbed people in a custodial situation, with no defined strategy, and no opportunity to influence decisions. In other words, the kind of remedy suggested earlier would greatly increase job satisfaction and would promote a positive and purposeful approach to an extremely difficult problem.

31. A further block is the difficulty of diffusing and demonstrating good practical ideas, without which the actions of staff become conditioned by the mores of the establishment and less and less is expected of the profoundly handicapped. This problem of disseminating ideas is dealt with below.

32. There seem to be two possible courses of action which might help the spread of ideas and good practices:

(i) A selected few can attend centrally organised courses of fairly long duration, and then return to their base in order to share their experience.

(ii) A visiting team of experienced workers could visit a hospital in order to demonstrate new approaches, over a period of several days, to a substantial proportion of the staff.

(iii) Staff can be seconded to acknowledged centres of excellence.

33. The central course method has sometimes proved extremely valuable: for example, the early National Association for Mental Health courses for teachers of the mentally handicapped. In the context of profound handicap it has some limitations:

(i) Only a few people can attend

(ii) It may make a multi-disciplinary approach difficult

(iii) There still remains the problem of dissemination at local level

(iv) The system encourages the 'ticket collector' who uses courses as a ladder for personal advancement, moving from job to job.

34. The visiting team approach has the following advantages:

(i) It can influence many people in a short time

(ii) It is essentially a multi-disciplinary approach

(iii) Dissemination is by direct confrontation with the people on the job

(iv) It is clearly aimed at improved performance for its own sake, rather than at professional career advancement

(v) A wide variety of hospitals can be visited, and helped with specific local problems

(vi) It encourages the development and interchange of the skills latent in many nurses and other staff

(vii) It bridges the gap which often exists between the successful demonstration of an idea, and its operationalisation on a wide scale

(viii) It would be a working programme, not a lecture tour.

35. Obviously there is a place for the centrally-organised course of long duration, particularly for the pursuit of specialist skills and interests; just as there must always be a highly important place for the statutory courses for training in nursing, social work and other professions. But for the immediate problem of improving services to the profoundly handicapped, the seminar saw much merit in the idea of the visiting team, which might, as a spin-off, produce useful field information for the organisers of statutory and professional courses of training.

36. The seminar had no opportunity to think through the visiting team approach in detail, but they envisaged the following tactics:

(i) The use of films, filmstrips, tapes and pamphlets, all of which would demonstrate what <u>can</u> be done and what <u>has</u> been done for the profoundly handicapped.

(ii) Actual demonstration of techniques by the team

(iii) Setting up demonstration centres in selected hospitals which would be organised so as to facilitate visiting and teaching

(iv) Examples of topics would be:

- How to organise highly programmed activities
- Operant conditioning or behaviour therapy
- Bobath system of physiotherapy
- Care activities in the school situation, and vice versa
- Music, drama and recreation
- Manipulation of environment
- The Rudolf Steiner approach

(v) In organising visiting teams, the existing framework of Board Training Project Officers, and Training Departments, could well be used

(vi) The framework of the training scene in profound mental handicap might be:

For trained staff:	extra modules of training and experience, coupled with secondments to centres of excellence
For care staff not professionally trained, e.g. ward assistants often locally recruited:	well-planned induction courses followed by regular short bursts of in-service training
For all staff, of all professions and all grades:	the visiting team system

THE RUDOLF STEINER APPROACH

37. An important contribution was made by a teacher working in a Rudolf Steiner-Camphill School in Aberdeen. His approach, and that of his movement, influenced many aspects of the seminar's discussion, but it did not always fit in with the organisational realities and problems of the existing statutory service. In many ways it represented an ideal which might be difficult to attain in 1972. For example:

(i) Each small family group would contain one or two children with profound handicap

(ii) The family group composed of handicapped and non-handicapped people, would influence the profoundly handicapped

(iii) From this homely family group the profoundly handicapped child would go out to daily school

(iv) The mix of the family group could be altered

(v) The family group would have its own kitchen

(vi) The non-handicapped would live in with the handicapped

(vii) There are no paid staff: there are resident non-handicapped members of the community who receive what they need from community resources

(viii) There is a waiting list of young people willing to live in on a pocket-money basis

(ix) Whilst they recognise the special contribution of specialist professions, they adopt one general training discipline in mental handicap.

RECOMMENDATIONS

38. The seminar recommended that financial support be sought for two ventures:

(i) a visit by a small team of specialist staff to the U.S.A. in order to study operant conditioning techniques and to diffuse the information in this country

(ii) experimentation over a period of two or three years, in staff training, using the visiting team approach.

SUMMARY

39. This report has attempted to define what is meant by profound handicap, and has concentrated on those profoundly handicapped people who have a dangerous or disruptive behaviour disorder, or who are anti-social and inaccessible.

40. An attempt has been made to describe the characteristics of a good service. These include early intervention; an environment geared to potentialities rather than to past performance; the overwhelming need for small-group living and learning; and the need to integrate the work of the teachers and the nurses.

41. Stress has been placed on the importance of nursery education for those in the age-group 2 to 5 years, since it is this period more than any other which decides future performance.

42. In considering the placement of the profoundly handicapped, account has been taken of the need to save the family from destruction at the hands of an extremely disruptive person. For many of the profoundly handicapped, the right placement could well be a hospital, but only if it is only to offer some service which is unobtainable in the home setting.

43. An attempt has been made to identify obstacles to a good service for the profoundly handicapped. These include poor management; professional isolation; absence of a team approach; absence of a concerted strategy; and the difficulty of diffusing and demonstrating such good practical ideas as do exist.

44. A description is given of the Rudolph Steiner approach to the care and education of the profoundly handicapped.

45. The seminar has been impressed by the view that the technique known as operant conditioning, or behaviour-shaping, might have great possibilities for the profoundly handicapped: recommendations have been made for experimentation in gathering and disseminating practical information in this and associated techniques.

* * *

APPENDIX

LIST OF PARTICIPANTS

Dr. Janet CARR	Senior Psychologist	Bethlem Royal Hospital, Croydon
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Printed in England by 'British Hospital Journal,' 27 to 29 Furnival Street, London, EC4A 1JR