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CASE REGISTERS FOR MENTALLY HANDICAPPED

PEOPLE

by

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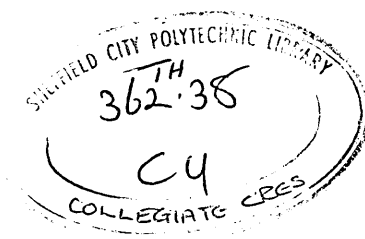Sponsoring Establishment: Sheffield City Polytechnic.

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Abstract

This thesis is an evaluation of mental handicap registers as planning tools and is based on a national postal survey and semi-structured interviews with register-operators. Registers have emerged from pressure for greater rationality in planning the health and social services, a co-ordinated approach to priority groups, and a radical change in attitude to mental handicap. Mental handicap registers are found to be organisationally, financially and morally feasible. Moreover they can develop naturally as by-products of Community Mental Handicap Teams, thereby significantly reducing the costs of data-collection. Registers provide a basis for service-planning which is more objective and takes account of more of the users of the service than the opinions of experienced professionals. Names, addresses, dates of birth and details of services used can make a considerable contribution to planning. In addition, some indicator of the services that subjects need is required. Register-operators tend to regard the widely-used Wessex Behaviour Rating System as a crude measure and hanker after a more direct assessment of need such as might be made at a multi-disciplinary review. Most registers hold identifying and service-details of their subjects; however there are a number of registers holding in addition a large amount of information for which there is little demand in planning. The data which registers have held have not been fully exploited partly because they have not been sufficiently closely linked to the planning process and the methods of planning have not been sufficiently receptive to quantitative data. Other statistical client-based data-bases for service-planning run the risk of similar neglect by decision-makers unless vigorous efforts are made to promote their use.

ACKNOWLEDGEMENTS

Introduction

Case registers of mentally handicapped people have mainly been set up and used to plan services. The aim of this essay is to give an evaluation of registers as planning tools. As a preliminary, the pressures which have led to the formation of information-bases on mental handicap and determined their form, operation and impact will be examined. This will pave the way for a more precise specification of the aims of the study in the second chapter. Both the first and second chapters have been based in part on directed reading in social research methodology, social administration and policy and the organisation of mental handicap services.

The demand for a common information-base for planning mental handicap Services

Despite periodic reorganisations, services for disadvantaged groups like the mentally ill, mentally handicapped and elderly have generally been provided at local level by several separate organisations. Partly in an attempt to cooordinate the development of health and personal social service delivery, central government has since the early 'sixties set up planning systems. This development may also be seen as a response to the extension of public expenditure, planning and control (PESC) which compelled Whitehall ministries to make far-reaching predictions of expenditure and service development. The pressure to make forecasts was next transferred from central to local government (Glennerster, 1981). At the same time, there may also have been a more widespread realisation that the best use would be made of shrinking resources only if there was effective planning.

In the early 'sixties there was a limited attempt by the centre to induce local bodies to draw up plans for welfare services. In 1962 **A Hospital Plan for England and Wales** (Ministry of Health, 1962) laid down principles for the development of district general hospitals. At roughly the same time health and welfare authorities were asked to submit ten-year plans to complement the planning of hospital services (Ministry of Health, 1962). But the intended process of annual review rapidly fell into abeyance.

In 1972 the newly-created Social Services Departments were asked to submit plans for the period 1973-83 (DHSS, 1972). Unlike the request of 1962, more definite parameters were set by Central Government. Again the system of planning foundered – on this occasion because of local government reorganisation in 1974. Parallel to the planning of social services, a new planning cycle was introduced in the Health Services (DHSS, 1972). Planning was to be a major link between the newly-created regional, area and district tiers. For the first time a national planning system made extensive use of the notion of "health care groups", such as the elderly, children and handicapped. At about the same time a client group focus was built into the structure of the DHSS itself. A final attempt at an ongoing planning system for health and social services was attempted in 1976 and 1977. **The Way Forward** (DHSS, 1977) laid down detailed plans linked to expenditure for health and social services. This provided the basis for shifting resources to neglected groups such as mentally handicapped people.

Several of the planning systems instituted since 1962 ground to a halt partly because of the sheer weight of bureaucratic effort that they required. It is worth mentioning that a common criticism of these systems was that their emphasis was neither on meeting needs, nor on the impact of services on consumers, but simply on the

production of more services (Webb, 1979; Booth, 1979b; Walker, 1984).

In recent years there have been moves towards more elaborate systems of planning health services at local level with a built-in requirement for more information about health care delivery. When the recommendations of the Korner Group have been implemented, managers at district and unit level will not only be confronted with a mass of additional statistical data on the recipients of services, but they will also be required in many spheres of activity to draw up an annual statement of policy, services delivered and expenditure (Steering Group on Health Services Information, 1982). Patient-based data-bases for service planning and management at District level are likely to become more and more sophisticated. The Financial Information Project at South Birmingham Health Authority has pioneered the development of data-bases on expenditure at patient level. This approach is beginning to be adopted elsewhere.

Also in the Health Service annual accountability reviews have been introduced which aim to ensure that Regions are using resources in accordance with Government policies and to set annual objectives which have been agreed at both Regional and Government level. They have facilitated financial planning on a client-group basis. The intention is to measure the activity of services against the objectives that have been set for them by means of performance indicators, which give information on what has been accomplished.

The development of planning in the health and social services in the last two decades - though it has not proceeded quickly enough - has nevertheless created a demand for planning tools and made decision-makers more planning-minded. In this planning climate - particularly with its growing sophistication - it has been natural for those involved in mental handicap services to want a planning tool.

As well as this movement towards planning and planning tools throughout the health and social services there have been changes in what may be described as the "philosophy of mental handicap" which have created a demand for a basis for planning services.

Since the war there has been a fundamental change in the conception of the services that should be provided to mentally handicapped people. Gradually different modes of care - some of them radically different - have emerged.

Under the National Health Services Act of 1946 all mental handicap institutions came under the control of the Minister of Health. Already physically isolated, large hospitals were isolated from the parts of the service provided by Local Authorities. They were staffed by unqualified and low paid nurses and ignored by both the public and the Regional Hospital Boards (Glennerster, 1983, p.60).

As early as the 'fifties, evidence was accumulating which suggested that large isolated hospitals were not appropriate for most of those resident in them. Higher than expected IQ levels were found among their residents (Hilliard and Mundy, 1954; O'Connor and Tizard, 1954; Brandon, 1960). Existing training methods in hospitals were found to be irrelevant to outside employment and to under-estimate seriously the potential of residents for working in the community (Tizard and O'Connor, 1952). A number of studies showed that residents had a capacity for learning industrial tasks, which was unrelated to IQ and improved with incentives (Claridge and O'Connor, 1957; O'Connor & Claridge, 1958; Gordon, O'Connor and Tizard, 1954; Gordon, O'Connor and Tizard, 1955). It was discovered that more stimulating environments were associated with higher levels of ability (Kirk, 1958; Mitchell, 1955; Tizard, 1964).

In the 'sixties more studies appeared which indicated the need for more stimulation than was provided in the large institutions.

Morris's study of 35 hospitals was very influential. It drew attention to the range of deprivations suffered by hospital residents. Accommodation was woefully unsatisfactory: buildings were archaic and decrepit; over a third of the patients were sleeping in over-crowded spartan dormitories of 60 people or more; day-rooms were too large and inadequately equipped; and provisions in sanitary annexes were often very basic. Personal possessions were discouraged: most of the clothing was communal; children usually either had no toys or tended to have little access to them. Because of the isolation of the hospitals, few visits were received from outside. Large numbers of the patients were suffering from little or no illness or disability; medical treatment and skilled nursing were not the predominant functions of the hospitals (Morris, 1969).

Another decisive event in the late 'sixties was the Ely scandal. Allegations of ill-treatment about a Welsh subnormality hospital were widely publicised. The Minister of Health appointed a committee of enquiry which eventually confirmed much of what had been claimed (Report of the Committee of Enquiry into Allegations of Ill-treatment of Patients and Other Irregularities at Ely Hospital, 1969). Despite the reluctance of Civil Servants, who had known of conditions in the hospital but had done nothing, Richard Crossman, the Secretary of State in the newly-created Department of Health and Social Security, ordered full publication of the findings of the committee and a complete review of mental handicap services.

The Ely affair and its aftermath together with research evidence of the inappropriateness of large isolated hospitals provided a background for the governmental initiative in mental handicap: the White Paper of 1971 advocated a reduction in the hospital population, an expansion of Local Authority day and residential establishments and

a higher level of support for families. Though not as progressive as it might have been, the White Paper called for a deep-rooted change in the pattern of service provision.

The next Government initiative was the announcement in 1975 by the Secretary of State for Social Services, Barbara Castle, of the establishment of the National Development Group for the Mentally Handicapped (NDG) and the Development Team for the Mentally Handicapped (DT). The function of the DT was to advise Local and Health Authorities on the implementation of the policies of the DHSS. The NDG, also made up of expert outsiders, had as its role the development of DHSS policy on mental handicap. Its Chairman was to have direct access to ministers at all times. In the five years of its life, the Group produced influential policy-documents and was able, through its connections, to ensure that the service needs of mentally handicapped people were given attention at the highest levels of the DHSS.

Throughout the 'seventies and 'eighties more radical schemes for community-based services than the White Paper have been produced - for example, by both the NDG and DT, the Campaign for Mental Handicap, the King's Fund and the Independent Development Council for People with Mental Handicap. Imported conceptions of care such as normalisation and core-and-cluster housing have become more widely known. Health and Local Authorities - often jointly - began to produce plans for the mentally handicapped people in their areas. Though these plans have frequently drawn heavily on the principles of the White Paper, some have ventured beyond them to make use of other more radical ideas.

As for the developments in the services itself since the White Paper, progress has been slow as is evident from the 1980 Review of the White Paper, though there has been a marked expansion in Local Authority provision.

There has, then, been a growing realisation in the last few decades of the need for a transformation of mental handicap services; and though action has been slow, some initiatives have been made. Mental handicap registers have come into being as tools with which to plan and monitor these initiatives. A DHSS report on psychiatric and mental handicap registers produced in 1975 pointed out that several mental handicap registers had been set up because a significant change in the service was taking place or about to do so. The registers were intended to evaulate the developments (DHSS, 1975). This continues to be an important reason for the setting-up of registers.

To some extent as a result of the awareness of the need for a deep-rooted change, attempts have been made to promote a movement of resources to mental handicap provision from the better-endowed areas of the health and social services. **Better Services for the Mentally Handicapped** (DHSS, 1971) made mentally handicapped people a priority-group. This was reaffirmed in financial terms in **Priorities for Health and Personal Social Services in England** (DHSS, 1976b). For the first time a long-term expenditure programme was devised which laid down target health and social services expenditure in real terms for each of the various client-groups. While the overall growth-rate for the following four-year period was to be just over 2%, the rate of increase in mental handicap services was to be 2.8%. More detailed expenditure targets were given in **The Way Forward** (DHSS, 1977a). Through the planning system, these priorities percolated to local level. The drive for a greater priority on mental handicap services has had some success: analysis of expenditure between 1975 and 1979 in Hounslow and Wandsworth revealed that mental handicap was given priority - especially by the Local Authorities (Glennerster et al, 1983).

One factor which made possible the modest shift of resources to priority groups was the introduction of programme budgeting, which originated in the late 'fifties and early 'sixties in the USA (Glennerster, 1981). As has been indicated, it was used in **Priorities for Health and Personal Social Services in England** (DHSS, 1976b) and **The Way Forward** (DHSS, 1977a). Though national programme budgets may have been followed independently by Health and Local Authorities; Glennerster et al have argued for a more coordinated approach to planning and expenditure at local level (1983).

Fragmentation of services has been a hindrance to effective planning for the elderly, mentally ill and mentally handicapped and to attempts to transfer facilities from hospital to the community. Most services are provided by Health Authorities and Social Services Departments, though Education Departments, voluntary organisations and even Housing Departments can have an involvement. Though health and social service provisions for the priority groups overlap in innumerable ways - and often essentially perform the same function - the organisation of the two services has various almost ineradicable features which run counter to coordinated planning and management. Health Authority members are appointed by the Secretary of State, whereas Local Authorities are made up of elected councillors. The political accountability of Health Service officers is ultimately to the Secretary of State. They, therefore, come under less scrutiny, and have greater freedom in the choice of issues to support, than the officers of Social Services Departments who are immediately accountable to local politicians and generally obliged to refer matters to the committee system before offering an opinion. Health Authorities are financed largely from general taxes, while Local Authorities are funded by rates and the Rate Support Grant from

central government. Finally the two types of agency have different organisational structures and administrative procedures and employ different types of professional (Booth, 1981a, p.26; Rathwell, 1984, p.123).

Over the last two decades there have been growing efforts to promote collaboration between Health and Local Authorities in planning. This has arisen to a large extent because of the emphasis given to planning for priority groups. The drive for coordination has been evident in the creation of a single ministry, the Department of Health and Social Security, with responsibility for all health and social services, the formation of unified Social Services Departments following the Seebohm Report and the introduction of complementary planning systems in the early 'seventies (Booth, 1981a, pp. 23-4). The reorganisation of 1974 made health and local authorities mainly coterminous; Area Health Authorities were to have members nominated by Local Authorities; Joint Consultative Committees (JCCs) were to be set up to advise on the planning of services of common concern to health and local authorities. One disadvantage of the reorganisation from the point of view of collaboration was that community health services were transferred from Local Authorities to the newly created Health Authorities and so became separate from the provision of social care. Health Care Planning Teams with some Local Authority membership and officer working groups from both authorities were commended in 1976 (DHSS, 1976a): they were to be an "additional vehicle for joint planning" (DHSS, 1973). These measures lacked teeth: agencies had no incentive to work together. Booth (1983) has described this as the "naive phase" of collaboration. In many areas the formation of JCCs proceeded unduly slowly - in London lack of coterminosity led to serious difficulties in even setting them up (Glennerster et al, 1983, p.140) - and once established, they found themselves unable to turn

decisions into actions since they were merely advisory bodies. There was an imbalance in the relationship between Health Authorities and Social Services Departments: while collaboration might lead to better use of hospital facilities with the transfer of patients to Social Services establishments, there was no corresponding gain for Social Services Departments.

Booth concludes from a detailed study of joint planning in Calderdale that commitment and goodwill do not alone lead to effective collaboration:

> "There always has to be some sort of inducement, in the form of a reward or sanction, which can be measured in terms of their own organisational interests before one or the other will press for an issue to be included on the joint planning agenda or show any indication to act on it." (Booth, 1981b, p.224).

Joint Finance was introduced in 1976 as an inducement to collaboration (DHSS, 1976a; DHSS, 1977b). It facilitates the use of Health Authority funds to support selected Local Authority schemes which are in the interests of the NHS as well as the Local Authority. Money received from Health Authorities under Joint Finance is a bonus to Local Authorities. Deductions are not made from the resources available to them from elsewhere. The incentive for Local Authorities to use Joint Finance is that it makes extra funds available for projects which they might wish to set up anyway. The advantage to Health Authorities is perhaps less obvious, since Joint Finance involves a transfer of funds from Health to Local Authorities. Joint Finance allocations to Health Authorities cannot be used for any purely Health Service purpose; and the schemes which qualify generally promote a transfer of clients from the responsibility of Health Authorities to that of Local Authorities - and so lead ultimately to a reduction in overall Health Service expenditure. A secondary aim of Joint Finance was the promotion of a shift of resources towards

community services and the priority-groups - the elderly, the mentally handicapped and the mentally ill. This is apparent from the stipulation that it should support social services projects which are likely to make a greater contribution in terms of total care than Health Services facilities costing the same amount (DHSS, 1976a and 1977b; Glennerster et al, 1983, p.162).

Joint Finance has been effective: it has stimulated joint planning and made some expansion of services possible at a time of limited economic growth. In Calderdale it undeniably gave a boost to joint activity (Booth, 1981b).

But even since the introduction of Joint Finance, joint planning has had, to say the least, limited success. The basic centrifugal forces - the lack of coterminosity and the differences in organisation, finance and accountability between Health and Local Authorities - together with the relatively small amount of money available under Joint Finance have meant that collaboration is still seriously deficient. Glennerster et al (1983, p.197) found a difference in planning methods between officers of the two Authorities: Local Authority officers aspire to the use of locally generated data, while their counterparts in the NHS attached greater importance to information from central government.

Though mutual understanding between the Authorities in Calderdale was greater than it had initially been, Booth's overall conclusion is negative:

> "In Calderdale, there was no sign whatsoever of any progress having been made towards securing.... genuinely collaborative methods of working through the process of planning. Indeed, the situation corresponded much more closely to that which the Working Party on Collaboration described as the opposite of its aim; namely one in which plans are prepared separately by the two sides and only brought together at a later stage to see how well they match up." (Booth, 1981a, p.46).

A similar picture is given in the study by Glennerster et al (1983, esp. pp. 141, 180-181; Marslen-Wilson, 1982). In their postal survey of AHAs in 1982, Wistow and Fuller (1983) found that only a minority appeared to have groups whose 'output' consisted of joint policies or strategies and they point out that almost all the published local studies provide no evidence of the successful development of joint strategic planning.

The radical change in the mental handicap service which has been called for cannot be achieved by a Health Authority or Social Services Department acting alone, since it only caters for a segment of the total mentally handicapped population. Joint planning allows the whole population to be held in focus. It, therefore, leads naturally to the formation of an information-base on all the mentally handicapped people in the district - which is a mental handicap register. Joint planning has not been very effective. So while it may spawn registers, it is to be expected that the planning process will not be such that the fullest advantage can be taken of the data that they hold.

Developments which have provided the means for meeting the demand for a common information base on mental handicap

When demands for a common information-base for planning mental handicap services were first making themselves felt, registers which had often been set up primarily for epidemiological research were already in existence. These demonstrated that comprehensive information-bases on mentally handicapped people were feasible. Though they had not been set up with planning mainly in view, they were used as examples by those Authorities wishing to develop a rational basis for planning.

At an operational level organisational divisions have weakened the effectiveness of service delivery to mentally handicapped people. In fact this has been noted in report after report (National Development Group, 1976, Section 20; Committee on Child Health Services, 1976, Sections 4.45 and 4.46; Development Team for the Mentally Handicapped, 1978, Sections 4.45 and 4.46). In their study of services in Sheffield and Leeds, Armstrong, Race and Race (1979, p.42) found there to be very little contact between staff in the different agencies except when clients were moved from the charge of one agency to that of another. Even then failures to communicate have occurred (Development Team for the Mentally Handicapped, 1980, Section 20 and Malin, Race and Jones, 1980, Chapter 11). Symptomatic of the rigid orientation of staff to their own particular field of activity is the ignorance about the Sheffield Development Projects found by the Evaluation Research Group (Armstrong, Race and Race, 1979, p.32). A perception of the need for greater coordination has led to support for Community Mental Handicap Teams (CMHTs) in which the work of different professionals can be coordinated in the provision of services to individual clients (National Development Group, 1976, Section 22; and Development Team for the Mentally Handicapped, 1982, Sections 26 and 41). Such teams provide a natural vehicle for the operation of registers since they have as members the staff of several agencies and are in touch with the bulk of the mentally handicapped people in the community. Registers based on CMHTs will therefore be more likely to be integrated with service provision.

However, not all registers have grown out of CMHTs. In some districts the maintenance of a register has been the first attempt at a joint operational activity. Without anything like a CMHT fragmentation of the services makes it likely that new channels of

communication needs to be developed to make the supply of data to registers possible. Also in view of the limited knowledge of staff about local developments of relevance to all agencies and professions it is likely that the full potential contribution of registers to the work of a motley collection of staff will not be achieved unless there is efficient dissemination of information about their capabilities.

The creation of research sections in Social Services Departments has provided as important a means of establishing registers as the CMHT.

Research by Local Authorities into social conditions can be seen as an instance of the tendency of Government bodies since the Second World War to make more and more use of social research. During the war normal democratic processes had been suspended. Parliament was less critical. There was no direct line of communication from the populace to Government. However there was a need for the Government to find out what people were thinking. This pressure for greater information about the population coincided with the development of sophisticated survey methods such as statistical analysis, sampling, interviewing, recording and the use of computers. As a result the Government began to use social surveys in earnest.

When Social Services Departments were set up in the early 'seventies there were a number of pressures on them to carry out social research.

The Seebohm Report which had advocated their establishment argued that relevant research should guide decision-making:

> "The planning of the personal social services cannot
> be undertaken successfully without the research which
> identifies emerging trends, assesses long-term
> repercussions, and estimates the character and
> dimension of future needs... Basic descriptive data
> about the personal social services and the communities
> they serve are essential, though at the moment sadly

lacking both centrally and locally... Social planning
is an illusion without adequate facts and the adequacy
of services mere speculation without evaluation."
(**Report of the Committee on Local Authority and Allied
Personal Social Services**, 1969, Chapter XV).

The Chronically Sick and Disabled Persons Act (1971) statutorily
obliged Local Authorities to identify the needs and numbers of their
handicapped populations - a task which was felt to require staff with
a research function. The request of the Secretary of State for
ten-year plans covering social services from 1973 also prompted the
creation of research units, which was made possible by the growth in
resources available to the newly created Social Services Departments
(Booth, 1979).

Though a research and development section covering all
departments of a Local Authority was recommended by the Seebohm
Committee (Section 466), very often Social Services Departments have
created their own research section. A survey in 1973 found that about
half the Local Authority Social Services Departments employed research
staff (Wedgwood-Oppenheim, 1974). In 1977 90% of Social Services
Departments had research staff (Harbert, 1977). Moreover the issues
investigated by research departments were very similar to those
addressed in surveys on which mental handicap registers have been
based: analysis of the University of Birmingham clearing house service
suggests that in 1973 and 1976 the emphasis of research by Social
Services Departments lay heavily on the identification and assessment
of needs (Leigh, 1977).

This growth in research has stimulated the setting-up of
registers in two major ways. It has provided a section of most Social
Services Departments which is able to organise data-collection for a
register. It has also created an intellectual environment in which
activities, such as the maintenance of an information-base on a

client-group is regarded as a worthwhile activity.

Social Services Research Sections are obviously separate from those that provide services. It is therefore to be expected that registers maintained by Research Sections will not be as closely integrated with service provision as those based on CMHTs.

Mentally Handicapped People as a Client Group

Most of the developments discussed in this chapter - the construction of planning systems, the emergence of priority groups, the philosophy of community care and joint planning - have created a demand for information with which to plan services for other priority groups - the elderly and the mentally ill. Though a number of psychiatric registers have been set up, far more joint information-bases have been compiled on mentally handicapped people than on any other client-group. The reason is that mentally handicapped people probably constitute the client-group most suited to being planned for on the basis of a data-base holding their details.

They are a relatively small group unlike the elderly or mentally ill. Though there are problems in defining mental handicap, they are not insurmountable and arguably less acute than those associated with the definition of mental illness. The circumstances of mentally handicapped people do not often change unlike those of the mentally ill; their future situation can be predicted with reasonable confidence. In fact future demand on the service can be predicted because the life expectancy of mentally handicapped people can be calculated reasonably precisely and few people become mentally handicapped during their life. Mentally handicapped people are also a relatively homogenous group - certainly more so than the elderly.

Conclusions

A demand for a common information-base on the need for mental handicap services has emerged from the development of planning systems in the Health and Social Services, the emphasis on priority groups in joint planning and the conception of mentally handicapped people as a priority group (cf. Cubbon, 1984). Joint finance has created the necessary supply of funds. At the same time the formation of research sections in Social Services Departments and attempts to increase collaboration between agencies at the operational level - in particular the establishment of CMHTs - produced organisational structures from which information bases on mentally handicapped populations could develop. Finally, changes in the philosophy of mental handicap care and recognition of the need for change have led to political pressure for a new service, of which registers are a part.

Such, then, has been the climate, which has given rise to mental handicap registers. Most of the developments belonging to this climate can be regarded as responses to the recognition of the importance of planning health and social services and the attempt to lessen the fragmentation of welfare services in general. As well as leading to planning systems, the former tendency has manifested itself in the appearance of a research function in Social Services Departments; the drive for less fragmentation has been evident at the level of planning in the efforts to promote joint planning, the creation of Joint Finance - and even also in the construction of planning systems - and at the operational level in organisational changes such as the setting-up of CMHTs.

This account of the origin of registers raises a number of questions. The large-scale pressures behind the proliferation of

registers have been described; but how exactly have they made themselves felt at local level in the process leading up to the formation of a register? Have they been the only factors involved? There have been organisational structures which facilitate the maintenance of registers: one type has appeared to be more integrated with the provision of services than the other: how far have registers been integrated or separated from service provision? Collaboration between agencies and professions in the operation of the mental handicap services has usually been slight; yet it is essential if a register is going to be complete. So how effective has collaboration been in the maintenance of a register? A similar question can be asked about the use of register-findings in planning: joint planning has not been a huge success. So has the potential contribution of registers to planning been limited by the inadequacies of the planning agent?

These are some of the questions which will be examined in this thesis. They will be refined in the next chapter.

Existing written material relating to mental handicap registers.

This chapter begins by looking at what has so far been written on mental handicap registers indicating the gaps as a prelude to a statement of the aims of the study. Then the methods adopted, their appropriateness to the aims and their basic strengths and limitations will be described.

There are very few published discussions of the workings of mental handicap registers, though there are a substantial number of journal-articles in which their epidemiological findings are presented. Significant written material on current developments in the health and welfare service is often not limited to what is published. Of significance also are unpublished but often quite widely circulated documents such as those produced by Local and Health Authorities. These have in fact played an important part in the dissemination of the concept of a mental handicap register and so will be discussed in this chapter.

Certainly until recently the registers most well-known in the mental handicap world were those for Sheffield, Wessex, Camberwell and Salford. The latter three are the only ones in England and Wales which were already in operation during the 'sixties. The Sheffield register was also started comparatively early on – in 1975. These four are also worth considering together because they rely very much on their own staff for data collection.

The most important export from the Wessex register has been Kushlick's Wessex Behaviour Rating System. It has become the standard method of assessing the abilities of subjects adopted by mental handicap registers. Word of mouth and individual contact between

Authorities may well have been at least as important in the spread of the method as the journal-article (Kushlick, Blunden and Cox, 1973) in which it is described in detail. Studies of prevalence based on the register have been published (Kushlick and Cox, 1970, and Kushlick, 1975). A useful paper in the implications for planning of geographical variations in rates of mental handicap based in the Wessex register recently appeared (Mansell and Felce, 1985). Publications emanating from the Camberwell and Salford Registers (both of which were originally set up essentially for research purposes) have mainly been epidemiological (Fryers, 1974, 1976 and 1977 and Wing, 1971). As well as studies of prevalence (Martindale, 1976 and 1980), the Sheffield register produced a number of reports which aimed to answer specific policy questions (Sheffield Development Project). Also in 1982 an article appeared which described the main features of the organisation of the register (Martindale and Steel, 1982). But the emphasis of the writings produced by the four best-known registers has tended to be on their findings rather than their organisation.

A number of epidemiological studies based on registers have been appearing since the 'sixties (e.g. Ross, Innes and Kidd, 1967; and Innes, Kidd and Ross, 1978). A point which they make again and again is that rates of prevalence of mental handicap vary markedly from authority to authority. This was recognised in the Review of the White Paper (DHSS, 1980, Sections 3.9 to 3.12). It was even found that there were substantial variations in prevalence among the districts of single cities (Russell, 1976, and Martindale, 1980). Martindale (1980) showed that both mild and severe mental handicap were more prevalent among families living in postal districts with a higher proportion of people in manual occupations.

As well as the Sheffield register, a number of registers have produced elaborate reports of their data as a basis for the formulation of policy (London Borough of Greenwich Directorate of

Social Services, 1974; Rotherham Community Health Council, 1979; Kerry, 1980; Gardner, 1981; London Borough of Hackney Social Services Department, 1982; Cornwall Social Services Department and Cornwall and Isles of Scilly District Health Authority, 1984). They have sometimes contained useful information about the organisation of the register itself, though this has not been their major focus.

The earliest reference by a Government body to a mental handicap register is perhaps the most favourable: the Seebohm Committee recommended that all local administrative areas should maintain a record similar to the Camberwell Psychiatric Register which included mentally handicapped people (Report of the Committee on Local Authority and Allied Personal Social Services, 1969, para. 341). But this does not seem to have received much attention.

When the White Paper (DHSS, 1971) appeared there were very few registers in existence. Though they were not specifically discussed, they were referred to: according to the White Paper, there was a need for better information about the prevalence of mental handicap and the numbers requiring particular types of services. Such information was, however, being obtained by surveys financed by the Department. The first pamphlet produced by the NDG (1976) and the first two reports of the DT (1978 and 1980) had brief discussions of registers which were neither wholly favourable nor wholly unfavourable but did offer a few useful tips about the possible pitfalls. Between 1975 and 1977 there were several meetings of DHSS officials and operators of registers. The minutes show that useful comparisons of organisation, data-sets and uses of registers were made and advice was given on the difficult decisions about the form of registers. However, these minutes were probably not easily accessible to Authorities seeking advice on the setting-up of a register. In preparing the Review of the White Paper, detailed information about the characteristics of the population

covered by five registers (Wessex, Camberwell, Salford, Sheffield and Lambeth) was obtained. It was found that prevalence ranged from 2.9 to 3.4 per 1000. So it was concluded that a single national prevalence rate could be misleading at local level and Health and Local Authorities were urged to assess jointly the needs of their mentally handicapped population (DHSS, 1980, Sections 3.8 to 3.11).

However, the Review like other documents emanating from the DHSS is non-committal:

> "We make no recommendation as to whether more Case Registers should be set up. This is something which should be determined locally, taking account of the considerable cost involved and of the use to which it is intended the proposed register should be put." (DHSS, 1980, para. 3.12).

Before this study there were only four published articles on the organisation of registers (Kushlick and Cox, 1970; Martindale, 1976; Elliott, Jackson and Graves, 1981; Martindale and Steele, 1982 and Farmer and Rohde, 1983). Kushlick and Cox (1970) give a detailed description of the sources of data and methods of updating used by the Wessex register. Martindale (1976) and Elliott, Jackson and Graves (1981) describe the organisation - in particular, the data-collection procedures - of the Sheffield and Oxfordshire registers respectively. Both also present epidemiological findings. Farmer and Rohde (1983) describe the Westminster register. A rationale is given for the data-set held and the initial process of compilation is outlined. The register is maintained on a microcomputer which can be used by people without computing experience. The system is being widely adopted. The article gives details of the hardware and software.

Though unpublished, Jones's booklet (1979) has been accessible to Authorities. It is essentially a discussion of the pro's and con's of establishing a register in Wandsworth. Though written primarily with

Wandsworth in mind, it contains valuable advice for any Authority considering the compilation of a register. Conferences on registers were organised by the Association of Professions for the Mentally Handicapped in December 1981 and by the South West Branch of the Social Services Research Group in June 1982. Such gatherings of staff from various Authorities inevitably spawn comparisons between registers. Minutes of the conference held in 1981 contain helpful remarks about data-collection, data-sets and access to information. As a result of the conference, a booklet was produced which gave advice on how to run a register (Fryers, 1983). It was the first widely available report based on the experience of several registers. It concentrated largely on data-sets and methods of data-collection. It is useful reading for anyone charged with looking into the feasibility of the register. Recently the Special Interest Group (Mental Handicap Registers) has been formed. It is intended that it will meet regularly. It should be a useful forum for the exchange of ideas among officers at different Authorities who are involved in some way in registers.

There has been some theoretical discussion of the use of Kushlick's Wessex Behaviour Rating System in planning services (Kushlick, Blunden and Cox, 1973). In the opinion of DT, the numbers of people shown by the system to have certain levels of incapacity are a guide to the number of places needed in various types of residential and day establishments (1979, Section 12). Palmer and Jenkins (1982) give evidence to show that Kushlick's system is reasonably reliable as a guide to the level of incapacity of groups of people in large-scale surveys, but that it should be treated with great caution as an indicator of the incapacity of particular individuals. The Wessex System has been taken up by many registers.

Kushlick (1975) gives an account of how plans were based on register findings, how these plans were implemented and their outcome; but apart from this article nothing has been written about the impact of mental handicap registers on service provision.

In Proceedings of the Conference on Psychiatric Case Registers at the University of Aberdeen (1973) comments were made about the use of data from psychiatric registers, many of which are applicable to those of mentally handicapped people: to prevent under-utilisation of registers it is necessary for register-operators and service-planners to work closely together. This study of mental handicap registers reaches a similar conclusion.

Perhaps the greatest gap in literature is the lack of any independent evaluation. Registers are viewed primarily as tools for research into mentally handicapped populations. This is reflected in the preponderance of discussions of their findings. So because they are seen themselves as tools for research, research into their role may have been neglected. The nearest approach to detailed social-scientific research into the workings of a register is Jones (1973). This, however, examines no existing register in detail.

Another major omission is that there has been no evaluation of the effect that registers have had on the planning process and so ultimately on the provision of services. Much has been written about the findings of registers; a number of register-operators have described how their data-bases are maintained. However the organisation of data collection and the data collected are of little use if the data do not guide the plans for the service; and how far they do this has been almost wholly unexplored.

Anyone who makes a thorough attempt to find out about the various types of register currently in operation will be bewildered by the immense variety. Therefore, the comparisons made by Fryers (1983)

between alternative forms are welcome. However, Fryers does not take into account all types of registers and his discussion does not cover several important aspects of their operation. No systematic comparative evaluation of registers had been made before this study.

Finally there is no written material relating to the most recent wave of registers which are integrated with service provision such as those operated by CMHTs and Specialist Social Workers. There is only a brief mention in Simon (1981).

This study removes the deficiencies in existing writing on mental handicap registers by being an evaluation of the role of registers as planning tools which includes a consideration of their integration with the provision of services.

Aims and Scope of the Study

The object of study is registers of mentally handicapped people as planning tools; and the aim of the study is to evaluate them.

The next chapter will, so to speak, set the scene for the subsequent evaluation by describing registers in broad-brush-stroke terms: the number, scope, operation and financial aspects of registers will be set out. At the same time the emergence of registers will be related to the development of planning for mentally handicapped people as a priority group, as outlined in the first chapter. Specific aspects of this large-scale trend which have played a crucial role in bringing registers into being will be highlighted.

Whatever the role of registers in the planning process they will be unacceptable if they have drawbacks outside the sphere of planning. So before looking at registers in planning, their organisational, financial and moral feasibility will be considered: can the data that

registers require be collected inexpensively and without undue distraction of professionals? will staff in different agencies and professions collaborate in supplying data? do registers pose a threat to the confidentiality and privacy of the subjects?

The role of registers in planning will be investigated in three stages: first, there will be a comparison of the contribution of statistical information on a mentally handicapped population with that of other planning tools; then the potential usefulness to the planning process of the individual data-items held on registers will be assessed; finally there will be a consideration of the use that has in fact been made of registers in the planning process. The final chapter will address itself to the question: how worthwhile a development has the recent proliferation of registers been?

How the Study was conducted

Before the project began, it was known that there were a large number of registers scattered throughout the country. So it was decided to investigate them by a survey. Owing to constraints of time and money, the survey was carried out in three stages:

1. A circular was sent to all agencies which might have mental handicap registers.

2. A postal questionnaire was sent to all English registers after a pilot survey in Wales and Scotland.

3. The operators of 22 registers within 80 miles of Sheffield were interviewed after pilot interviews in London.

Before an attempt could be made even to establish where registers existed, it was important to secure approval for participation in the

research from relevant bodies and to decide exactly what was meant by "register of mentally handicapped people".

On 10th August 1982 a letter was written to all Regional Medical Officers in England and Wales and to the Association of Directors of Social Services, seeking their support (see Appendix I). All responses received were positive. After the decision had been taken to include Scotland in the pilot survey, letters requesting support were sent in late May 1983 to the Scottish Association of Directors of Social Work and the Chief Administrative Medical Officers at each Scottish Health Board.

It was decided that whatever met the following three criteria should be counted as a "register of mentally handicapped people" for the purposes of the project:

1. It should aim to include all the mentally handicapped people living in a given geographical area, like a Health or Local Authority District (as far as possible).

2. It should record more substantial information about each individual than merely his name, address and age.
    It might have in addition details of services used or details of the handicap.

3. It should be seen to have some relevance to planning.

Though in retrospect one could point out weaknesses in this working definition, it does seem to have been understood in such a way that its basic purpose was achieved: it was mostly taken to exclude the records standardly kept in client-indexes of Social Services Departments, but equally it was not so restrictive that only the most sophisticated and established registers were regarded as meeting its conditions.

A handout on the project, including this definition, was produced in July 1983 (see Appendix II). It proved very useful not only in contact with questionnaire-respondents and interviewees but also as a means of giving information about the project to anyone interested.

Finding out where registers existed

To establish where there were registers, a circular (see Appendix III) accompanied by the handout was sent to individuals in all agencies in England, Scotland and Wales which might operate registers:

202   District Administrators of Health Authorities in England and Wales.

116   Directors of Social Services Departments in England and Wales.

11   Directors of Regional Services of MENCAP.

         The Regional Medical Officer of Wessex Regional Health Authority.

15   Chief Administrative Medical Officers or other staff at Health Boards in Scotland.

12   Directors of Regional or Islands Social Work Departments in Scotland.

5   Directors of Divisional Social Work Departments in Strathclyde.

         The Assistant General Secretary of the Scottish Society for the Mentally Handicapped.

Each recipient of the circular was asked whether his or her agency operated a mental handicap register, and, if so, to whom a questionnaire on the operation of the register should be sent; if the agency did not have a register, it was asked whether it had any plans

for setting one up and, if so, what stage these plans had reached.

The circular was despatched on 2nd August and reminders were sent on 13th September and 11th October. By the end of the sixth week (11th September) a few days before the first reminder was sent off – 248 (75%) of the 330 agencies had replied; by the end of the tenth week (9th October) – a few days before the second reminder was sent off – 295 (89.5%) of the agencies had responded. By the 30th October 313 (94.9%) of the 330 agencies in England and Wales had replied. Only one was unwilling to take part. The 17 non-respondents were rung up in November. Only one, a Director of Regional Services of MENCAP, did not have the information available.

The following factors were probably responsible for the high response rates:

1. Only four questions were asked in the circular and they were all relatively straightforward.

2. Support for the project had been obtained from the Association of Directors of Social Services, the Association of Directors of Social Work, the Royal Society for Mentally Handicapped Children and Adults, the Scottish Society for the Mentally Handicapped, and a number of Regional Health Authorities and Scottish Health Boards. Where appropriate, this support was mentioned on the circular.

3. The handout which accompanied the circular explained the benefits of registers and the need for a national survey and evaluation.

Altogether 108 of the 364 respondents wrote that their Authorities operated registers – 100 of those in England and 8 of those in Scotland. The circular drew attention to the definition of mental handicap register in the project handout. However, a few

Authorities which replied that they had registers appeared not to have a data-base which quite met all three conditions given in the working definition. The replies also revealed a serious inadequacy in the questions asked, namely that the questions only allowed for the following possibilities:

1.　agencies which operated registers

2.　agencies which were at the stage of planning registers

3.　agencies which neither operated registers nor had plans for setting them up.

However, a large number of agencies were setting up registers. So they could well wish to describe themselves as beyond the stage of planning and not quite at the stage of operating registers. As well as providing answers to the questions asked, responses to the circular gave on occasions useful information about registers or plans for them - often in the form of reports produced by Authorities. Another valuable spin-off of the circular was that it made the project known throughout the country. Individuals or Authorities wishing to know about the development of registers elswewhere could therefore request information; and many did.

The Postal Questionnaire

The issues covered on the questionnaire were determined by the aims of the project. The specific design of the questionnaire was guided also by written material relating to registers and interviews with seven register operators and one former operator. (By "register operator" it is meant anyone whose job may be said to include the maintenance of a register or the direction of its operation - in

short, anyone who may be said to work on a register). These interviews were given between July and September 1983 in all cases except one at the office of the interviewee - in other words, where the register was maintained. They lasted about an hour and were taped. Six of the registers had been in existence for some years and were often visited by people elsewhere wishing to set up registers of their own. In December after the postal questionnaire had been despatched, a further two registers were visited and their operators interviewed on tape. In all these interviews the major aspects of the work of the registers concerned were discussed. The information obtained was valuable at all subsequent stages of the project.

On Friday 11th November 1983 a postal questionnaire consisting of 21 sides of A4 paper together with a stamped, addressed enveloped, a project handout, and a covering letter was sent first-class to each of the 23 registers in Scotland and Wales (see Appendix IV). By Tuesday, 29th November, only four (17%) of the 23 had responded. So it was decided that an approach should be made by telephone. On 30th November and 1st and 2nd December, the majority of the non-respondents were contacted, the remainder all being reached by mid-December. Many of the non-respondents expressed a definite willingness to complete the questionnaire; only one was at all reluctant to participate. It emerged that one of the non-respondents did not operate a register. The telephoning had a marked impact: by Christmas a further nine questionnaires were received. This pushed the response-rate up to 60% which was still not satisfactory. So in early January 1984, the remaining non-respondents were contacted by telephone; a further two were discovered not to be operating registers. Seven questionnaires were returned after this second reminder.

Several of the completed questionnaires contained inappropriate or inconsistent answers. Frequently open questions were answered very briefly or yielded information that could have been obtained by pre-coded questions. Thirteen of the returned questionnaires (69%) were unaccompanied by the form standardly used for recording data about clients despite requests in both the covering letter and the questionnaire overleaf.

It was clear that the questionnaires to be sent to English registers would have to be substantially different not only because of the quality of the answers but also because it would be impractical to give the majority of the 137 recipients one, if not two, telephone reminders. Contacting an administrator or professional in the Health or Social Services by telephone can often itself take half a dozen calls.

So on 9th February 1984 a postal questionnaire half as long and requiring four sheets of A4 (since it was printed on both sides of each sheet) was sent to each of the 137 people in England who appeared likely to have a register on the basis of the response to the circular of 2nd August (see Appendix VI). Here is a breakdown of the time-span of the responses:

9th February: 137 questionnaires together with stamped, addressed envelope, covering letter (see Appendix V), and project handout, were despatched first-class.

27th February: 54 replies (39%) had been received.

15th March: 79 replies (58%) had been received.

5th April: 109 replies (80%) had been received. Reminders in the form of a letter, another copy of the questionnaire, and a stamped, addressed envelope were despatched.

| 17th April: | 112 replies (82%) had been received. Telephone reminders began. |
| **To Date:** | 131 replies (96%) have been received. |

The response rate has been substantially better: eighteen days after the despatch of the questionnaire, 39% of the respondents had replied whereas only 17% had replied after the same length of time had elapsed from the posting of questionnaires to Scotland and Wales. Also the English questionnaires were completed in generally greater detail.

What complicates the response-rate is that 31 of the respondents (23%) did not have registers and so did not complete the questionnaire. Also many of the others had registers at an early stage of development and so did not answer many of the questions. Of the 19 respondents who replied after the beginning of the telephone reminders, 7 reported that they had no register. This was usually in the telephone conversation initiated by the researcher. Only one person who received a questionnaire refused to take part. The response was sufficient for it to be possible to speak in general of registers of mentally handicapped people in England. It is perhaps worth noting that the first reminder – a brief letter – seems to have had greater effect than the second – a letter plus a stamped, addressed envelope, and another copy of the questionnaire.

A large number of the questionnaires received were from registers which were at some stage of being set up. Some had not had staff appointed to run them; a number were at various stages of the initial data-collection; some had not been used at all or had hardly been used; a few were still operated manually but were due to be computerised; a large proportion had not been fully updated, and so on. A decision had to be taken as to which questionnaires were to be

computerised with a view to the calculation of statistics about all the registers in England - in other words, it was necessary to decide what was to count as a "register of mentally handicapped people" for the purposes of analysis of the returns from the postal survey. Several completed questionnaires described data-bases which did not appear to meet one or more of the criteria for a register given on the handout. They could not be assigned to the group of questionnaires from which statistics were to be derived about registers throughout the country - in other words, they could not be regarded as describing registers for the purposes of the survey - because there might well have been other data-bases which were the same in all relevant respects but were unknown because their Authorities had, in response to the circular, correctly stated that they did not have registers. However, if too narrow a definition of "register of mentally handicapped people" were taken - for example, if it was a necessary condition that the register should not still be in the process of being set up - many registers which were operational in all major respects would be excluded. The solution adopted was to regard a data-base as a "register of mentally handicapped people" for the purpose of analysis of the questionnaire if it appeared to meet the three criteria on the handout and if the data it held were used in some way. There were 59 registers which appeared on the basis of the completed questionnaires to meet these criteria (cf. Cubbon and Malin, 1984). Answers to closed questions on these questionnaires were analysed on computer using the SPSS package. A course on SPSS was taken in January 1984 at the Computer Services Department at the University of Sheffield. As with the circular, respondents often enclosed locally-produced documents relating to their registers.

The great advantage of a postal questionnaire in this case was that it enabled information to be collected about facilities throughout the country at very little cost in terms of time and money.

Postal questionnaries can only be appropriate if they contain questions which are unambiguous and easy to understand. Most of the questions on both the pilot and the main questionnaire did not present problems. The exceptions on the main questionnaire were Questions 6 and 15(a). In Question 6 "borough" is ambiguous: does it mean only the area covered by a metropolitan borough? does it include what were called "boroughs" before the reorganisation of local government? It is not difficult to see from Question 15(a) what was intended by it. However, it was difficult to find a formulation which was not too cumbersome or did not give expression to the major attitudes of register operators on the question of the degree to which the potential contribution of the register was realised. Several of the respondents who ticked "The planners and providers of the service make generally as much use of the register as they reasonably can" pointed out in subsequent interviews that there was scope for greater use of their registers.

Response rates to postal questionnaires have been found to be lower than average among less educated people, those in low occupational categories and those uninterested in the subject of the survey (Moser & Kalton, 1971). We therefore expected that register operators would make a good response to the questionnaire which sought data about a new facility with which they were closely involved and promised to provide information which would be helpful to people like themselves developing the facility. This expectation was justified despite the poor response to the pilot.

In both the pilot and the main questionnaire the questions were mainly closed. A greater number of open questions might have lowered the response-rate. Though answers to open questions sometimes provided a degree of detail which would not have been possible in answers to closed questions, they were on occasions rather obscure and raised as many questions as they answered.

Basic factual information obtained from the closed questions such as the number of register staff, the sources of types of information held and the uses of registers often only made sense in the context of further information which could not be given on the questionnaire. Numbers of staff working part-time do not indicate the number of hours actually spent on the register; a list of sources of information tells one little in the absence of any indication of their relative importance and precise nature - the same goes for a list of uses; details of general types of data held such as were obtained in answer to Question 13(a) are too unspecific. These problems may just be the result of the particular closed questions asked. But it may well be that a postal survey of anything as organisationally complex as a mental handicap register is bound to provide data in response to its closed questions, which need considerable elaboration.

The Interviews

As will be explained, respondents in Greater London and within 80 miles of Sheffield were interviewed. Mostly what was said at these interviews was consistent with the returned questionnaires. There were a few discrepancies. In a minority of cases a different number of staff were said to be working on the register. This was probably because often so many people work on the register in different ways for different amounts of time each week that there is no clear division between those who may properly be said to "work on the register" and those who may not. On a small number of occasions a different picture of the types of use made of the register was given at the interview from that given in response to the postal questionnaire. Again this can be put down to the indefiniteness of

the concepts in the question: the five types of use specified in Question 14 on the questionnaire shade into one another.

In February and March 1984 eight users of the Sheffield register were interviewed. Two were practitioners and six had administrative and managerial responsibilities. Of these six, three were employed by the Health Authority and three by the Local Authority and five were members of the joint officer body with responsibility for planning services for mentally handicapped people. Six of the interviews were taped. Interviewees were asked about their use of the register, its contribution to the service, its accuracy and value and about the Wessex scale. These interviews lasted about 40 minutes each. They provided a clearer understanding of the role of registers in the planning process.

The schedule for interviews with register operators was piloted in Greater London. Nine register operators were interviewed. Eight of the nine interviews were taped. A schedule based on what was known about each register from the questionnaire and other sources was constructed from each interview. It therefore reflected special features of each register, but the schedules covered the same basic issues and there were many questions common to all or most. The pilot interviews were very much more successful than the pilot questionnaire. They yielded useful information and it was found that the questions asked were almost as suitable.

Between 18th June and 9th August, interviews were conducted with the operators of 22 registers within 80 miles of Sheffield. In all, 25 interviews were given: in one case someone setting up a large elaborate register was interviewed; three people involved with the operation of a single register were interviewed separately; and the remaining 21 interviews were with the operators of 21 different registers. The choice of area was determined by constraints of time

and money: it in fact covered the greater part of the industrial heartland of England - Merseyside, Greater Manchester, the West Midlands, the whole of Lancashire, almost the whole of Yorkshire and the Trent Region. All interviews except one were taped. They lasted between half an hour and two hours; most took about an hour.

The Appendix shows the schedule for the questions asked at the interviews (see Appendix VII). It was adapted for each register on the basis of the answers to the postal questionnaire and any other information available. The adapted schedule was not adhered to rigidly at the interviews: the wording and order of some questions were changed; supplementary questions were posed if the interviewee said something of special interest. However, most of the questions asked in the interviews appear on the schedule in the Appendix. Most of the talking in the interviews was done by the interviewee. This method of conducting interviews was adopted not only in the interviews with operators of registers within an 80 mile radius of Sheffield, but also in all the other interviews during the project, though with different question schedules.

The interviews with the register operators produced very much more data than the completed questionnaires. They - so to speak - added flesh to the bones. Henceforth whenever an unattributed quotation appears it is to be taken as the verbatim record of something said at an interview.

Because so much of the interviews dealt with details of organisation which were often complicated, it was essential to tape them. Where interviews were not taped it was with one exception because of failure of the recording equipment. The exception was an interview with an operator who felt that he would feel less inhibited if he was not on tape. Whether the interview was taped or not, a hand-written record was made during the interview by the interviewee.

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All operators in London and around Sheffield who were asked if they were willing to be interviewed agreed and almost all were able to arrange dates in the following few weeks. In 26 of the 33 interviews with staff of registers for which a questionnaire had been completed, the person who completed the questionnaire was the person who was interviewed. In the seven cases in which he or she was not interviewed, he or she either was unable to be present or was no longer working on the register or it was felt that a colleague would be more appropriate. In the seven cases in which the interviewee had not completed the questionnaire it was not apparent that what was said contradicted the answers on the questionnaire any more than in other cases. In 13 of the 33 interviews more than one of those working on the register participated. This was perhaps not ideal: the interviewees might have been restrained by the presence of their colleagues in unknown ways. However often those present had different tasks in relation to the register. So their comments complemented one another.

Confidentiality was stressed at both major stages of the research. The questionnaire contained an assurance that answers would be treated in strict confidence; when the interviews were arranged, interviewees were told that nothing that they might say would be reported in such a way that they or their registers might be identified.

As well as data from the surveys, written material and information resulting from informal contact with Health Authorities and Social Services Departments have provided the basis for this report.

The little published material on registers has already been discussed. There has been a fair amount written on matters of relevance to registers - in particular, the development of the mental

handicap service and of planning welfare services, CMHTs and issues of privacy and confidentiality raised by computerised data-bases. Documents produced by individual Authorities in which registers have been discussed have sometimes been very useful. A definite effort was made from early on to collect as many of these documents as possible.

Informal contacts have been built up with a number of staff planning or running registers. Sometimes these have been generated by the requests for information which were received. Because the project was the only source of information about all registers in the country, these requests were encouraged. There was close liaison with Huddersfield Health Authority in its development of plans for a register. The Authority was provided with information and it was possible to observe the process of planning a register by attendance at meetings of the District Planning Team for Service for the Mentally Handicapped and other meetings of Health and Local Authority officers. This experience gave an extra dimension to the understanding of the emergence of registers.

Advantages and Disadvantages of the Methods Used

The obvious strength of the survey-method is that it has enabled a comprehensive coverage of registers. Since the aim of the study was an evaluation of mental handicap registers in England and Wales, information on all registers was essential. The survey was quite adequate as a means of finding out the major features of registers - which had never previously been attempted. It also brought out general tendencies in the operation and use of registers. This provides a reasonable basis for deciding whether the recent emergence of registers has been worthwhile. It is also sufficient for showing

how major national developments in the health and social services, such as Joint Finance and collaboration between agencies, have made themselves felt in the emergence and operation of a new type of planning facility in local mental handicap services.

In an 18-month survey a detailed examination of all registers is not possible. The most information collected on any register was what emerged from a completed eight-page questionnaire, an interview with one person involved with the register and locally produced documents. This was far from being sufficient evidence for evaluating the register - that is, for deciding which parts were working well or badly or how they might be improved. To assess the effectiveness of a register, it would be necessary to know about the present state of the mental handicap services in the district concerned, and their history, to give detailed interviews to at least a cross-section of those involved with the register - not only the register staff, but also those outside who supplied information and people involved in planning - and actually to observe the register in operation at various levels.

Because of the superficiality of the information collected on each register there was a danger of not comparing like with like.

Registers form part of the highly complex network of relationships and pressures which make up the mental handicap service. This network includes a welter of professions, establishments, administrators and agencies, Health and Local Authorities with their political representatives, the clients and their families, the constraints imposed by the need of other priority groups, the legacy of previous service provision, and so on. An idiosyncracy in any part of this network can significantly affect the form and uses of the register. A single interview with a register operator might not reveal such an idiosyncracy. So a register which appeared to have a form which made it less effective than others might nevertheless have

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the best organisation in view of special features of the local situation which had not emerged.

It is therefore difficult to say of any feature of a register which appears to be working well or badly that other registers should emulate or avoid it, because the feature in question may only be effective or possible in the register concerned because of special unknown local circumtances.

People are normally surveyed - by postal questionnaire or interview - to obtain information about themselves and their attitudes. In this case they were surveyed to obtain information about a part of an organisation. An individual who is being asked **his** opinions has, of course, direct access to them because they are his opinions. A part of an organisation, like a register, cannot be said to have an opinion; however each of the individuals involved in it may have opinions which are relevant to an understanding of its operation. In the case of a register, people involved include the staff of the register themselves, those who supply it with information, those who use the information and even those whose personal details are held on it. These people may be in a number of different offices, professions and agencies. If, as inevitably happens, a postal questionnaire or an interview about something like a register is given to a single individual, he cannot be expected to give an accurate account of the views of all the people involved in its operation; and even if he could he might not want to. Nor is there any guarantee that his views will be representative; he can only give **his** opinions. Similarly any individual working on a register is likely to know best those aspects of it which concern him most. For example, register operators might have little knowledge of processes in which data from the register are being used.

So the views expressed by a single register operator on a postal questionnaire or in an interview about his register may be

unrepresentative of the views of all the people involved and his knowledge about the register may be substantially lacking in some areas. These difficulties were to some extent avoided in the postal questionnaire because only two of the fifteen questions sought the respondent's opinion and the remainder - apart from Question 12 which had a "Don't know" option - asked for information which most people working for registers would have at their fingertips.

However, in so far as the survey could only obtain the views of usually a single operator and could not elicit data about every facet of the operation of the register, it was significantly limited.

In short the quantity of information collected on each register was not extensive and so evaluation of individual registers was not feasible. The diffculties could be overcome if a single register were examined for longish periods. A cross-section of staff in the mental handicap service could be interviewed. As a result the service as a whole could be understood and the standpoints of a range of staff involved with the register in different ways taken into account. Observations could be made of the various processes essential to registers such as data-collection and the passage of data from the register to the planning bodies, ultimately issuing in decisions. A detailed comparison of mental handicap planning with and without a register would provide rich and substantial information on the effect of the register on planning. This study will show that it is very difficult to compare two registers because of the great difference between them. So it would probably be better to carry out long-term observation of mental handicap planning in a district before and after the introduction of a register than to conduct a similar study of planning in two districts - one with and the other without a register. Long-term qualitative research into the place of a single register in the mental handicap service was not possible; but it would have added

a dimension of understanding to the findings. It would give satisfactory ground for an evaluation of the register in question, though, of course, it would be a dubious basis for generalisation to all registers in the country.

Although the survey produced a limited amount of information about each register it did cover **all** registers. This is its strength. It has provided a better basis for generalisation than an examination, however detailed, of a few. It has revealed that the same problems are shared by a number of registers and that various measures have been successful in overcoming these problems. This will be very useful to those Authorities contemplating the establishment of a register.

The Emergence of Mental Handicap Registers

The number of mentally handicap registers being set up has never been higher than during the 'eighties.

On 13th July 1982 the DHSS Statistics and Research Division 6 sent a postal questionnaire to the 108 Directors of Social Services in England and Wales on their records of mentally handicapped people. A total of 92 replies were received - a response-rate of 85%; 10 (11%) of the respondents indicated spontaneously that they would soon have registers.

On 26th July 1982 Dr Sheila Adam, Specialist in Community Medicine at Brent Health Authority, sent a letter with questions on mental handicap registers to all District Medical Officers in England. Of the 193 Health Authorities, 101 (52%) replied. The overwhelming impression given by the responses was one of change. Throughout the country registers were being set up, planned, discussed, and developed. Their organisation was often also in a state of flux. About half the Authorities without registers indicated that the establishment of a register was one of their current objectives.

The response to the circular despatched on 2nd August 1983 revealed that 98 of the Health Authorities and Social Services Departments in England and Wales had registers and that an even greater number (141) were involved in planning them. Of the 57 respondents who answered the relevant question in the postal survey of English registers, 34 (60%) had registers which were still being set up. Table 1 shows the dates of first use.

TABLE 1   TABLE OF DATES OF FIRST USE OF REGISTERS

Date of First Use	Number of Registers	
1963	1	(1.7%)
1964	0	
1965	0	
1966	0	
1967	1	(1.7%)
1968	1	(1.7%)
1969	0	
1970	0	
1971	0	
1972	0	
1973	0	
1974	1	(1.7%)
1975	2	(3.4%)
1976	1	(1.7%)
1977	2	(3.4%)
1978	4	(6.8%)
1979	3	(5.1%)
1980	8	(13.6%)
1981	7	(11.9%)
1982	10	(17.0%)
1983	10	(17.0%)
1984	8	(13.6%)

The rise in the rate of establishment of registers in the decade between 1974 and 1984 is at first sight surprising. For this is precisely the period is which the money available to Health and Local Authorities for development has been dwindling.

Moreover no official body has given registers of mentally handicapped people its wholehearted support. Though it felt that there was much in registers to commend, the NDG did not consider that planning groups necessarily needed to set up new registers to find out exactly who they would be providing services for (1976).

The Review of the 1971 White Paper was lukewarm. It made no recommendation about whether more registers should be set up but left this question open to local bodies to decide for themselves in the light, amongst other things, of "the considerable cost involved" (DHSS, 1980). This remains government policy.

A final reason for surprise at the recent proliferation of registers is that registers can easily be regarded as something of a luxury. The most urgent need is for an extension of, and radical change in, the services which mentally handicapped people receive. A register is not itself one of these services - it is at least one stage removed from them. So one might expect that Authorities would not regard registers as a priority. It is noteworthy that in all the interviews with those involved with registers this point was almost never raised.

So much for the countervailing pressures. In this chapter I shall describe the economic and organisational factors which have made the recent rise in the number of registers possible. This will give a basic characterisation of the object of research.

Most of the registers in England cover areas which coincide with the boundaries of single Health or Local Authority Districts (see Table 2).

TABLE 2   AREAS COVERED BY ENGLISH REGISTERS

Health District and Metropolitan Borough/County (where these coincide exactly)	12	(20%)
Metropolitan Borough	11	(19%)
Health District	9	(15%)
County	8	(14%)
Some other geographical unit	19	(32%)
Total	59	

Of the 19 registers not covering areas coterminous with those under the aegis of the main tier of local government, one covers a Health Region, three cover areas roughly equivalent to a County or Health or Metropolitan District and the remaining 15 (25% of the total number of registers) cover parts of Health or Metropolitan Districts - often Social Services areas - and most are closely linked to the work of Community Mental Handicap Teams or Specialist Social Workers or Community Nurses.

Only eight registers (14%) had staff working on them full-time. All but one of these cover areas corresponding to the main tier of local government administration - shire-counties, health or

metropolitan districts. The three registers with the largest number of subjects have at least one member of staff working on them full-time. There are 24 registers (41%) maintained by a single member of the register staff working part-time. Of these, 18 cover shire-counties, health and metropolitan districts; 5 of these 18 have more than 1000 subjects. Of the 40 registers covering health or metropolitan districts or counties, 18 (45%) are operated by one member of staff working part-time and 7 (18%) by one member of staff working full-time on the register.

The completed postal questionnaire revealed no discernible difference in organisation between those registers financed by Health Authorities and those financed by Local Authorities or between those staffed predominantly by Health Service personnel and those with mainly Local Authority personnel. This was confirmed in the interviews.

Of the 59 registers in the postal survey of English registers, 32 (54%) were on computer and 26 (44%) were kept manually. The great advantage of computers over manual data-bases is that information can be quickly and easily stored and extracted. The three oldest computerised registers - first used in 1963, 1967 and 1968 - were funded respectively by a Regional Health Authority, the Medical Research Council and a number of bodies including the DHSS. In the 'sixties the establishment of a computerised data-base was very much more costly. This was probably why the earliest registers were not funded by the Authorities which ran them but needed external funding of some type. However, in the last ten years a number of registers have been set up with Health or Local Authority Funds. Peter Donaldson (1982) graphically illustrates the drop in the price of computers:

"If the car industry had been able to reduce its
price and size of product, and increase its efficiency
at the same speed (as in microelectronics), a Rolls
Royce would today cost £1.45, would do 3 million miles
to the gallon and six of them would fit on a pinhead."

Moreover it is now possible to operate on a microcomputer a register holding substantial information on anything up to 2000 mentally handicapped people (Farmer and Rohde, 1983). So capital expenditure on a register may now be less than £10,000. The falling price of computer facilities may well have facilitated the recent register boom. Computers are the office-tools of the future. One register-operator said that his register was being revived as an experiment in the use of computer-based records. Computers are also fashionable and this may have been a contributory factor.

In recent years there has been a mushrooming in the development of computerised data-bases on client-groups living in the community. The NHS Child Health System with its child register, immunisation and vaccination, pre-school health and school health modules reduces clerical chores by providing details on individual children and arranging appointments, but it is not primarily a planning tool. The same applies to cervical cytology recall-systems and computer systems operated by Family Practitioner Committees and General Practitioners. However, handicapped child and psychiatric registers have resembled mental handicap registers in that they are essentially planning tools. The greater availability of computers coupled with pressures for more rationality in planning has led to their proliferation.

Mental handicap registers are now relatively cheap: many are operated by one member of staff part-time. The computers needed are comparatively inexpensive. Registers have even been set up to cover only parts of Health Districts. So all in all, they are decidedly less expensive than some other parts of a community-based service.

This must have been an important consideration for Authorities looking
into the possibility of setting them up.

Collaboration and Specialisation

There have been a great number of facets to the growth in
collaboration at various levels of the mental handicap service. One
of them is Joint Finance. Introduced in 1976-1977, it has provided
the means for the establishment of many registers (DHSS, 1976; DHSS,
1977). It accounts for much of the increase during the 'eighties (see
Table 3). It supports over a quarter of the registers currently in
operation. The high proportion of registers funded by the Local
Authority may in part reflect the fact that Social Services
Departments take over funding at the end of a period of Joint Finance.

TABLE 3   DATE OF FIRST USE BY FUNDING AGENCY

Date of First Use	Funded by the H.A.	Funded by the L.A.	Receiving Joint Finance	Funded in some other way
1963				1 (1.7%)
1964				
1965				
1966				
1967				1 (1.7%)
1968				1 (1.7%)
1969				
1970				
1971				
1972				
1973				
1974		1 (1.7%)		
1975	1 (1.7%)			1 (1.7%)
1976				1 (1.7%)
1977		1 (1.7%)		1 (1.7%)
1978		4 (6.8%)		
1979		2 (3.4%)		1 (1.7%)
1980	3 (5.0%)	1 (1.7%)	3 (5.1%)	1 (1.7%)
1981	2 (3.4%)		5 (8.5%)	
1982	2 (3.4%)	3 (5.1%)	5 (8.5%)	
1983	2 (3.4%)	4 (6.8%)	1 (1.7%)	3 (5.1%)
1984	2 (3.4%)	4 (6.8%)	2 (3.4%)	
Total	12 (20.3%)	20 (33.9%)	16 (27.1%)	11 (18.6%)

The hypothesis that the availability of Joint Finance is a reason for the large number of registers in England will be corroborated if there are fewer registers in a country which resembles England as far as possible in all relevant respects except that it lacks anything which quite corresponds to Joint Finance. Scotland is such a country and the indications are that the development of registers there is less advanced. This comparison of Scotland and England is a clear-cut case of "ex post facto" research which resembles experimentation in that it involves the comparison of two situations which are as similar to one another as possible, except that a crucial variable is present in one but absent from the other. However the method differs from that of a true experiment in that the main variables cannot be manipulated but have to occur naturally.

TABLE 4   NUMBERS AND PERCENTAGES OF AGENCIES
                       WITH REGISTERS

	Total	Having Registers
Social Services Departments in England & Wales	115	44 (38.3%)
Social Work Departments in Scotland	12	2 (16.7%)
Health Authorities in England and Wales	202	54 (26.6%)
Health Boards in Scotland	15	6 (40.0%)

The differences between the percentage of Social Services Departments and Social Work Departments with registers (21.6%) and between Health Authorities and Health Boards with registers (13.4%) are not statistically significant.

TABLE 5   NUMBERS AND PERCENTAGES OF AGENCIES
                 INVOLVED IN PLANNING REGISTERS

	Total	Involved in Planning Registers	
Social Services Departments in England & Wales	115	45	(39.1%)
Social Work Departments in Scotland	12	3	(25.0%)
Health Authorities in England and Wales	202	96	(47.3%)
Health Boards in Scotland	15	3	(20.0%)

The difference between the percentage of Social Services Departments and Social Work Departments planning registers (14.1%) is not statistically significant; but the difference between the percentages of Health Authorities and Health Boards planning registers (27.3%) is statistically significant (p<0.05).

TABLE 6   NUMBERS AND PERCENTAGES OF AGENCIES WHICH EITHER HAVE
             OR ARE INVOLVED IN PLANNING REGISTERS

	Total	Having or involved in Planning Registers	
Social Services Departments in England & Wales	115	87	(75.7%)
Social Work Departments in Scotland	12	4	(33.3%)
Health Authorities in England and Wales	202	145	(71.8%)
Health Boards in Scotland	15	9	(60.0%)

The difference between the percentages of Social Services Departments and Social Work Departments having or planning registers (42.4%) is statistically significant (p<0.01); but the difference between the percentages of Health Authorities and Health Boards is not.

Though Tables 4, 5 and 6 show apparently higher levels of register activity in England and Wales than in Scotland, some caveats need to be made. First, the replies on which the tables are based have turned out to be inaccurate in some respects. Secondly, the number of agencies compared are quite different (12, 15, 115 and 202). Thirdly the size of the population for which Social Work Departments in Scotland have responsibility vary enormously - from 2,431,000 in Strathclyde to 18,000 in Orkney. However, Social Work Departments and Social Services Departments are corresponding administrative units in many ways and the average sizes of populations for which they have responsibility are comparable.

There are other indicators of a lower level of development of registers in Scotland: there is no computerised register in use there, while 32 (54.2%) of the English registers were on computer; none of the Scottish registers receives Support Finance though 16 of the English ones receive Joint Finance (the equivalent of Support Finance).

The only relevant difference in the health and social services of the two countries is that there is less effective collaborative machinery - in particular, financial incentives for collaboration - in Scotland. This provides an explanation of why Scottish registers appear to be lagging behind those in England. Section 10 of the NHS Reorganisation Act 1973 requires Authorities in England to set up Joint Consultative Committees (JCCs) (Act of Parliament, 1973). Four years later a circular recommended the establishment of Joint Liaison

Committees, the equivalent of JCCs, in Scotland (Scottish Home and Health Department, 1977). But this does not have the force of law. In 1977 a DHSS circular recommended that Joint Care Planning Teams (JCPTs) should be set up to advise JCCs (DHSS, 1977). The circular also suggested the formation of a JCPT sub-group to look specifically at services for mentally handicapped people. This circular seems to have had an impact: a survey of the 90 AHAs in England in August 1978 revealed that almost all had JCPTs and just over half had mental handicap sub-groups (Plank, 1979). However, the Scottish Home and Health Department has not made any similar recommendations for the establishment of joint-officer bodies to plan services. Support Finance which is equivalent to Joint Finance was introduced in Scotland in 1980 - three years after the introduction of Joint Finance (Scottish Home and Health Department, 1980). The money available under Joint Finance is substantially more than that available under Support Finance. In 1982-3 the money available for Support Finance in Scotland was £2m. gross and £0.39 per capita, while in England the corresponding figures for Joint Finance were £84.7 m. and £1.82. In the following year Scotland's allocation was nearly doubled, but it was still nearly three times less than England's on a population basis (Farquharson, 1983).

The striking increase in the number of JCPT sub-groups for Mental Handicap since 1976 may also have been a factor leading to the proliferation of registers. In 1976 only 6% of Authorities had established JCPT sub-groups for Mental Handicap, while in 1982 the comparable figure was 68% (Wistow and Fuller, 1983).

The moves away from fragmentation and towards specialisation at the operational level have sometimes been decisive. Sometimes it is the creation of posts or sections in administration devoted to mental handicap which provide the spark (cf. Cadbury, 1982). A register

covering one of the six areas administered by a single Social Services Department was set up when the four patch-teams covering the area were replaced by four specialist teams, one of which had responsibility for mentally and physically handicapped people. This reorganisation led to a greater focus on mentally handicapped people which in turn brought about the establishment of a register. The appointment of specialist social workers and community nurses can give rise to the compilation of registers for similar reasons. A respondent to the 2nd August circular wrote:

> "Two geographical areas within the county have begun to maintain mental handicap registers and it is significant that this information gathering has only been attempted where a specialist social work service has been established for the mentally handicapped."

The importance of CMHTs for the development of registers has already been discussed. A significant number of respondents to Dr Adam's circular of July 1982 wrote of their own accord that the establishment of a register was linked to that of a CMHT. The teams provided a vehicle for the collection of data for registers. So several have been set up with the establishment of a register as one of their tasks. Sometimes CMHTs themselves have decided to set up registers:

> "The setting up of a register goes hand-in-hand with CMHTs... It seemed a logical first step to the CMHT Senior Social Workers to set up a register to find out the nature of the problem."

> "The Teams felt that some record ought to be maintained... the registers were drawn up with a minimum of direction from the centre... They grew naturally out of the core teams."

The establishment of a CMHT highlights the total needs of the mentally handicapped people in a given geographical area; and it is a small step from this to the decision to set up a register.

A disturbing number of interviewees said that their registers had been set up in part at least because registers were being set up elsewhere. Here are a few remarks made in reply to the question "Do you know why the register was set up?":

"Registers were the 'in' thing at that time."

"Also registers were - are - trendy."

"Everybody else seems to be doing it."

"I think the main driving force behind doing anything like this was because someone else had done it as well."

"Perhaps also in the back of our minds the idea was that registers were a good idea - full stop - they were things that other places had."

There is no harm in an Authority looking into the possibility of setting up a new facility like a register because others have them or have found them useful. But this must always be followed by careful consideration of how such a facility would fit in with conditions in the District in question - what contribution it would make, how it would best be organised in view of local circumstances. The mere fact that some Authorities have set up registers is not a sufficient reason for any other Authority to do so. Three of the five interviewees who said that their registers had been set up because others had done so had seriously flawed registers - in one case the register was two years out of date and in another it was incomplete. In a further case a Specialist Social Worker was appointed with one of his tasks being to set up a register because it was felt to be a useful tool. However, the post-holder said that there were no clear objectives for the register prior to his appointment. Blindly setting up a register is plainly not sensible.

How Registers are Planned and Set Up

The last section pointed to the tendency to set up registers blindly. There is certainly evidence that many Authorities set up registers without an adequate knowledge of how they have functioned elsewhere.

Authorities frequently hear only about those registers which have been in existence a long time. Though contact with them and visits can be useful, longer-standing registers very often have methods of data-collection which are more costly and require more staff-time than most Authorities can afford. They use large computers which could be replaced by microcomputers and they collect scores on Kushlick's Wessex Scale. It is too seldom that Authorities find out about the more cheaply run registers which are more integrated with the rest of the service.

The first phamplet produced by the NDG (1976) suggests that Authorities wishing to explore the possibility of a register should approach the DHSS Statistics and Research Division for advice. The standard response of this Division has been simply to put enquirers in touch with two long-standing registers which in the opinion of the Development Team (itself also under the umbrella of the DHSS) are far from exemplary.

Staff given the task of planning registers tend to find out about registers elsewhere to a considerable extent by informal contact and word of mouth. As a result the information they gather is haphazard and registers which might be useful models remain unknown. Often developments in neighbouring Authorities are not easily heard about. In reply to the circular of August 1983 a Specialist in Community Medicine requested details of registers elsewhere in his Region so that his Authority could look into the possibility of setting one up. The fact that he needed to ask an outside body is significant.

There is a tendency to spend a great deal of time debating issues which have been resolved elsewhere - in particular, criteria for a mentally handicapped person. A few locally-produced planning documents give evidence of an extensive consideration of rival legal, clinical, psychometric, educational and sociological definition of "mental handicap" though they almost invariably conclude by adopting essentially an administrative definition - that is, one which is formulated in terms of the use of specialist mental handicap services. If it were more generally known that almost all registers use an administrative definition and that such definitions are quite adequate for planning purposes, much unnecessary deliberation could be avoided. Hopefully the criteria given in **Standardisation of District Mental Handicap Registers** (1983, p.4) will become known to those Authorities wishing to set up registers.

Registers are a comparatively recent development; they are less likely to be generally known than more established features of the service. So it is almost inevitable that Authorities planning registers should not find out about all those whose experience they might benefit from. However the novelty of registers does not wholly account for the limited level of dissemination of information about them.

Information-exchange or direct contact between Social Services Departments and between Health Authorities tends to be slight because of the lack of organisational links; where it exists it tends to be informal. There is no centrally kept record of all innovations in the mental handicap service throughout the country. The DHSS, the King's Fund and the DT accumulate information which, though useful, is not comprehensive. There is a special need for pooling information on innovations in the mental handicap service, especially because so much of what Authorities are now planning is innovation. In fact lack of

communication about innovation and good practice in the mental handicap service has been remarked upon elsewhere (Independent Development Council for People with Mental Handicap, 1984). The emphasis in the All-Wales Strategy on sharing ideas is, therefore, to be welcomed. The Welsh Office has a very active role within the strategy. Its functions include providing guidance on the preparation and implementation of local plans for the implementation of the strategy, encouraging the pooling of ideas and information and disseminating good practice and monitoring and evaluating the development of services to ensure, amongst other things, that lessons learnt are applied to successive phases of development (Welsh Office, 1983). To carry out these functions the Welsh Office will need to be up-to-date on innovations being made within the Principality. At county level, lessons learnt nationally in the implementation of the strategy should be made known and applied to the development of services at the local level; and good practice should be generally disseminated (Welsh Office, 1983). At the moment Regional Health Authorities would be quite unable to tell any Local or Health Authority where in the Region there were mental handicap registers. At least one other study has pointed towards the value of Regional Health Authorities acting as clearing houses for ideas on mental handicap services (Glennerster, H [forthcoming] **Darenth Park Project: Regional Strategic Planning**). They might hold day-seminars or conferences for people setting up new services such as CMHTs and new types of residential care.

The ignorance of Authorities planning registers about parallel developments elsewhere seems to be an instance of a widespread tendency not just in services for mentally handicapped people but in the social services generally. The establishment of the Practice and Development Exchange by the National Institute for Social Work to

promote effective exchange of information is, therefore, to be applauded. Even outside the social services, there is a tendency for dissemination of innovation to be weak. The Plowden Report makes a point which will sound very familiar to those concerned with innovation in the Health and Social Services:

> "At the local level, schools in adjacent areas may be engaged in interesting innovation, the results of which are never made more generally known or evaluated. A more comprehensive service for disseminating the results of research at all levels seems to be required." (Central Advisory Council for Education [England] 1967, Section 1159).

The importance of ensuring the utilisation of register data is not sufficiently appreciated. Almost none of the planning documents that have been accumulated in the course of this study gives consideration to possible means of ensuring that the greatest possible benefit will be derived from what is held on the register. Lack of use of register-data will emerge as perhaps the major limitation to the contribution that registers have made.

Conclusions

The first chapter outlined some of the major developments in social policy which have made the establishment of registers possible. These developments cannot alone explain the acceleration in the rate at which registers have been set up during the 'eighties. The explanation is to be found in the coincidence of three factors : the introduction of Joint Finance; a reduction in the price of computers to a level at which they can easily be bought by Health Authorities; and organisational developments – the appointment of CMHTs and JCPT Mental Handicap Sub-groups – from which registers arise naturally.

This consideration of the specific reasons for the current number of registers shows that the compilation and subsequent operation of a register is not a great undertaking with significant "opportunity costs". Capital expenditure on a register is no longer as great as it was and, together with some of the revenue expenditure, is available to Authorities from outside their normal financial allocations. Registers can be operated by a single member of staff working part-time and may even cover areas much smaller than a Health District. They can develop naturally as by-products of new organisational structures aiming to give better patient care. Authorities, though, have on occasions set up registers without sufficient knowledge of the options open to them. But, to sum up, the outlay needed to set up and run a register is small; and the remaining chapters will look at whether it is worthwhile.

Introduction

As a prelude to the consideration of the role of registers in planning, this chapter will examine possible drawbacks in their operation. Two questions will be answered: are the main methods of maintaining registers practical and not extravagant? are there moral objections to registers as data-bases holding personal information?

The Methods of Data-Collection

Registers use one or more of the following three methods of data-collection.

1. Register staff collect information by scanning case-notes and talking to professionals and perhaps clients and their families.

2. Staff in the field are called upon to send written updates to the register staff at regular intervals.

3. The register receives information through data-generating processes which have functions as well as that of providing information to the register.

Method 3 includes:

3a. The records made by staff in the field for the purpose of individual case work also provide data for the register.

3b. Multi-disciplinary reviews occur at regular intervals and data which come up at these reviews are fed into the register.

Methods 1 and 2 are alternatives. Under method 1 the onus for data-collection is on the register-staff - they go to professionals, subjects and families to collect data - while under method 2, the onus

is on staff outside whose responsibility it is to send data to the register.

Where method 1 is used one can guarantee that the register will be updated when it is supposed to be. There will also be far fewer people collecting data than under method 2. So there might be a higher level of consistency of interpretation of the questions to be asked. Moreover the staff collecting data would be register-staff whose major task it would be to collect the data. So they would be fully committed to the maintenance of the register and to ensuring its accuracy. In its extreme form the case for method 1 was put as follows:

> "Our experience is that where you rely on service personnel (the register) is neither accurate, reliable nor comprehensive. These are the three things an information system is aiming to do well... We take all the initiatives."

The accuracy of data collected under method 1 should not be over-estimated. Though it can provide as accurate a picture of a mentally handicapped population at a single point in time as any other method, it does not allow the record of data to be changed as changes occur in the situation of the subject concerned unlike method 3. So if method 3 is effectively employed it can provide a more up-to-date record than method 1 which relies on updates taking place at regular intervals. Under method 1 register-staff use as sources not the real data but staff who know the subject concerned and case notes. This provides an opportunity for misunderstanding which is not present when the professionals who know the client collect the data.

Visits to families have been found to be very time-consuming. A register which has two staff employed full-time to visit establishments and families to collect data has found that interviews with families take substantially longer than interviews with care

staff because families like to talk about the experience of having a mentally handicapped child and the difficulties that they have had. In fact staff of several registers who have visited families primarily for the purpose of data-collection have taken on other functions:

> "The length of home visits varied between 15 minutes and nearly 2 hours depending on the needs of the family being interviewed. For some clients the register visit was the first contact for many years and it provided an opportunity for the expression of feeling by some parents regarding services for their mentally handicapped child. As a result of the home visiting, the Research Officer referred cases needing further support to the Community Nursing Officer for Richmond Borough and the Senior Social Worker for Kingston Borough." (Gardner, 1981).

> "Most families appear to have been pleased to have the chance to tell someone about their problems and needs." (Devon County Council Social Services Department, 1977).

By giving information, counselling and making referrals to professionals, these staff are performing a valuable service. However, since they have been given the task of collecting data, they are often unlikely to have any special training for these informal services to families. Ideally, then, the additional roles taken on by register-staff who collect information on home visits should be performed by professionals such as the members of CMHTs. In fact one of the first tasks attempted by a few CMHTs has been to use method 1 to carry out surveys of mentally handicapped people in their patches. Method 1 is an accurate means of maintaining a register though it may not involve the best use of staff-time. Few registers being set up nowadays use method 1 because at least one full-time member of staff is likely to be needed to collect the data.

Many registers which have adopted method 2 have been accurate enough for their purposes which have mostly been service-planning. For a single update of data held on a subject under method 2, all that

would be required would be that a single member of staff who knows the subject well would send in an update. Under method 1 the time of two staff may be involved in the update if the register staff need to interview professionals to obtain data; and instead of the cost of postage there is the time and cost of the travel to the professional and even the family. In other words, method 2 - the use of essentially a postal questionnaire - is less costly than method 1 which requires face-to-face interviews. A disadvantage of method 2, however, is that a variegated mass of staff are relied upon to provide information. Some of them may be inefficient; they may not all interpret the questions in the same way. The question of how much staff outside the register have cooperated in the supply of information will be looked at later on. As far as accuracy is concerned, it should be said that many registers using method 2 have been found to be accurate enough for their purposes. Moreover registers used primarily for service planning do not need the accuracy of those geared towards epidemiological research.

Q. "Is the information on the register generally accurate enough for its purposes?"

A. "Broadly speaking, yes, when you bear in mind it's only meant to be a planning tool. There are the... minor inaccuracies and the fact that some things are always out of date is less important when it's all aggregated up. It's swings and roundabouts."

"If it's even ten or fifteen percent inaccurate it's still well worth having... and it's... very useful."

Method 3a is only feasible when the staff supplying information have contact with the great majority of the mentally handicapped people in a given geographical area. It has been used successfully by CMHTs and specialist social workers. Peripatetic professionals are expected to record in their case-notes changes in basic details

(address, marital status and so on) and in services used. This serves as an aide-memoire for the professional in the course of his dealings with the client concerned and it enables the professional's colleagues to help the client effectively if he is referred. In other words, the record of basic and service data on clients routinely kept by peripatetic professionals is maintained and has an important function, whether or not a register is maintained. So if professionals have contact with the mentally handicapped people in a given geographical area, a register holding basic and service details can be maintained relatively painlessly: professionals note changes as they normally would and this information is transferred to the register. It may be that professionals note changes in their case notes and these are transferred to the register by clerks; or that they announce any changes at meetings for the information of their colleagues and these changes are then recorded on the register; or that they make the changes to the register themselves. Though fieldworkers are in the habit of noting changes in personal and service details as they occur in the course of case-work, they are not used to recording in the same way other changes in the information held on clients - for example, scores on Kushlick's Wessex Behaviour Rating System. In more than one case it was found that fieldworkers were more efficient at notifying changes in personal and service information than changes in behavioural assessments when called upon to notify the register of changes as they occured and not at regular intervals. Collection of scores on Kushlick's Wessex Behaviour Rating System would appear to be more satisfactory if method 2 is used. For then register operators would know whether or not scores have been updated. Method 3 seems to have been more successful, when data-collection has been the responsibility of a small group of staff specialising in mental handicap rather than an amorphous mass of personnel.

If every mentally handicapped person in a district is given a multidisciplinary review, a register can be maintained at almost no cost. Personal and service data will be assembled at the review-meeting; and judgements will be made about clients' needs. All this information could simply be stored on a register. Reviews are often organised so that personal and service data and review assessments are recorded whether there is a register or not. The maintenance of the register will then be simply a question of transferring data from one record to another.

This method of data-collection is consistent with one of the basic recommendations of the Korner reports, namely that information for use in planning and management should be obtained as a by-product of existing operational procedures (Steering Group on Health Service Information, 1982).

There are a whole range of benefits from integration with the service which is essentially a feature of registers which used method 3. Visits by staff of registers using method 1, no matter how carefully prepared and tactfully executed, must to a greater or lesser extent interrupt the day-to-day work of the service providers. Similarly requests for information from registers which use method 2 may be felt by the staff who receive them to be unrelated to their normal work. With method 3 there is not the same gulf between data-collection for the register and the provision of service. A Specialist Social Worker who operated a register which relied primarily on method 3a made a similar point when comparing his register with one using method 1:

> "I could see defects in that register... They had a register which... was separate from anyone who was actually working in the field whereas what we've gone for is a register that is located where the workers are... the updating is better... If the clerk who's doing the Team typing and seeing the files regularly has got the files in the same room, that updating happens almost automatically."

At least one major objection can be made against this method: it is that it is not worthwhile to make regular visits or to carry out regular reviews of all mentally handicapped people living in a District. Many CMHTs and Social Services Departments do not have the manpower for this. The Development Team does not advocate comprehensive coverage of the mentally handicapped population by CMHTs (1982). However the members of several CMHTs strongly favoured comprehensive contacts:

Q. "If you had the staff... would you like your Teams to be in touch with all the... mentally handicapped people in the county?"

A. "Yes, most definitely... If a family is less demanding or is maybe just basically known I think there should be definite visits, be that one six-monthly... or annually.."

Q. "... What do you see as the benefits of contact of a Community Mental Handicap Team with people who aren't necessarily presenting problems?"

A   "... A family may well be more than capable and... doing... an excellent job in relation to caring for this mentally handicapped person, but the inevitable day comes when in fact they're no longer... or a death in the family or whatever, and if there isn't somebody in contact with this end identifying and actually anticipating... human frailties - people just not being able to cope quite as well as they (could)... How many mentally handicapped people are in the community that we don't really know about? - Because we had a true emergency presented to us one weekend when in fact nobody knew anything about this person at all, and yet this person was in his late twenties and had remained at home and there was no contact with any particular agencies and in desperation, as it were, our 'phone number here was acquired and the biggest help you can imagine... was asked for. Now that is one example of how... If there had been contact then definite anticipation and even to the point of encouraging short-term care because many parents... need assistance, guidance, help, whatever".

"There are lots of people who are quite convinced they don't need short-term care or don't want an ATC place and they can say so quite adamantly... and yet within a year their circumstances have changed and they would very much like to be offered it again. I think it's insufficient to rely on the fact that they will come to you again. I think you've got to go and offer again to have things changed... I think the people who aren't using services are strangely a very important group to keep your eye on because their needs do change."

A CMHT member pointed out a further advantage of this total coverage of mentally handicapped people – namely that everyone will know as a result the services available and how they are being developed. There is then considerable support at grassroots level for the view that a group of specialist mental handicap professionals in the community, such as a CMHT, should aim to have contact with all the mentally handicapped people in their area. This will bring benefits quite apart from enabling the professionals to note changes to the clients' situation as they occur (cf. Independent Development Council for People with Mental Handicap, 1982, p.25). Multi-disciplinary reviews at which the needs of a mentally handicapped person are assessed provide a means of guiding his development. They facilitate coordination of services which might otherwise be highly fragmented. All the professionals working with an individual client should meet at a review. Each can find out what goals the others have for the client and how they see his problems. The inputs of the different professionals can be integrated and a plan agreed. A further benefit of the review system is that it ensures that clients' needs are highlighted. Regular multi-disciplinary reviews of clients who may not be presenting problems can have a useful preventive role. A Social Services Officer felt that this justified the considerable cost of the reviews given by his Department to the users of day and residential establishments:

> "(The review process) is a useful injection of resources because traditionally we would play at fire-engines rather than fire-prevention officers... We are doing much more work as the fire-prevention officers and spending very very little time rushing out as fire engines."

> "(Reviews provide) a pre-crisis intervention. If someone's got a problem... coming up... and it really has not got to the point where it's a crisis, the team can intervene."

If multi-disciplinary reviews are to have this preventive function, it is quite reasonable to give reviews to all the mentally handicapped people in the District. In fact there was considerable support for this. At least one register was based on multi-disciplinary reviews which were given to all the mentally handicapped people with whom a CMHT was in touch.

The review of the methods of data-collection used by registers shows that, though each has its advantages and disadvantages, none is excessively impractical or expensive. But all depend to a greater or lesser extent on staff outside cooperating in the supply of data. These staff may belong to a range of professions and even agencies. The crucial question of how far staff outside have cooperated will be looked at in detail in the next section.

Cooperation from staff called upon to supply data to the register

The dependence of registers, especially those using method 2 on data supply from a variety of sources, cannot be overstressed.

The postal questionnaire revealed that most registers seemed to receive a high level of cooperation from the agencies which supplied them with information. Of the 49 registers to which more than one agency contributed information, 29 (59%) were wholly positive in their comments about the cooperation that they received; of the other 20 the majority seemed to be generally satisfied. Criticisms on the postal questionnaire tended to be made only of a particular agency or professional group.

There was only one respondent whose register appeared to have serious problems through lack of cooperation:

"The keeping up-to-date of the register is the most difficult part of keeping a register."

Sometimes doubts about the confidentiality of the data and the subjects' privacy are responsible for unwillingness to cooperate in the supply of data. A respondent in the process of setting up a register wrote on the postal questionnaire that the confidentiality of information obtained by other statutory agencies had prevented exchange of information. Staff are also hesitant about supplying information when they know that it will be computerised. A register which used method 1 found that fear of redundancy, fear of criticism, and a deep-seated cynicism about activities like data-collection for a register lay behind the few instances of reluctance to cooperate that were encountered.

Registers can place a heavy burden on staff in the field by requiring them to complete regularly lengthy questionnaires including, for example, a Wessex Behaviour Rating System:

> "On the annual updates when they receive ten or perhaps 20 forms, that'll be a bit of a burden for them... Or an Adult Training Centre Manager who gets fifty or sixty of them perhaps... (Staff themselves regard it as a burden)... The only solution to that is to do a continual update initiated from the centre - 10% every month... But... to be able to do it that way... you need somebody working permanently on the Index... I believe the Index is a good thing and take the trouble to do it. We haven't had anybody complain about being asked to do it, they've complained that there's a lot to do and that it will take them time and this sort of thing."

The burden on staff outside can be substantially reduced if the computer software can be so arranged that they can easily be sent printouts of data held rather than questionnaires, so that all that they are required to do is to make changes as necessary - which is much less time-consuming than completing a whole form from scratch. This method has been successfully used by a number of registers.

Sometimes staff fail to give an adequate supply of data for reasons other than scepticism or lack of goodwill towards the register. Two respondents to the postal questionnaire wrote:

"The amount of cooperation has been reasonable, once (the Core Teams) spent time helping the project. The problem is getting them to spend time on it."

"Reasonably good cooperation from all agencies in principle at least - Social Workers and others don't feel like filling forms so there may be a gap between goodwill and practice."

Register staff often have no authority over staff in the field who may well be in a separate part of their department or even in a different agency. For example, several registers are operated by research, planning and information sections of Social Services Departments. They may rely upon a supply of information from field-workers:

"One of the things one has to remember if you're working in research and on this sort of thing is that you keep a nice line and you don't cross it... into social work or administration. It's quite a tightrope to walk because you have to cooperate and sometimes cajole Social Workers, but you have no jurisdiction over them. So it has to be done on a... tactful basis. But they're very cooperative..."

"The disadvantage... is that it does require securing commitment from a large number of people and there's a limit to what you can do through managerial authority because you don't have control over half the staff... you can't instruct health staff..."

A busy employee of a Health or Local Authority will often treat work on the register as one of his lower priorities because it is less urgent than some of his other commitments and not essential to most of his immediate tasks. A Specialist Mental Handicap Social Worker who was responsible for a register said:

"If someone rings you up and says 'I've got a problem' then you're under pressure to deal with that problem. The register is one of those items which you have not got to deal with today. You can always do it tomorrow - which tends to mean that its updating is less frequent... than I would like it to be."

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In the responses to the postal survey, GPs were singled out most frequently for their reluctance in providing information. A comparatively small number of respondents indicated that GPs provided information. So it would seem that the chances of encountering unwillingness among GPs are particularly high. The lack of cooperation from GPs was explored at the interview-stage. It was pointed out that GPs, unlike others called upon to supply information, did not spend a large proportion of their time in mental handicap, that they did not have the time to deal with the requests and that they tended to be sent masses of documents which they had little time to give attention to.

The Education Department was cited in the postal survey next most frequently as uncooperative. One can only conjecture about the possible reasons. Education Departments have less need of registers than Health Authorities or Social Services Departments - this will be explained later - and they may feel sometimes less committed to maintaining them. Under the 1981 Education Act, Education Authorities are obliged to make assessments of children whose needs are, or probably are such as to require Authorities to determine their special educational provision. The focus is on the individual, rather than the disability, and the assessment is of special educational needs and the provisions to meet them. Authorities, therefore, are not called upon to specify whether children are mentally handicapped or not. This together with a general reluctance to dub children 'mentally handicapped' may lie behind some of the complaints about lack of cooperation from the staff of Education Authorities.

Social Workers have been found to be unreliable sources of information. This emerged in the interviews rather than the responses to the postal questionnaire. The operators of two London registers said that they found those in charge of day and residential

establishments more efficient at providing information than field social workers:

> "With the superintendents... I would say we would both have a fairly good working relationship... field services is different altogether because the Social Workers are extremely hard-pressed and although there is a willingness to assist because they know it's going to be beneficial in the end, but the work - they just don't want to take any more work on at all."

> "Social Workers are slower in returning forms than staff at day and residential establishments... They see the register as just another paper exercise... staff at establishments, on the other hand, see their role as including information."

These remarks were echoed by the operator of at least one other register. It may be that generic Social Workers feel less commitment to the register than specialist ones, who are more likely to feel the benefits of the register, and that the criticisms were directed mainly at generic Social Workers. A number of registers have been very effectively maintained by Specialist Social Workers.

Paediatricians are often reluctant to label children under five as 'mentally handicapped'. A number of registers have therefore decided to limit their registers to the over-fives (Doncaster Health Authority, 1983; Ealing Health Authority, 1983; Farmer and Rohde, 1983). Registers which have attempted to include under-fives have experienced difficulties as a result. The following comment probably describes a common state of affairs:

> "Below four we have a great difficulty of picking up mentally handicapped children at a very early age, because of problems with paediatricians not making diagnosis, lack of liaison with the Health Department because of medical confidentiality... It is only usually when they in fact need to be assessed for educational purposes... that... tells us: 'here's a mentally handicapped child'."

It is apparently not always clear whether the retarded development of pre-schoolchildren is due to mental handicap and not some other cause. So doctors not unreasonably do not wish to classify them.

In two cases the readiness of relatives to cooperate was mentioned:

"Families so far contacted have been very positive about the project."

"Parents and relatives have been the best source of help with the minimum of fuss."

This confirms indications elsewhere that relatives are more enthusiastic about registers than many professionals and others believe.

Cooperation from outside can be raised to a very satisfactory level if efforts are made to promote the register. In fact if any message can be extracted from the responses to Question 9 on the postal questionnaire, it is that to the extent that staff outside the register are relied upon to provide information, register-staff should take positive action to encourage them to provide it.

Methods 1 and 3b are often such as not to require much time and effort from anyone apart from those responsible for the maintenance of the register. Efforts to ensure the cooperation of staff outside will not need to be so great. Method 2 usually requires a fair amount of time and commitment from staff outside. It correspondingly requires more efforts from the register staff to ensure cooperation. If method 3a is such that data-collection is the responsibility of a small group of professionals who have a special commitment to mental handicap and the register and collect data smoothly in the course of their work, less effort is needed than if a range of professionals who may sometimes not be specialists in mental handicap are called upon to

notify the register of changes as they occur or if they are responsible for maintaining a substantial body of information about each subject. Explaining the register as early as possible to everyone involved in the service and involving as many agencies and professional groups as possible in planning and management have been effective means of securing cooperation. Also it was clearly apparent from both the postal questionnaire and interviews that information-supplying staff need to be informed about the register - in particular, its purposes and the rules governing access to it - and to be given evidence of its value. On the basis of a study of all types of registers of patients used in health care, Brooke (1974) concludes that the staff of registers in general should have substantial contact with the staff who provide them with data. This contact should be personal and information-supplying staff should be consulted and made aware of the value of the register.

The dependence of registers on a range of staff does not present insuperable problems. By and large, registers have received adequate cooperation. The personnel who have tended not to supply data as requested - GPs and staff in the Education Department - are not normally the sole repositories of much crucial information for the register. It has probably not normally been worthwhile to try to keep a complete record of mentally handicapped pre-school children. But this is not a serious limitation: such information is only a very small part of what is required in the planning of mental handicap services.

Registers which have fallen into neglect

Though registers have been maintained, apparently effectively, at little expense and with no serious practical problems, the fact

remains that a disturbing number have lapsed. This may undermine their value as planning tools.

It should be stated at the outset of this section that the data collected do not allow a statement of the major reasons for the discontinuation of registers. The question was not broached in the postal questionnaire. In the interviews it was raised where appropriate. But interviews were not conducted with a representative sample of register-operators and the reasons for the neglect of a single register can easily be given different interpretations by different staff. The most that can be said with any degree of confidence is that the termination of temporary arrangements - in particular, funding - for a register is often a reason for its demise. Whether other factors are equally or more important is unclear.

The tendency for registers not to be updated was observed by the Development Team in a letter dated 18th July 1983:

> "Regard must also be paid to methods of updating registers. We have found instances of registers having been started, then those working on them have left and, by the time another person has been appointed, the register is some two years out of date."

In fact the DHSS itself has also expressed an interest in why registers have been discontinued.

Though no questions were specifically asked about discontinuation in the circular of 2nd August 1983, the data stored on at least eight registers were said to be out-of-date. Among the reasons given for the lapsing of registers were lack of time, staff shortage, NHS reorganisation and change of personnel. In one case data-collection ceased because the register was not proving worthwhile.

The interviews revealed that in at least three cases the neglect of the register was a partial consequence of the termination of Joint Finance for the payment of running costs. The termination of Joint

Finance can mean the end of the contract of someone temporarily employed to compile a register who is known to all the people involved and has developed a special expertise. If this person is not adequately replaced the future of the register is jeopardised. Though some registers have managed the changeover from Joint Finance to Local Authority funding without lapsing, at least one operator of a register dependent on Joint Finance said that he was concerned about what would happen when it came to an end. In a city where an elaborate register is being planned, special measures have been taken out to ensure that the running costs of the register will be met from the mainstream Health and Local Authority funds when the Joint Finance comes to an end:

> "As the tapering arrangements of (Joint Finance) work, the Local Authority will pick up half and Health will pick up the other half. So it's actually shared funding from then on and that's the breakthrough. It is recognised by both sides that the funding is open-ended... it was an exception that our City General Purposes Committee had to agree... (As the Joint Finance tapers off) the revenue will be picked up open-ended half by the Local Authority and half by Health; whereas (in) all other joint funding the city refused to take on any revenue costs because of the rate-capping implications."

On a few occasions staff have been temporarily employed to carry out the initial data-collection. When their contracts have come to an end, permanent staff with other responsibilities have been given the task of maintaining the register but have lacked the time or the will to do so satisfactorily. When temporary arrangements for a register come to an end staff-cuts often make continuation difficult:

> "At the time that we... planned it... we could... fairly easily identify that there would be staff available to carry on the support of the register... The development work was done within... our Development Research and Training Division. We always envisaged though that once it was developed we would hand over the day-to-day support to.. Central Registry... It was possible to see that happening - that there was

> "sufficient staff to keep the mental handicap register... Over the last 18 months quite dramatic cuts have been made within this Division and there just isn't now that administrative support which it needs."

> "We for some years... couldn't appoint a Clinical Psychologist... and the DMT agreed that we could use the money... lying fallow to appoint someone for a year to put the (register) together. When we appointed a Clinical Psychologist... that source of funding dried up. We wrote the responsibility for the maintenance and upkeep of the register into the psychologist's job description... But we didn't have any additional extra resources to run it at all. And that really was a problem."

The frequency with which the termination of temporary arrangements such as Joint Finance was given as a reason for discontinuation suggests that it is indeed an important factor. But it might have been accompanied by other factors of which the interviewees were unaware.

This section can only end inconclusively because of the lack of relevant data. However the registers which have fallen into neglect are definitely a minority. Very often, it seems, this has been the result of external factors and not failings of the registers themselves. So, though the tendency of registers to be discontinued is one to be noted, it does not seriously undermine them in their role as planning tools.

Moral Objections to Mental Handicap Registers

There is probably no issue connected with mental handicap registers which causes more concern than that of access to named information - that is, names of individuals or information about named individuals. Yet the main function of registers is to produce anonymous statistical data for use in planning and the few requests for named information come most frequently from staff close to the

register and so hardly raise issues of privacy and confidentiality. However the presence of named information has been a reason for concern. So any evaluation of registers as information-bases would be incomplete without an examination of the moral objections made against them because of the named information that they hold.

Any data-base holding a mass of personal data may be deemed morally unacceptable if the subjects do not know what data are held on it and to whom they are accessible. This is a very extreme position and would rule out a number of computerised and manual information-bases, which are widely accepted. The argument gains in force if the subjects have provided the data themselves in the belief that they would only be available to a specific group of people which does not include all the users of the data-bases. In this type of case confidentiality is breached.

Confidential information is information which has been made available in such a way that the recipient is under an obligation to make it known to a restricted number of people or to no one at all. The manner or context in which information is made available will make it plain whether or not it is confidential. When information is made available by a patient or client to Health or Social Services professionals, it is usually understood by both parties that the information will either not be communicated to anyone at all or only to staff working very closely with the professional concerned. Named information on registers is useful to a range of professionals in a number of agencies. It will originally have been made available by the clients or patients themselves. Unless they are told otherwise they will have made it available on the understanding that it will only be accessible to the professional to whom they made it available and perhaps a few of his closest colleagues. So if named data on

registers are available to all the professionals and others who might have an interest in it, the consent of the subject or, if he is unable to give it, his family to this broader access should be specifically sought, if confidentiality is not to be breached. For example, when register staff look through medical records of subjects they will be looking at the data which subjects or their families would have given - in the case of information about family background - or made available - in the case of diagnosis - to a professional on the understanding that he would pass them on either to no one or only to his closest colleagues.

Many registers have each of the following characteristics:

1. They hold information which subjects or their families have given on the assumption that it will only be available to a small number of people working very closely with the professional to whom it was originally given.

2. Once on the register, the information is available to a broad mix of staff of a number of agencies.

3. The consent of the subject or his family to the release of certain information about himself to the staff of several agencies is not sought.

Any register which has each of these three characteristics is strictly speaking breaking the confidence of the subject or his family who initially passed on named information on the assumption that it would be available to a narrower section of staff than in fact it is. This breach is not removed by the requirement that the permission of someone or somebody outside the register should be given for each release of information. Confidentiality can only be maintained if the subject or his family gives consent to the wider availability of the data. It is not difficult or expensive to seek the consent of

subjects of their families. Several registers were visited which sought consent at the same time as collecting data. None of them found that it took long. If however there is no direct contact between register staff and subjects, a letter could be sent giving information about the register and asking parents to make contact if they are unwilling for their children to be registered (cf. Harvey, 1983).

Several of those interviewed did not realise that the availability of register-data to a broader group of staff than subjects or families would normally expect was a threat to confidentiality. Few gave this greater accessibility as a reason for seeking the consent of clients; and, where clients' consent was sought, they were frequently not told that data on the register would be available to a mix of professionsals in a number of agencies. Parents have objected to named information being given to staff or Authorities remote from the register. One register had passed named information to a District Health Authority. The Authority had then straightaway approached the parents who were very annoyed as a result. The register had therefore adopted a stricter procedure for issuing data in these circumtances. This underlines the importance of seeking the consent of clients or families to registration in the knowledge of exactly who will have immediate access to the data held.

There is a widespread tendency in the Health Service for confidential data to be made available to a broader group of people than the subject realises. In a study carried out in the medical records departments of six districts, all of which had a district policy on confidentiality, it was found that a significant amount of disclosures were being made to staff outside the Authority without appropriate consent being obtained (Steering Group on Health Services Information, 1984). The draft code on confidentiality prepared in the

light of the Data Protection Act (1984) may imply that Health-Service-funded registers should only make data available to those concerned with the health care of the subject (DHSS, 1984). This is still under discussion, but it underlines the need for consent to be sought from subjects to the availability to a number of agencies of data relating to themselves.

If consent is sought, subjects who do not wish to be registered will be excluded. So there is a danger that the register would as a result be less accurate. However, it looks most unlikely that the accuracy of any register would be significantly affected in this way. A number of the registers visited sought the consent of subjects or their families to registration. All of them received either no refusals or only a miniscule number; and their operators felt that no real loss of accuracy resulted (cf. Wynne, p.2). Parents were in fact very cooperative:

> "It seems to be people other than parents who say: 'Oh, parents won't like (registration)'."

> "Families seem to be only too keen to have their children brought to the forefront of the people who are providing resources."

The inclusion of value-judgements on registers has been a cause for concern. A professional may develop a biased opinion about a client whom he hardly knows as a result of access to a value-judgement which has been made by a colleague and stored on the register. If subjects have access to the data relating to them, most of this difficulty is removed. In fact, under the new Data Protection Act (1984) the subjects of computerised data-bases have a right of access to the information held on them and are entitled to have this information corrected or erased where appropriate and to be compensated if they suffer damage because data are inadequately

protected or inaccurate. Though this right of access may rarely be exercised, its existence should encourage those responsible for maintaining the register not to hold data to which subjects might reasonably object.

Some people have felt that there might be stigma attached to registration.

It may be that the subject is not regarded by either himself or by his family as mentally handicapped or that he or his family feel - rightly or wrongly - that he will be stigmatised. Philip Jones (1979) refers to a case in which a man who was doing well in the army had his promotion blocked when it became known that he had been in a mental handicap hospital. The dangers of stigma because of registration will be substantially reduced with the implementation of the second of the five principles advocated by the Lindop Committee "in the interests of the data subject", namely "Personal data should be handled only to the extent and for the purposes made known when they are obtained or subsequently authorised." (Home Office, 1978). This principle can be put into effect by arranging the security and distribution of the data so that they are only available to bona fide professionals - which is generally not difficult.

Stigma from registration will probably never be entirely eradicated, though it can be reduced. Any data-base which is designated as specifically for mentally handicapped people can generate feelings that its subjects are different in some way. The same applies to any segregated facility for mentally handicapped people. In an integrated utopia such facilities would not exist. Nevertheless, for as long as mentally handicapped people remain neglected and services for them are under-resourced, there is a good case for conceiving of them as a separate group if only because of

their deprived situation. For example, to monitor improvements in their situation, it is necessary to regard them as a district group. This provides a justification for mental handicap registers, even though the very notion of such registers does conflict with the ideal of total integration.

There is some suspicion of computerised registers:

> "(A) problem-area was actually a computer-based register which is actually a whole new can of worms if you like - of actually having your name on a computer-based information-system."

There is a general fear of computers in Britain today. It is sometimes the result of the threat which they pose to jobs. Sometimes they are seen as having a sinister power over individuals because of their potential for storing masses of personal information. They are even viewed as eventually controlling peoples' lives. Much of this is irrelevant to the choice of rules governing access to data that they hold. In general, computers have a potential both for increasing and for decreasing the safety of personal information. A computer makes it possible for a data-base to store more data about more individuals and for data to be more easily and quickly extracted. If the computer operator abuses the power that he has, very great harm can be done. However, the number of people able to operate computers is small. Sometimes computers can be programmed so that only those knowing a password can have access to them. They can also be programmed so that certain operations cannot be carried out and an alarm is given if anyone attempts to perform them. Other devices include the logging of all operations for subsequent inspection (Home Office, 1975, paragraph 23). Registers can be so constructed that specified people can only have access to specified parts of what is stored (Croydon Health Authority, 1983, p.5). All in all, computerised data-bases can, if

they are appropriately designed and operated, afford greater protection to information than manual systems (Home Office, 1975, Para. 25).

Conclusions

The practical and moral objections to registers are not overwhelming; at most they set constraints on their operation. However, the integration of data-collection with community-based service-delivery is probably the best way forward, being cheap and meeting well with current mental handicap philosophy (Cubbon, 1985). All methods of data-collection are workable; cooperation from different bodies in the supply of data is by and large satisfactory, though registers are probably more successful if no attempt is made to collect comprehensive data on the under-fives and little reliance is placed on GPs and sometimes also the Education Department. The most serious moral objection to registers is that a great number of them technically breach confidentiality. But this can be removed with a minor change in procedure. The threat that computer-based registers have sometimes been thought to pose to privacy and confidentiality has often been grossly exaggerated.

THE POTENTIAL CONTRIBUTION OF REGISTERS TO THE PLANNING

OF SERVICES

Introduction

The contribution of registers to planning will be examined in two stages: first their potential input to the planning process; then the extent to which their data have in fact been used. In this chapter the potential value of registers will be looked at. The following issues will be addressed: do registers provide data on planning which would not be available from any other source? what is the nature and value of the contribution of registers? what types of planning can registers contribute to? what is the value in planning of the various items of data held on registers?

The difficulties of planning without a Register

Again and again register-operators commented on the haphazardness of planning without a register. "Guessing" was a word that came up a few times to describe the process. The following remarks are not untypical:

> "(The original purpose of the register was to be) a planning tool because of the incredible lack of information that we had... I think a typical example was when we were looking towards setting up two fairly independent living hostels... We had no idea of the numbers there might be to make use of this facility... I mean some of the information that we got out in the early days (of the register) was really quite frightening because we had no idea of the likely demands that were going to made of us. So it was in two senses: we (had been) trying to make plans without knowing how many fitted the target group and we had no idea of the likely future demands."

> "A number of projects had gone ahead without really the statistical kind of information that was required to really plan the numbers... In some ways we were

floundering about a little in the dark when it came down to looking at: how many community units do we need? how many hostels do we need? how many ATCs do we need?"

Reports produced by two Social Services Departments which at the time had no register, revealed that some fundamental questions could not be answered - for example how many adults from the borough were in mental handicap hospitals, how many children had gone into mental handicap hospitals the previous year, where the mentally handicapped were located, and how handicapped they were (Jones, 1979, p.10; Birmingham Social Services Department, 1983). Such records of mentally handicapped people as there were, were neither comprehensive nor standardised. Different data were held in different places with the result that a variety of criteria were used for determining priorities (Birmingham Social Services Department, 1983).

There is growing support for planning in a piecemeal fashion as far as possible on the basis of the needs of each individual as assessed by the professional who knows him best. The Independent Development Council has recently stated that too little attention has been paid to planning on an individual basis and that planning needs to move away from its emphasis of capital developments and units with so many beds (Independent Development Council for People with Mental Handicap, 1984, pp 14-17). It might be thought that this approach significantly reduces the need for a register. However, even if planning is, as it should be, based as much as it can be on the needs of each individual, and proceeds in a piecemeal fashion, an overall picture of the client population is still essential. The most obvious reason for this is that unless the needs and situation of all the mentally handicapped people to be planned for are known, it is impossible to decide which individuals or groups should be given priority in the planning process:

"Community Nurses... were providing an answer to the problems that hit them in the face. I was concerned at the time that whilst there might have been a reasonable amount of money available to develop these ad-hoc type units - like 'we must have a child residential unit', 'we must have a day care unit for adults'... I was concerned that we weren't operating on a systematic basis and we weren't looking at the over-view picture and then allocating priorities and working in a structured manner towards providing services. We may well have provided £2000 of services for the lesser need."

Setting on one side the question of strength of need, it may be that the need of some particular group of people should be satisfied first because of the dependence of future developments on previous ones. But to discover whether this is so, it would be necessary to know everyone's needs. For example there may be financial, administrative or other grounds for providing one group of four people with a group home before certain other groups, even if all were in equal need. Alternatively a certain number of people may need a facility of some type. This might be provided in such a way that it cannot easily be adapted to meet the needs of some other group as well. This may not matter - and may indeed be the best option - if there is no other group who could use the facility in question. But to find this out one would need a comprehensive picture of the mentally handicapped population. So, to sum up, individual-based planning is still best guided by a register because priorities should be determined on the basis of the urgency of needs of different individuals and the various practical consequences of the provision of the facilities which might meet those needs.

There are a number of pressures on leading Authorities to strive for a greater precision in planning which can best be achieved by a register. In many districts there is not such a lack of services for mentally handicapped people that any new facility will be used. Planning, therefore, needs to be rational. Moreover as a result of

declining finances any new development may mean the closure of some existing service and fewer funds available for other necessary developments. A Social Services Planning Officer said:

"In the past we were providing additional resources from a very low base. This is the point. Anything we provided was likely to be used by and large. If we put a Training Centre down, it was where no Training Centre was before and it would be filled up; but now we're getting to the point where resources are much scarcer - we're in the zero-growth situation... but having got the basic infrastructure now, anything we add now is additional and it's more marginal and we can't just put down something on the assumption that it will be needed because (a) we've got to justify closing something else to release the money and (b) if we put it down and it's not needed we've wasted resources... Now we're nearer the margin and we have to be that much more careful at working out what we need."

When Authorities cover large areas, the need for accurate planning of the location of facilities is acute:

"If we were a compact county borough it wouldn't matter so much where we put the Adult Training Centre or the Group Homes. People would be able to reach them from the whole of the area. But (in a shire-county like ours) you've got to know where as well as how much. It was that sort of thing that led us to the first ideas of setting up a register."

Where services are so underdeveloped that any new services will be fully used, a register may seem a luxury:

"Generally we have adopted the view that adequate information for planning is obtainable from local professionals. As well as this we have not achieved the guidelines of the 1971 paper Better Services for the Mentally Handicapped - struggling to achieve this standard does not imply the need for greatly detailed planning."

"We have nothing. That's my argument against a register. Whatever we provide we will have more clients than we can cater for."

But the reasons for maintaining a register when planning is based as far as possible on individual need apply here also. Even when the condition of the service is such that any new facility will meet an existing need, it will still be necessary to know the total population to be planned for so that the new developments can be fitted into a coherent strategy. Such a strategy can only be formulated if the relative urgency and strength of the need for different possible developments and the financial, administrative and other practical consequences of the various options have been examined. This requires a knowledge of the whole mentally handicapped population.

The advantages of a register over other bases for planning

One might suppose that the impressions of an experienced professional or administrator would be sufficient for planning a mental handicap service. However there is no single person who knows the entire mentally handicapped population, so complex and vast are the services. Instead there are a number of people - Social Workers, Community Nurses, doctors, staff in institutions, some of which may be distant - each of whom knows only a part of the service. A doctor explained that she and her fellow CMHT-members realised that none of them had a satisfactory overview of the needs of mentally handicapped population:

> "I've worked eighteen years in the School Health
> Service... so I obviously know an awful lot of people
> also at the ATC... But it was just apparent to all of
> us that we each worked in different fields. The Social
> Worker only worked in one area... I only know the
> school and those younger people at the ATC. It was
> just obvious that we had to get a comprehensive view of
> it."

No-one has an equal level of contact with all parts of the service:

"(The views of experienced professionals) tend to be
fragmented and people's own individual personal views
over-ride. Their knowledge of a ward sometimes makes
them look very insularly at the needs of their ward."

Without a register individual professionals or administrators may
be the only people with access to some of the relevant facts to
planning. They are thus able to present the facts in any way they
choose. However, as a Health Service administrator pointed out, the
beauty of a register was that it made the facts available to everyone,
however one might choose to interpret them.

Professional interest may lead to bias. The opinions of some
professional group might be coloured by the desire to preserve its
sphere of activity. This was given as a reason for using a register
to take planning decisions centrally rather than relying wholly on the
opinions of staff of the establishments which would be affected.

A Social Services Planning and Research Officer considered that
professionals in the field were less able to take a balanced overview
because they were concerned with individual clients:

"The point is also... (officers in the field) don't
have this information (which is on the register). They
have information on individuals but they don't put it
together in blocks which is what we're talking about
with this register - what we're doing is adding people
together, comparing people. Individual practitioners
aren't good at that, because they consider people as
individuals which is what they're supposed to do. If
you take the case of the new Training Centre - when we
were talking about that originally, we said: 'Let's
built one at F...' - which everyone thought was the
best idea. But when people were plotted out on a big
map, it turned out that that was not the best
solution... So looking at the numbers and figures you
get a different picture from the one you get from the
individual workers."

Since different members of staff know only about different
segments of the service, one might imagine that a group of them might

have between them the necessary knowledge. But even a group of mental handicap specialists cannot, it seems, come up with figures:

> "In the mid-'seventies a Working Party from the three agencies tried to map out the future provision for the mentally handicapped and had a number of very able professional people... who were capable of assessing needs of individuals, designing imaginative services to be provided. But they didn't know how many and they didn't know where and there was a dearth of quantifiable information."

A Health Service Administrator felt that the group dynamics of the joint body which planned mental handicap services, the magnitude of its task, constraints on time and the need to make changes could lead to bad decision-making.

The advantages of a register over any purely human planning mechanism were summed up by a Specialist in Community Medicine who said that the register imposed a discipline on the data which was theoretically possible in professional work but very hard to achieve in practice. Register-data have an indisputability and neutrality which professional opinion lacks:

> "I would like (the register) to be used... as a common language between Health and Social Services... I'd like it to be available so that we don't spend our time arguing, as tends to happen, about how many people there are in different categories, where they are and what they're doing and get beyond that and spend more time... discussing the kinds of services that are going to be provided and who's going to provide them and how."

Statistical data from registers may carry greater weight in the decision-making process than impressions:

> "It is the general usefulness in a sense of having the numbers as well as in having discussions with other agencies. People don't like vague replies if you're planning a service; they want to know how many people are using it and you can, you know, check through registers to get numbers".

Authorities without registers sometimes instigate analyses of data held on existing records when a new service is being planned. Quite apart from the fact that these records are often incomplete, out-of-date and maintained in different ways by different agencies, the process of assembling the data is immensely time-consuming:

> "I've been involved in planning... care in the community initiatives in bringing people out of hospital. And it was so dreary going through card-indexes which... we hadn't been able to keep very much up to date. But as soon as it was put on computer and the whole thing was checked then immediately it was done in days where it would have been weeks and weeks... We got some money to build a new day care resource... and there wasn't going to be enough places to look after every mentally handicapped (person)... and we wanted to look at things like... 'what if we took everybody who was under 25 into the day centre?' To find that information took me hours and hours but it would literally have taken a matter of pressing a few buttons on computer."

The benefits of a register are apparent from comparison with planning for other client groups for whom there is no effective register. A Social Services Planning Officer said that when planning for these other client-groups his Department "went round and round in circles (getting) into terrible trouble." Under the Chronically Sick and Disabled Persons Act (1971) his Department was required to keep a list of handicapped people; but there was only partial coverage and no updating with the result that identification was very difficult. He said that the two new Day Centres for physically handicapped people had been built on the say-so of professionals. Enough clients had been found for one but not the other. The planning had been "all really guesswork... a very hit-and-miss method." A Health Services Administrator remarked that in the preparation of annual and five-year plans, information about mentally handicapped people had arrived from the register in days but with the elderly and mentally ill for whom there was no register it had been a matter of months.

Health Service Staff and GPs and Social Services staff make substantially more requests than the other categories of register-users (see Table 7). This is to be expected, since Health Authorities and Social Services Departments are being called upon to provide the bulk of the new community-based service.

TABLE 7   FREQUENCY OF REQUEST BY AGENCY FOR DATA
                     FROM THE REGISTER

	More than 3 requests made per month from	Less than 1 request made per month from
Health Service Staff and GPs	17 (33%)	25 (49%)
Social Services Staff	19 (37%)	19 (37%)
Education Authority Staff	2 (4%)	47 (94%)
Joint Care Planning Team or some other joint body	6 (11%)	37 (70%)
Voluntary and private organisations	1 (2%)	47 (92%)

The comparatively slight use of registers by Education Departments is unsurprising. They are not being called upon to shift large numbers of clients or operate radically different types of establishment in the way that Health Authorities and Social Services Departments are. They have recently been placed under an obligation to integrate children with special educational needs in ordinary

(Education Act, 1981, Sections 2(2) and 2(3)). Mentally handicapped children unlike adults are not scattered so much throughout a number of districts and a number of ill-suited residential establishments; nine-tenths of severely mentally handicapped children live at home (DHSS, 1980, paragraph 2.6). It would seem that they are almost all likely to be known to the Education Departments; many mentally handicapped adults, however, may not be known to the Social Services Departments with responsibilities towards them. An Officer of an Education Department with responsibility for special education felt that register-information about the under-fives was of special use to his Department:

> "I would see the under-fives being the principle target group for our information for planning simply because they are the unknown. Although the Health Authority notify us, there's always a chance that we don't get to know everybody and we're also able, by looking at the register, to get an overview of how many there are aged one and under who will require a service aged four or five."

However, few registers hold data on children in the pre-school years which are complete or accurate.

How the various types of data held on registers can contribute to the planning process

Names, addresses, dates of birth and details of services used are easy to collect and can make a contribution to the planning process.

If an Authority knows the number of people at mental handicap hospitals who are its responsibility it is able to make a start on planning their return. Knowledge of numbers of people not using some service can provide a basic indicator of need - for example the numbers of people in the community who are not attending an ATC.

Addresses of mentally handicapped people in the community and the addresses from which the rest were admitted to residential establishments can provide an invaluable guide to the siting of services. Ages can give an indication of future demands. For instance the number of those approaching school-leaving age will give a forecast of the number of places needed at ATCs. The numbers of subjects over 60 will give an indication of the type of need for special day or residential facilities for elderly mentally handicapped people. Statistics of age, geographical location or origin and service use could combine in a mass of ways with the impressions of professionals and administrators in the formulation of plans. But useful though these data are, alone they provide little guide to services needed. For this some type of assessment of ability or need is required. Several of the staff involved with registers holding only basic and service information said that they wished that their registers held also an assessment of this type.

Any assessment of services needed derived from a register is open to criticism based on Smith's (1980) study - that professionals impose their highly routinised categories of need on clients. According to this view, by making need-assessments the basis of planning decision, one is allowing priorities to be determined by professional and bureaucratic interests. If this attack is valid, social workers and others need to adopt a radically different outlook. However in present circumstances professionals' judgements of need are the only such judgements widely and easily accessible. If they were abandoned there would be nothing which would take their place immediately. So for all their faults they should continue to be used.

The method of assessing need which is used most frequently by mental handicap registers is Kushlick's Wessex Behaviour Rating

System. It is made up of two scales – the Social and Physical Incapacity (SPI) scale and the Speech, Self-Help and Literacy (SSL) Scale. The SPI scale collects information on incontinence, mobility and behaviour problems; and the SSL scale assesses speech, self-help (feeding, washing and dressing) and literacy (reading, writing and counting). A three-point scale is used to answer each question except for those on speech where a four-point scale is used. Overall SPI and SSL scales can then be calculated. The SPI scale allows subjects to be divided into CAN ('continent, ambulant and having no severe behavioural disorder') or CANT (the remainder) (Kushlick, A., Blunden, R., and Cox, G., 1973). The Development Team has divided scores on the Wessex scale into four groups and suggested that the numbers falling into each group is a guide to the numbers needing a specific type of residential accommodation and a specific level of staffing (1979, Para. 10).

Perhaps the most significant finding of the interviews was that a very large number of register operators were dissatisfied with the Wessex scale as a guide in the planning of services and felt that a more direct assessment of need was required.

A general criticism of the scale was that it was not an indicator of services needed:

> "The problem is... the Kushlick bit describes the person but you've got to guess what the need is."

> "(Wessex scores) invariably grossly underestimate people's potential... They function as photographs of a moment in time."

> "It doesn't really seem to address the problem of how self-sufficient people are."

Several interviewees pointed out that people with similar Wessex scores could have very different service needs. In the one case the

score may be a reflection of particular features of the environment; in the other it might remain constant in all circumstances. Someone for example, might be rated as having severe behaviour problems because of his environment; the behaviour problems of someone else might be independent of the environment. Equally the same behaviour might be regarded as difficult and disruptive in one situation and unremarkable in another. Someone who is permanently incontinent may simply need incontinence aids. But this is not necessarily an indicator of dependence because many people who are not mentally handicapped may be equally incontinent and not regarded as dependent. However another client may have the same scores on incontinence but not because of any pyschiological condition making his incontinence permanent, rather because he has not been toilet-trained. Such a person would require training more than aids and so would make very difficult demands on the service. The training might lead to a greatly improved score - which the permanently incontinent person could not attain. Moreover scores on the Wessex system do not necessarily give even a rough indication of how a client's family is likely to be coping with him.

More than one interviewee gave examples of clients with high scores on the Wessex scale who were nevertheless unsuited to the community-based accommodation on offer:

> "As an example we've got a girl here who's a resident of our one heavily handicapped house... She's on obsessive rocker... People leave her pretty much to her own devices... she's not someone who really participates in the Activity Centre programme. She wanders about on the site... People would be able to say that she's able to dress herself with some help. She's not a major behavioural problem. She's continent; she's ambulant. And, as a consequence, she gets quite a high score on the Kushlick Behaviour Rating Scale and comes out as one of the people who really ought to be discharged. But... she wouldn't be able to function in a Social Services hostel at all, if for no other reason, of course, than that they don't really have working night staff."

Similar levels of dependence or types of problem do not necessarily imply the need for similar treatment. In fact the greater a client's problems are, the less likely he is to benefit from being mainly with others with similar problems (Guy's Health District, 1981, p.24).

There are grounds for dissatisfaction with regarding the numbers of people falling into a Development Team category as a basis for planning corresponding numbers of places in certain types of residential establishments. A detailed study of group homes has shown the importance of group behaviour for the success of group homes. 'Leader/follower' and 'mothering' relationships enable the more able to assist the less able, thereby lessening the need for outside support. The study concludes that a wide range of mentally handicapped people are suited to group homes. No clear-cut criteria for admission can be given since the right combination of individuals is essential (Malin, N.A., 1980 pp 104-5, 108). A register operator said:

> "My own personal view is that the (Wessex Scale) makes less and less of a contribution... The whole concept of mental handicap is changing. A person's potential in relationship to some form of alternative living accommodation is not so much now dictated by the Wessex grouping as it was. I mean once upon a time it was absolutely rigid: if it was Category I or II (the Development Team Categories derived from the Wessex Scale) they should be out. But since that time we've learnt that that isn't always the case and that now Category III and IV (can) live perfectly reasonable lives in the community depending on staff input to them. So I don't think (the Wessex Scale) is as important as it was."

The Wessex Scale has been felt to be too institution orientated:

> "There's been quite a lot of resistance (to the Wessex Scale) particularly among Clinical Psychologists... because they say it's too crude and in any case was designed for use in a more institutional setting."

> "Broadly (Wessex scores) were very helpful in
> planning hospital discharges. I don't think they would
> be so helpful on people living in the community because
> in a way we need more sophisticated assessments... I
> suppose it reflects our sort of service we provide."

Another bias of the Wessex Scale which was pointed out was that it over-penalised disruptive behaviour. Even considered as a measure of behaviour, the Wessex Scale was criticised for being insensitive:

> "The questions are so black-or-white... For
> instance... there's a question on there about speech –
> 'Does the client (a) have no speech at all, (b) ask for
> basic beeds, or (c) can he hold a conversation?' Well,
> OK, if you put: 'he doesn't ask for basic needs – i.e.
> can I go to the toilet?' or 'can I have a drink?'...
> But he does say... 'dog' or 'cat'... But there's
> nothing in between. You've either got to say: he asks
> for basic needs or he's got no speech at all. And
> there's a big difference. And that is in a lot of
> cases – there are a lot of questions there which you
> can only answer (a) or (b) to (with) nothing in
> between."

A number of register operators were unhappy about the levels of inter-observer agreement in the classification of people on the scale. It was pointed out that the same person was often given a higher rating at school than at home where he would be overprotected; more experienced staff would make different ratings from less experienced ones; and staff at hospitals are inclined to make different assessments from staff at Local Authority hostels. However nobody contradicted the conclusion of Jenkins and Palmer that the inter-rated reliability of the Wessex Scale was such that it could be used in large-scale surveys but in the assessment of individual clients it should be treated with great caution (Palmer, J. and Jenkins, J., 1982).

There were some who were happy with the Wessex Scale. One operator reported that low-scorers on a 0-6 scale derived from Wessex had tended to attain near-independence while those with higher scores, in particular those with behaviour problems, had been less successfully

rehabilitated. He still felt that his register should be used to conduct sample-surveys in which professional assessments of need for service could be recorded. Another operator said that the Wessex scale indicated the level of staffing needed - this was a guide to the crucial question of the level of resources required. The Wessex Scale may be a better guide to levels of staffing than to types of services needed - that is, to numbers of Group Homes or sheltered lodgings or ATC places - though even this is questionable.

How beneficial then, is the contribution to planning made by statistics derived from scores on the Wessex Scale which registers hold? The evidence assembled here makes an answer to this question difficult. Nevertheless it seems likely that Wessex Scale statistics have led to the implementation of policies which have been in line with a philosophy of mental handicap which has ceased to be the conventional wisdom. This is not perhaps a fault so much of registers as of the attitudes towards mental handicap services of many of those who have set them up.

Many register operators said that they wished that their registers held information specifically on the services which clients needed. A register organiser whose register held a version of the Wessex Scale said:

> "I felt personally that it could be improved to
> incorporate more detailed assessment of needs which are
> being met and which aren't being met and in that way
> could be a far more useful tool for planning... You
> would then be able to say: 'we have four people in a
> particular area... who have shown a need for a
> particular type of service'. Therefore we can set up a
> very local service from that information."

Assessments of the service needs of a subject are likely to depend even more on the individual making them than those on the Wessex Scale. Professional training and roles would determine the

assessments made. As a Social Services administrator put it, a Charge Nurse in a hospital would not assess need for hospitalisation like an ATC Manager. Some professionals would not have sufficient knowledge of all the services available. Also some members of staff would be more progressive in their thinking about mental handicap than others. It would therefore seem better for assessments of need to be made by a group of staff rather than an individual. Such assessments can be made at multidisciplinary reviews; and, as I have explained, a register can feed off them.

Glennerster et al (1983) point to the advantages of a register based on a joint assessment of patients:

> "One of the valuable consequences of the appointment of joint professional teams was that they began to generate a joint appreciation of the problems they faced. As they go about their task of assessing patients and discussing with clients' families and their clients what kind of care and support is available, they will generate a view of mismatch between needs and services. It will be a marginalist and incremental view of what is needed next. The firmer and more quantitative this can be, the better. Thus individual programme plans for a client could be drawn upon by the team in giving advice about immediate service or priorities. For example: 'Individual plans discussed over the past year suggest that twenty families will reach the position in the next two years when they would no longer feel able to look after their adolescent child but would support him/her if a different job and group accommodation could be provided. This suggests to us the urgent need to...'" (pp. 281-2).

Though no register has yet been based on individual programme plans, registers based on annual multidisciplinary reviews have recorded needs in general terms - for example, current need for residential accommodation broken down into "own home with relatives", "hospital", "residential home for the mentally handicapped", "minimum support hostel", "fostering", "sheltered lodgings", "warden service accommodation", "group home", "own independent home" and "other".

Another register specified need in terms of five alternative settings with different levels of support. Both held assessments of both present and likely future needs. However there were few others holding judgements of service needs as formulated in general terms at the benefits or otherwise of this type of data in planning. Despite its difficulties it can assess overall service-needs in accordance with the latest thinking on mental handicap - which the Wessex Behaviour Rating System cannot.

Again and again in the interviews importance was attached to knowing the number of subjects in the community with one or both carers over the age of 60. This information would be useful both in planning residential services and in drawing up lists of parents with whom the possibility of children leaving home could be discussed.

For similar reasons it was felt to be important to know how many people were being cared for by a single person.

How far registers hold the types of data that are useful in service-planning

It has been argued that the following items of data need to be held on registers:

Name, address and date of birth

Details of services used

Assessments of services needed

Risk-indicator - whether one or both of the carers is over sixty

and whether there is only one carer

All the registers in the postal survey held basic details (name, address and date of birth); 92% held details of service used; and 54% an assessment of services needed. Exact figures on the proportion

recording risk-indicators are not available; but it must be considerably less than 50%. So registers have very often not held by any means all types of data which are useful in planning, though almost all held basic and service details which, as I have indicated, are very valuable.

Many registers held items of data for which there would be little demand in the planning process. This is often because registers have been the outcome of uneasy collaboration between different agencies and professions. Of the registers in the postal survey, 66% held details of medical condition and 22% IQ scores and details of welfare benefits. However there does not appear to be much demand for these data.

In the postal survey those who had ticked six or seven of the boxes in 13(a) were directed to 13(b) and 13(c) where they were asked to specify the two most frequently and the two least frequently requested types of data. The results are shown in Table 8:

TABLE 8   FREQUENCY OF REQUEST FOR VARIOUS TYPES
                               OF DATA

	Most frequently requested	Least frequently requested
Basic details (Name, address, date of Birth)	6	1
Details of services used	8	0
Information about clients' relatives and/or domestic situation	1	2
Information about clients' medical condition	0	6
Assessment of clients' abilities and disabilities	7	1
IQ	0	6
Details of welfare benefits	0	6
TOTAL	11	11

The picture given by the postal survey of English registers of low demand for IQ scores was corroborated by the survey of Scottish and Welsh registers as well as by detailed analysis and requests for information received by two of the longer-standing registers. The low demand for IQ scores is not surprising: more and more people feel that they are misleading. Information about welfare benefits is not obviously relevant to the planning of services and it is probably for this reason seldom requested. However it has been found worth holding - for example - where there is a special interest in welfare rights. The low level of demand for medical data is probably a reflection of their slight relevance to the planning of services. These data are, however, relevant to planning preventive programmes and have their uses in individual case-work. Also registers which have a strong research function find them useful to record. However for most registers they are not essential. In fact they are difficult to collect accurately. There may nevertheless be a special case for recording whether or not subjects have Down's Syndrome since this is of special interest to certain groups of people and relatively easy to collect (Fryers, 1983, p.8). Information about family background and home circumstances apart from the risk indicators has little to offer planners. Analysis of requests received by a long-standing register revealed that the date of birth, disability, occupation, employment and relationship to the subject for each person in the family as well as details of the biological mother and the subjects' position in the family were only rarely sought, though collection of this information must be time-consuming (cf. Fryers, 1983, p.8). The precise number of registers holding these items of data was not looked into; but there were certainly quite a few.

Conclusions

Registers have a potential for transforming the process of planning mental handicap services. They can produce a quantitative, balanced picture of the target population and its needs which is more complete, objective and accurate than impressions or conjectures of professionals, however well they may know the services. Though many registers do not hold all the items of data which can aid planners, and though registers tend to use a method of assessing service needs, Kushlick's Wessex Scale, which is ham-fisted and based on an outdated ideology of mental handicap, the vast majority, since they hold at least basic and service details, have a number of vital applications in planning. The question which remains is how much this significant potential of registers has been realised. This will be considered in the next chapter.

Introduction

This chapter begins with a brief outline of general trends in planning likely to affect the use of register-data - the utilisation of the findings of research in social planning and the receptivity of the planning process to register-findings. The remainder of the chapter will set out what was discovered in the postal questionnaire and interviews about the extent to which register-data have been used.

Trends in Planning which might affect the use of data from Registers

Mental handicap registers may be said to carry out research since they provide fairly objective statistical data as a result ultimately of direct contact with the mentally handicapped population. Some registers are especially identified with research because they are operated by research sections of Social Services Departments.

It is widely recognised that research has not made as much of an impact on policy-making as it might have. The main reason for this has frequently been the lack of any suitable link between researchers and administrators (Leigh, 1977). A research manager who can move easily between the two sides can, however, in Leigh's view, provide such a link. He also makes the point that the determination of researchers to make a contribution to decision-making has been a significant reason for such success as they have had. This was echoed by Booth (1979) who argues that the researcher should advocate within the policy-making process his interpretation of what he finds. The

need for close liaison between research and administration springs in part from the format in which research is presented. Many of the findings of surveys carried out by researchers in Social Services Departments have been written up in booklets of well over twenty pages which a busy councillor or high-ranking officer will not be able to digest fully. A more direct and authoritative presentation is required.

Booth points out three respects in which the character of policy-making conflicts with social research: policy-makers are usually unspecific about their objectives and, as a result, researchers are not properly able to meet their needs; social research can uncover many pro's and con's of policies which makes political agreement difficult to achieve; in general, issues tend to be complicated by research while policy-making works in the opposite direction - simple perspectives provide the basis for securing change (Booth, 1979a, pp. 174-75). Research, even if fully supported by policy-makers, cannot solve all their problems. It rarely presents clear and definite conclusions for a decision-maker to act upon. The policy-maker is subject to other constraints and pressures than facts about the population under consideration - for example, he will need to take into account the views of others, the political climate, his other priorities and so on (Booth, 1979a, p.177). It should be added that research is inclined to take longer than the time policy-makers have to make their decisions (Booth, 1979a, p.178).

Register data may therefore be expected to make less of a contribution to planning than they might because of the conflicting requirements of research and decision-making and the lack of an adequate link between them.

The methods of planning detract from the fullest consideration and appreciation of the findings of registers. Registers reveal the

peculiar characteristics of the local population. There is still a tendency to see planning in bricks-and-mortar terms: since the 1962 Hospital Plan the emphasis of health service planning has been on capital developments. This emphasis is not suited to planning mental handicap services (cf. Glennerster et al, 1983, p. 112). There remains an inclination to rely on norms laid down by the DHSS which, of course, make no allowance for local variation. Glennerster et al found that the Authorities in their study were heavily dependent on information from central government, though they made increasing use of locally-produced data (1983, p.242). A further problem is that many of those involved in planning services for mentally handicapped people have an accumulation of relevant experience to which they are often inclined to attach greater weight than to the findings of a piece of research. Research-findings do not, of course, make the judgement of experienced staff irrelevant: The two perspectives can complement one another. However, because of its novelty and the threat that it may appear to pose to the judgement of many decision-makers, social research is likely to be unduly neglected. As well as a disinclination to make use of research-findings in planning, there is a tendency to ignore the possibilities of evaluation: policies arising from the planning system are seldom evaluated to ascertain their impact on the public nor indeed to see if the original aims of the policies have been achieved (Barnard et al, 1980). Glennerster et al made a very similar finding (1983, p.209). The obvious tool for evaluation of mental handicap services is a register or survey.

As the first chapter showed, efforts to stimulate the development of effective joint planning bodies at local level had seldom been effective. So it can be expected that registers have been set up in Districts which have either insufficiently integrated joint planning

bodies or no joint planning body at all and that, as a consequence, the data that they have held have been underused.

Findings of the Study

There were 24 respondents to the postal questionnaire who considered that service providers and planners made generally as much use of the register as they reasonably could, while 18 felt that they did not make as much use of the data as they might. There were indications that Question 15(a) may have been misunderstood by some respondents and that more than 18 considered that their registers could be put to significantly greater use. Some of those who had written that sufficient use was made of their registers revealed serious reservations in the interviews.

Reason	Frequency
A - Because the planners and providers of the service do not know enough about the register	7
B - Because staff working on the register do not themselves know what their information needs are	7
C - Because staff working on the register do not have enough liaison with the planners and providers of the service	3
D - Because the register is not located close enough to the planners and providers of the service	2
E - Because the provision and planning of services for mentally handicapped people is a low priority in the area	2
F - Because the planners and providers of the service are sceptical about the value of the information on the register	1
G - Because the agency which funds the register has insufficient liaison with the other agencies concerned with mentally handicapped people	0
H - for some other reason	11

Table 9 shows that organisational failure and ignorance are important reasons for lack of use. Reasons, A, C, D and G may often be closely related: they all point to a lack of coordination. The two most frequently cited specific reasons both mention ignorance on the part of service providers and planners. Of the eleven respondents who

gave some reason other than those specified on the questionnaire, four mentioned the incompleteness of the data-base, three organisational factors, two the low level of planning in the area and two ignorance of some type on the part of service providers and planners.

Only one respondent indicated that scepticism of potential users about the register was a reason for lack of use. He in fact substituted "accuracy" for "value" in F. One might argue that register operators would be reluctant to admit to scepticism about the value of the register, because this would cast doubt on the value of the work that they were doing. But scepticism about the value of the register hardly ever came up in the interviews in which register operators were usually very frank about the deficiencies of their systems. So service providers and planners are probably not hostile to registers even if they do not always exploit them to the full. This suggestion is reinforced by the number of respondents who had only praise for the cooperation they received in the supply of data, but who felt that service providers and planners did not make as much use of the register as they reasonably could. In general, provision of data to registers is more of a chore than requesting data from it. Also staff derive less immediate benefit from providing information. So one might expect people outside registers to be far readier to use information than to supply it. Yet of the 28 registers to which more than one agency contributed information and whose operators had only positive comments about the level of cooperation in supplying information, eight were, according to their operators, not put to as much use as they might be. When this paradox was pointed out to the operator of one of these registers, he said:

> "Everyone has the idea that the register's a good thing and very useful and provides useful information, but when it comes to actually using the information then that's another question."

It seems that there is no lack of enthusiasm for registers and that if ignorance and organisational difficulties could be overcome the will would be there for them to be used to the full.

It will be evident that many of the factors described in the previous section which tend to reduce the impact of research findings on decision-making were shown by postal survey also to limit the use made of data from mental handicap registers. These factors were elaborated on in the interviews.

The lack of an adequate link between register and decision-making was discussed on several occasions. On a few occasions the barrier was practical: data were inaccessible or inconvenient to extract. In at least two cases the location of the register in one agency was said to be a reason for lack of use by the other agencies - in one case, the agency concerned was a Health Authority and in the other it was a Social Services Department. Twice the direct accessibility of data only to a single person was said to be a handicap. Physical remoteness of the register and delays in responding to enquiries, such as might be caused by a mainframe computer, also reduce willingness to make requests. Registers have often also been underused because inferences from them have not been made known to the planners:

> "You can't keep a register going without somebody who is going to go out and literally twist people's arms and say: 'Look here. We have got the register here and you are not using it.' And we just haven't got the manpower to do that - that is what a director is for... I think you can't expect people to come and ask for things. People are making decisions all the time and they should be asking you for information; but they just won't. You have to go and say: 'come and ask for me'. You have to take the first steps and then hope that the next time they have a problem they will immediately think about you. But you have to do the initial thing."

"How far they as groups of fieldworkers are able to
handle the more detailed analyses that the (registers)
should be capable of producing is a matter for some
doubt, I think, and that's why I think the people who
control the (register) really ought to be able to
explore it themselves and promote discussion from the
things they find... to be able to handle the numerical
data and interpret it and act as a bit of a catalyst -
a bit of a thought-provoker, an initiator of thinking
amongst the fieldworkers along the lines that the
(register)... indicates... The senior managers - the
ones who really ought to be capable of handling the
detail and looking at it closely and interpreting what
it means and turning it into a plan or policy - they're
the ones either with the least time to do it or the
ones who don't want to do it - it's too nitty-gritty
for them. And it leaves a bit of a gap which only
someone like (the newly appointed Senior Officer
spending half his time on the register) can fill really
or somebody like my section if we had the time to do
it..."

The form that the relationship between the register and its potential

users should take will depend on a mass of characteristics of the

district in question. However, the involvement of a number of the

register-staff in the decision-making process was often a crucial

determinant of the extent to which register-data made their due

impact. A Unit Administrator for Mental Handicap Services who was in

overall charge of an underused register said:

"On the new Joint Development Team... there are only
two representatives (of the Unit) - Director of Nursing
Services and a consultant... there wasn't direct input
from (the register operator). And... they didn't
actually invite her along to talk about it.

Equally a number of register operators regarded their involvement in

the planning process as the principal mechanism by which data from the

register came to the attention of the decision-makers:

Q. "How do service providers and planners in the various agencies
   know about the register and its potential?"

A. "... Partly they know about it because I'm a Social Services
   planner... On the Health Service side my boss and I are on the
   various teams for joint planning and therefore we can say:
   'Ah well, the register can give you the information on that'
   ... or we can present the register's findings."

Q.　"So data from the register come to the attention of people
involved in planning through you?"

A.　"I'm responsible... for managing and planning services within
this Authority.　And I'm also a member of the Joint Planning
Team between ourselves and the Health Authority... It's my
personal knowledge of the information (on the register) that
helps us as a Division and as an interface with the Health
Authority."

"Now I'm a member of the (extended) Community Mental Handicap
Team... I am in much easier contact with the (Health Service
staff)... I'm in more direct contact with them and they
appreciate the amount of information I shall be able to give
them... I don't think it was so much that they probably
didn't know, because they've been told umpteen times; but
... you see it on a piece of paper, but when you see a person
and you happen to mention something and they come back with
all the information, you think: 'my word, they really do know
something...' it's all getting about."

Until recently the person in charge of a sophisticated register
covering a metropolitan district worked on it full-time but was not a
member of the joint officer body responsible for planning mental
handicap services and was only involved in planning in an advisory
capacity.　Recently the post has been changed into that of Principal
Administrative Assistant in the Mental Handicap Unit of the Health
Authority with responsibility for planning and information as well as
the register.　The post-holder is also now a member of the joint
officer body responsible for planning.　The present incumbent regards
his membership of this body as the ideal mechanism for ensuring that
information from the register is available to all the agencies.　A
colleague in Social Services felt that the new arrangement was better:

"It certainly makes a difference in that the (person
in charge of the register) is part of the planning
process and that he isn't shut away in his little
computer box... In a meeting he might say: 'Oh yes; but
that might be on the register', where people hadn't
even thought that we could get that information out of
the register.

Unsuitable approaches to planning were held by several register
operators to prevent the fullest use of their registers.　There was

apparently a tendency to view planning as expansion of services without a detailed appraisal of what was needed:

> "You should be able to develop... a profile of who our customers are... We ought to do that first... and tailor our services to meet the needs of our customers... Of course it tends to work backwards way on... They decide they'd like to build an ATC... and then they say: 'now if we do that, who's going to use it?' - which is really putting the cart before the horse... People still look upon planning in terms of bricks and mortar. Planning is... things like saying... where we want Day Centres or where we want Community Houses or where we want ATCs. Planning isn't about saying: '... within five years... we're going to have x number of elderly mentally handicapped people - what are we going to do for them?"

Another interviewee said that a great shortfall in ATC places had led to the decision to build a new ATC but no close examination of the need was carried out. Similarly more Community Nurses had been appointed without any investigation of the work undertaken by those already in the post. He felt that planning in mental handicap was conceived too much as a matter of pouring resources into the service:

> "We are not that sophisticated in our planning... We either throw in more resources to what seems an almost bottomless pit - so we needn't think too much about how we plan - or alternatively there are things given to the mentally handicapped by the Health Service and are assumed to be a good thing and no one wants to question."

Inevitably there will be occasions when people involved in planning fail to use the register because they have not fully digested its potentialities:

> "I am sure there are people who produce information which didn't originate from a register and, as such, is inadequate. I mean you might find a Nursing Officer, for example, produce a report on the need for a unit for behaviour problems and he puts (in) things about his unit instead of it being a more global view. People should be thinking: 'Right, to make my case, first of all, I need to find a need within the city; and the place for that is the register'. And people don't think like that; they only think within their four walls."

"Possibly planners... perhaps don't make so much use of the register as they might. I think there's been a tradition in the county of ad-hoc data-gathering. When the problems come up, everybody rushes round and gathers data in an ad-hoc form - which still goes on to some extent."

The types of neglect mentioned in the last two quotations probably become less common the longer a register has been in existence. Many of those involved in planning are used to thinking in terms of individuals and so may find it uncongenial to think in the aggregate way necessary when formulating a planning strategy for the mental handicap services:

"The service providers are not used to using statistical information in this way... Their training and the bulk of their work is dealing with individuals... and many of them would not particularly be numerate in the sense that they would need to use planning information of (the sort produced by registers)."

One register operator felt that the unfamiliarity of practitioners involved in planning with statistical data made them uncertain about what types of data they wanted on the register:

"You ask anybody what they want on a register and they look quite blank and they say: 'Oh, er, well, I mean names and addresses and, er, I suppose we ought to have date of birth. And they don't even come up with something like sex. And I think it's because the people who're doing the planning are the social workers, medical workers - they're not administrators, they're not people who normally work with paper. They work with people - they don't see people in the aggregate as administrators and researchers do."

This tendency of professionals and other service-providers to think in terms of individuals was also given as a reason for giving preference to register-data over professional opinion.

The tendency of people involved in planning to under-use the register because of a lack of sophistication - in particular, an

among those who are specialists in mental handicap, since their main function is client care. One would suppose that the senior administrators and others with more general responsibilities who have an involvement in planning would be more likely to think in the numerical terms neccesary to make use of the register. However they would know less about mental handicap than the specialists and so they might not fully exploit the register. In fact two operators said that ignorance of planners about mental handicap had been a reason for lack of use. A related point was made by another:

> "The... problem... is... the special nature of mental handicap, that all the other services... you plan on a provision norm per 1000 population - homes for the elderly, hospitals for the elderly - you try and plan so many beds per 1000 population... for mental handicap it's different... you can actually identify your population which stays comparatively static and you're going to have to provide services for those people for the rest of their lives... that's a difficult concept... for people to get to grips with. They have to make... a bit of a mental adjustment."

The question to be asked about the ways of thinking which prevent the full potential of registers being tapped is: are they not adjusted to the possibilities of registers only because registers have appeared so recently on the scene? Certainly the novelty of registers was mentioned a few times as a possible reason for their being underused. In time, registers will become better known and established and, as a result, planners will become more inclined to use them. But a review of the types of approaches to planning which inhibit exploitation of registers indicates that in some cases significant changes of attitude need to be made. These cannot be achieved without some positive effort.

As expected, several registers were wasted because there was no effective joint planning body - or even a mental handicap service with specialist posts which might give a boost to interest in the register.

An operator of a Health Authority run register felt that it might
not be adequately used by the Social Services Department because of
the lack of a structure linking Health Service and Social Service
administration. He went on to say:

> "The difficulty that we have yet to resolve is that
> there has been no clear indication as to which agency
> we jointly agree should take prime responsibility for
> the provision of services."

On the other hand, where agencies were cooperating satisfactorily in
service-planning, it was a different story:

> "I suppose the fact that we do work very, very
> closely together - the main agencies... does help.
> Because we have Social Services and Education
> representatives on the Community Mental Handicap Team
> and because particularly the Social Services
> representative and myself do most of the planning we
> work very, very closely together and therefore can use
> the register creatively."

A few registers have been under-used because Authorities have set
them up without a clear idea about how they should be used. In giving
an explanation of the lack of use of his register one operator said:

> "When we set the thing up we had an idea that it was
> going to be a useful planning tool - it was something
> that everyone should do and should have - but perhaps
> people didn't give so much thought to what they were
> going to do with it when they had it."

Conclusions

It is plain from the evidence presented in this chapter that the
effectiveness of registers has been seriously reduced because the data
that they hold have not been exploited to the full by planners. When
experience of registers has grown, some of the difficulties will

disappear, but not all. Changes in organisation and attitude are also needed. These changes may take many years to bring about. A greater integration of research and information-gathering with planning is required throughout the Health and Social Services. The tendency to rely on impressions and DHSS norms and a reluctance to take an aggregate view of a service provision are deep-rooted traits in many of those involved in planning.

Introduction

In this chapter major the findings of the study will be highlighted so that a reasoned evaluation can be made of information-bases on mentally handicapped people as planning tools.

The Feasibility of Registers

The compilation and maintenance of registers is relatively uncostly in terms of manpower and expenditure. A variety of data-collection methods have been used; but all of them have been relatively successful at keeping registers sufficiently accurate and up to date. Registers have mainly depended on the cooperation of different professions and agencies in the provision of data. By and large, this cooperation has been forthcoming. This may be surprising in view of the evidence of lack of communication between the various parts of the mental handicap service at the level of service-delivery. However the periodic supply of data on clients to a different agency or a remote part of one's own is no great burden. It is largely unaffected by the differences in ethos, organisation and funding which so afflict attempts to work together in planning services. Moreover the cooperation between different parts of the service in the provision of data may be seen as a result of the recognition of the importance of cooperation at the operational level which has led to the formation of CMHTs.

Mental handicap registers are the only widespread data-bases holding both Local and Health Authority data (Glennerster et al, 1983, p.272). Their performance suggests that information-bases on

other client-groups holding data from the same sources could certainly be maintained with a high level of cooperation from the staff called upon to supply data.

Though many registers currently in existence technically involve breach of confidentiality, some of the suspicion of registers as information-bases potentially harmful to their subjects is unjustified. Computerisation can make data more secure; danger of stigma from inclusion can be substantially lessened; and informed consent to registration will not only remove the main source of breach of confidentiality but also much of the suspicion that subjects and their families might otherwise have of the register.

The Benefits of Registers

There is no doubt that registers have a potential for directing plans to the needs of the target population which fully justifies the resources of money, time and manpower put into them. This applies whether registers hold only a minimal data-set, whether they hold items of data with little application and whether the district concerned has a complete lack of mental handicap services.

Most Authorities have had, and continue to have, as a medium - or long-term aim - the creation of a new mental handicap service. This will require a shift of resources affecting the lives of hundreds of people. Great opportunities could be missed and funds wasted with effects which would last for years. Against this background the costs and drawbacks of registers are small and benefits that they are capable of conferring are large.

However the degree to which registers have realised their potential for contribution to the planning process has been mixed. To some extent this has been a result of their novelty; but the essential

reason is that the changes in organisation and attitude which have made their emergence possible have not been widespread or deep enough for them to be fully integrated in the planning process.

The first and third chapters described some of the pressures which have led to the formation of registers. There has been greater emphasis on rationality in planning with more attention paid to objective factual data on service delivery and to social research. There has been a movement towards joint planning with much of the pressure coming from central government. These developments have made those involved in planning and management more receptive to the type of quantitative information supplied by mental handicap registers. However conflicting attitudes and organisational arrangements remain. There is still a reliance on the impressions of professionals and DHSS norms - sometimes to the exclusion of statistical data on local need; and planning is still conceived of in non-numerate terms. Attempts by the DHSS to induce Authorities to plan jointly through Joint Finance and the requirement to establish joint bodies may sometimes have led to the formation of registers; however such external pressure has not been sufficient to produce genuinely collaborative bodies which have systematically and comprehensively planned mental handicap services. Joint planning tools require effective joint planning bodies. But as such bodies have so seldom existed, a number of registers have held data which have been neglected.

In short, the two large-scale trends mentioned in the first chapter - recognition of the importance of planning and recognition of the need for lessening the fragmentation of the welfare services - have been strong enough to lead to the setting-up of registers but often not strong enough to ensure their integration with the planning process.

Different Types of Register in relation to the Provision of
Community-Based Services for Mentally Handicapped People.

Very broadly, registers may be divided into one or other of the
following three types:

1. Those whose staff collect information by scanning case-notes and
talking to professionals and perhaps clients and their families.

2. Those which call upon staff in the field to send written updates
to the register staff at regular intervals.

3. Those which receive information through data-generating processes
which have functions as well as that of providing information to the
register.

The third category of register is the most recent and has the most
cost-effective method of data-collection. It consists essentially of
registers based in CMHTs which feed off the records made by
CMHT-members for the purpose of individual casework and regular
multi-disciplinary reviews. Such registers are most in line with
current thinking on mental handicap which stresses small-scale
de-centralized community-based services (Hadley and McGrath, 1984).
Though more research into their operation is probably needed, their
integration with the work of CMHTs in service-delivery is likely to be
linked with a close involvement in decisions about the future
development of the activity of the Teams. Registers based on CMHTs
have therefore probably the greatest potential.

**The Implications of the Performance of Mental Handicap Registers
for other Client-Based Data-Bases**

Many of the pressures mentioned in the first chapter have made
themselves felt in other areas of activity of Health Authorities and
Social Services Departments. Registers of the elderly and of the

physically handicapped and child health registers - to name but a few - are being established in ever-increasing numbers as tools for service-planning.

Perhaps the most important development has been the recommendation of the Steering Group on Health Services Information (Chairman: Mrs. E. Korner) that more extensive data-bases on patients be formed throughout the Health Service. The data-sets recommended are intended to generate statistical information (NHS/DHSS Health Services Information Steering Group, 1982, Section 1.5 and 2.1; and Steering Group, 1982, Section 1.1 - 1.3, 1.10 and 5.10). However the Group recognises that this has been underused in the past:

> "Though much lip-service is paid to the crucial and central importance of high quality statistics, few Health Authorities management teams or heads of department currently analyse data expertly, present them informatively or use them intelligently in the performance of their management task. Despite certain acknowledged inadequacies of the NHS data systems, far greater use could be made of existing statistics. As an inevitable consequence of infrequent use, the accuracy and general quality of data deteriorate and the timely production of outputs is neglected."
> (Steering Group, 1982, Section 1.3)

The Group also recognise the importance of ensuring that information derived from their recommended data sets are used to make decisions about the allocation, planning and review of resources (Steering Group, 1982, Section 1.21).

The strategy adopted by the Group has been first to review and improve current statistics and then to instigate a major drive to promote better use of information (Steering Group, 1982, Sections 1.10 and 1.15). The first stage is still in progress.

By and large statistics on patients are now being collected in the Health Service primarily as a means of monitoring the performance of individual members of staff and completing DHSS returns. Since the

data collected are geared to DHSS returns and the evaluation of indiviual staff performance they are not ideal as a basis for service-planning at district level. On occasions, therefore, their implications for planning and management have perhaps understandably been neglected. The implementation of the Korner recommendations will resemble the establishment of mental handicap registers in that those in charge of the service will be presented with a mass of statistical data with planning implications which they will not have had before on the same scale. This evaluation of mental handicap registers points to the importance of taking measures to ensure that the resulting data will be used. It is, therefore, regrettable that the Reports of the Korner Group and the training-material produced so far give little guidance on the use of data. The Korner Group might respond by pointing out that in the second phase of their activities they would attempt to educate staff in taking advantage of the data available. Before this, they would claim, it is necessary to set up a satisfactory data-base. However the delay in starting a systematic programme of training managers and others in the use of data could well mean that in the first few years after the implementation of the recommendations of the Group data would be under-exploited.

The lesson of the experience of mental handicap registers for the implementation of the Korner recommendations - which will be a major task for every Health Authority in the next few years - is clear: strenuous efforts in both training and organisation will need to be made to ensure that Korner data are not neglected in the planning process. This lesson applies not only to the establishment of data-bases in line with the Korner requirements, but to data-bases of all other types which are being set up as aids to planning the Health and Social Services.

Are Registers Worthwhile?

It is difficult to make an overall assessment of mental handicap registers as information-bases for use in the planning of services. However it can be said that outside planning registers do not have any serious flaws: they are relatively uncostly; they have usually overcome practical obstacles to their organisations; moral objections are either unwarranted or can be removed by minor measures. Everything, therefore, is left to rest on their contribution to planning. Many registers have made a major contribution to planning; equally some have been peripheral and ignored. These unsuccessful registers have mostly not had ill-effects. So the trend for setting up registers may as a whole be considered worthwhile because of the actual impact on planning of some already in existence and the potential impact of others in the future.

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Head of Department Miss J. Challinor BEd (Hons) SRN SCM HV Cert

Our ref: NAM/JW

10 August 1982

The Regional Medical Officer

Dear

CASE REGISTERS FOR THE MENTALLY HANDICAPPED: A NATIONAL SURVEY AND
EVALUATION

I am writing to request the support of your Regional Health
Authority in undertaking the above-named research study. I enclose
a copy of the full research protocol plus a brief note on my
curriculum vitae. The study has received recent approval from
the Social Science Research Council (SSRC) (letters of
correspondence available on request) and is due to commence,
for an eighteen month period, in January 1983. In essence, as
you will observe from the enclosed, the intention is to contact
individual authorities (Health, Social Services and Education)
to request whether a case register for the mentally handicapped
is maintained. Where an affirmative response is received,
relevant officers will be asked to complete a postal questionnaire
covering basic details on the scope and operation of the register.
A selected sample of authorities, chosen for their relative
proximity to the base of the research (approximately 80 miles),
will be approached subsequently for interview purposes in order to
extend the range of data available. I would be grateful for your
help and support on this matter regarding the approach towards
individual District Health Authorities within your Region.
Please do not hesitate to request any further details on this
issue.

Yours sincerely

Nigel A Malin, PhD
Senior Lecturer

CASE   REGISTERS

FOR   THE

MENTALLY   HANDICAPPED

*   *   *

A   NATIONAL   SURVEY

AND   EVALUATION

THE NEED FOR A NATIONAL SURVEY OF
MENTAL HANDICAP CASE REGISTERS

Within Great Britain, there are a number of case registers of mentally handicapped people, maintained principally by Health Authorities and Social Services Departments. Although some have been in existence for over ten years, no detailed survey of all of them has yet been attempted. Our research study aims to fill this gap. It would appear that there is a great range in the form, scope, operation, and purposes of case registers. This reflects in part the almost complete lack of any extensive comparative evaluation of them. Such an evaluation, to which our project should make a contribution, would be useful both to those interested in setting up registers and to others wishing to improve registers already in existence.

The Association of Professions for the Mentally Handicapped (APMH) has already identified several key issues relevant to the maintenance of case registers, for example, confidentiality and accuracy of data. ("Standardization of District Mental Handicap Registers" T. Fryers, 1983). The DHSS has also shown an interest in the subject.

The utility and cost-effectiveness of the registers need to be considered. A number of questions arise at this point: how is the data collected? how much should be collected? how is it used? who has access to it? who maintains the register? how does the data-base contribute towards service planning? how exactly is it used to improve services? and so on.

Our study, which is funded by the Social Science Research Council (SSRC) for 18 months, will first establish where case registers exist. Subsequently a postal questionnaire will be sent to relevant officers of Health, Social Service and other agencies, which operate case registers, so that a clear picture of each register can be built up. In addition a number of detailed audio-taped interviews will be conducted mainly within an 80-mile radius of Sheffield.

The basic goals of the project are:

1) to determine the existence, scope and operation of case registers for the mentally handicapped throughout the country.

2) to find out how case register data have been and are being used.

3) to devise a national data-base on the purposes, operation and scope of case registers.

The second goal - finding out about the uses of registers - is a high priority and will require special attention to be given to the role of case register data in planning the detailed operation of services.

POTENTIAL BENEFITS FROM CASE REGISTERS

Services for mentally handicapped people in individual areas should be planned by means of estimates of need. (DHSS (1971) Better Services for the Mentally Handicapped Cmnd. 4683 London HMSO para. 22). National figures based on sample-surveys have been shown to be inappropriate because of the variations in the prevalence and characteristics of mental handicap from area to area. This was recognized in the review of the 1971 White Paper Mental Handicap: Progress, Problems and Priorities DHSS 1980 pages 28-29.

Accurate information about the total mentally handi-
capped population of a given geographical area can be
obtained only through the proper maintenance of a case
register. A major aim of our study is to discover how
information from case registers has contributed to
planning.

Case registers are probably of greatest value in the
planning process when the service is being substantially
changed: without an accurate information-base a new service
may prove to be wholly unsuitable. So, where services are
becoming community-based in accordance with Government
policy, special benefit could be derived from having case
registers and lessons could be learnt from those Authorities
and Departments with established registers.

Health Authorities, Social Services Departments,
Education Departments and voluntary organizations can each
make a considerable impact on the lives of individual
mentally handicapped people; and one of the most frequent
criticisms made of the service as a whole is that there is
little collaboration among these agencies in the planning
and delivery of services. Case registers can promote
co-ordination by gathering data from a wide range of
professionals - for example, social workers, nurses and
educational psychologists - and so enabling individual
professionals to find out the nature and extent of the
involvement of their clients with other professionals.

Mental handicap registers have enormous potential.
Our project aims to discover how far this potential has
been realized and, by looking at successes and failures of
pioneering case registers, how these registers can be most
effective.

WHAT COUNTS AS A CASE REGISTER

A case register of mentally handicapped people has the following features:

1) It aims to include all the mentally handicapped people living in a given geographical area, like a Health District or Local Authority (as far as this is possible).

2) It records information about each individual which is more substantial than merely the name, address and age of the person concerned. It might have in addition details of services used or details of the handicap.

3) It should be seen to have some relevance to planning.

Defined in this way, a case register will be different from any registers of disabled persons (including the mentally handicapped) which do not go beyond the minimal requirements of the Chronically Sick and Disabled Persons' Act 1970.

Informal enquiries, as well as information relevant
to the study, are most welcome.

Dr N. A. Malin (Director)
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Department of Health Studies

2 August 1983
JEC/PW

I would be grateful if you could supply me with a small amount of information
for our research project on case registers of mentally handicapped people.
The Association of Directors of Social Services has approved the project and
recommended it to Directors of Social Services.

I enclose an information sheet on the project which explains the possible uses
of mental handicap case registers and the need for an investigation of them. It
also states precisely what is meant by "case register" for the purposes of our
study.

Please could you answer the following questions:

a)   - Does your Department operate a mental handicap case register?

b)   If so, to whom would it be most appropriate for me to send a postal
       questionnaire on the operation of the register?

c)   If your Department does not have a register, does it have any plans
       for setting one up?

d)   If so, what stage have these plans reached?

Thank you in advance for your help.

- Yours sincerely

John Cubbon
Research Associate

QUESTIONNAIRE FOR MENTAL HANDICAP REGISTER OPERATORS

ALL ANSWERS WILL BE TREATED IN STRICT CONFIDENCE.

THE QUESTIONS WILL BE OF TWO TYPES.

SOME QUESTIONS WILL CALL FOR WRITTEN ANSWERS VARYING
IN LENGTH FROM A WORD TO A FEW SENTENCES; AND THEY WILL
BE FOLLOWED BY AN EMPTY BOX, WHERE THE ANSWER IS TO BE
WRITTEN.

THE OTHER QUESTIONS WILL SIMPLY REQUIRE A NUMBERED BOX
OR BOXES TO BE TICKED.

IF YOUR REGISTER IS IN A STATE OF CHANGE, PLEASE TAKE
ALL THE QUESTIONS AS REFERRING TO THE REGISTER AS IT IS
AT PRESENT (UNLESS OTHERWISE STATED IN THE QUESTION).

IF YOU HAVE ANY QUESTIONS ABOUT THE COMPLETION OF THIS
QUESTIONNAIRE, OR INDEED ANYTHING ELSE RELATING TO OUR
PROJECT, DO NOT HESITATE TO CONTACT ME: JOHN CUBBON
(TELEPHONE NUMBER: SHEFFIELD (0742) 665274, EXT. 3355).

	Card column
Serial number	1 2 3
Card number	4 5

1 What is the name or title of your job?

PLEASE WRITE YOUR ANSWER IN THE BOX BELOW

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┌──────────────────────────────────────────┐
│                                          │
│                                          │
└──────────────────────────────────────────┘
```

2 How is your register funded?

PLEASE TICK ONE BOX ONLY (✓)

By the Health Authority   [1]

By the Local Authority   [2]

By Joint Funding   [3]

By some other agency (PLEASE SPECIFY)   [4]

6

....

....

3 (a) Are register-staff volunteers or paid staff?

PLEASE TICK ONE BOX ONLY (✓)

Volunteers   [1] ⟶ NOW GO TO Q.4

Paid staff   [2] ⟶ ANSWER Q.3(b)

7

3 (b) By what agency are register-staff employed?

PLEASE TICK ONE BOX ONLY (✓)

By the Health Authority   [1]

By the Local Authority   [2]

By some other agency (PLEASE SPECIFY)   [3]

8

....

....

4 | What is the area covered by your register?

PLEASE TICK ONE BOX ONLY (✓)

The County | 1

The Borough | 2

The Health District | 3

The Health District and the Borough (where these coincide exactly) | 4

Some other geographical unit (PLEASE SPECIFY) | 5

....

....

9

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5 | (a) Is your register at the moment in the process of being set up?

PLEASE TICK ONE BOX ONLY (✓)

Yes | 1 ⟶ ANSWER 5(b) AND 5(c)

No | 2 ⟶ NOW GO TO Q.6

10

5 | (b) Does the register contain the names of the majority of the clients whom it is intended to register?

PLEASE TICK ONE BOX ONLY (✓)

Yes | 1

No | 2

Don't know | 9

11

5 | (c) Has the register yet produced information which has been used in the planning of services?

PLEASE TICK ONE BOX ONLY (✓)

Yes | 1

No | 2

Don't know | 9

12

IF YOU ANSWERED "NO" OR "DON'T KNOW" TO 5(b) AND 5(c), A FEW OF THE FOLLOWING QUESTIONS MAY BE INAPPLICABLE. IF THEY ARE, LEAVE THEM AND ANSWER THE OTHERS.

6 Please list the grades of each of the staff of the mental handicap register and the approximatelnumber of hours (to the nearest 10) normally worked by each of them on the register.

<u>Grade of each of the staff</u>   <u>Estimate of amount of hours</u>
                                      <u>spent per week on the register</u>
                                      <u>(to the nearest 10)</u>

PLEASE WRITE IN BELOW ·   PLEASE WRITE YOUR ANSWER IN
                                      THE BOX BELOW

....   [   ]   13 14

....   [   ]   15 16

....   [   ]   17 18

....   [   ]   19 20

....   [   ]   21 22

....   [   ]   23 24

....   [   ]   25 26

....   [   ]   27 28

....   [   ]   29 30

....   [   ]   31 32

                                                               33 34

7 How many clients are on your register (to the nearest hundred)?

PLEASE WRITE YOUR ANSWER IN THE BOX BELOW

[   ]   [| | |]

                               35 36 37 3

8 | Which of the following are used as criteria for inclusion on the register?

PLEASE TICK ALL BOXES THAT APPLY (✓)

Diagnosis of mental handicap by a medical practitioner `1` 40

Registration of mental handicap by the Social Services Department `1` 41

Current use of a service for mentally handicapped people `1` 42

Past use of a service for mentally handicapped people `1` 43

Likely future use of a service for mentally handicapped people `1` 44

An I.Q. of less than 50 `1` 45

An I.Q. of less than 70 `1` 46

Some other criterion or criteria (PLEASE SPECIFY) `1` 47

....

....

....

9 | Which of the following groups of mentally handicapped people are included on the register?

PLEASE TICK ALL BOXES THAT APPLY (✓)

People who live outside the geographical area covered by the register but receive services within it `1` 48

People who live in the geographical area covered by the register but at present only receive services outside it `1` 49

People who originate from the geographical area covered by the register but at present live and receive services outside it `1` 50

10 | (a) Does a Community Mental Handicap Team(s) work in the geographical area covered by your register?

PLEASE TICK ONE BOX ONLY

Yes [1]   No [2] ⟶ NOW GO TO Q.11   51

10 | (b) How does the Community Mental Handicap Team(s) contribute to the register?

PLEASE WRITE YOUR ANSWER IN THE BOX BELOW

___

11 | Which of the following provide the register with information about clients?

PLEASE TICK ALL BOXES THAT APPLY   (✓)

NHS establishments or personnel or records   [1]   52

General Practitioners   [1]   53

Social Services establishments or personnel or records   [1]   54

Education Authority establishments or personnel or records   [1]   55

Voluntary or private organizations or establishments   [1]   56

Clients themselves or their families   [1]   57

12	How is information about clients obtained?

PLEASE TICK ALL BOXES THAT APPLY (✓)

Register staff visit establishments,
records departments, etc., to collect
information

| 1 | 58 |

Staff at establishments, records
departments, etc., collect information
themselves and send it in to the
register

| 1 | 59 |

13	(a) Do one or more of the register staff routinely visit the parents of clients living at home to collect data for the register?

PLEASE TICK ONE BOX ONLY

Yes [1]   No [2] ⟶ NOW GO TO Q.14   60

13	(b) What types of information in general are collected on visits to parents?

PLEASE TICK ALL BOXES THAT APPLY (✓)

Basic details (name, address, date of birth, sex)	1	61
Family and domestic situation	1	62
Services received	1	63
Medical condition	1	64
I.Q.	1	65
Assessment of the client's behaviour	1	66
Parents' opinions about client's needs	1	67

14 | How much cooperation have you received from the agencies which provide information?

PLEASE WRITE YOUR ANSWER IN THE BOX BELOW

15 | How often in general is the data on the register updated?

PLEASE WRITE YOUR ANSWER IN THE BOX BELOW

16	When information about clients is updated, is the old information generally retained?

PLEASE TICK ONE BOX ONLY   (✓)

Yes   [1]

No   [2]

68

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17   (a) Is the consent of the client or his family to registration sought, where possible?

PLEASE TICK ONE BOX ONLY   (✓)

Yes   [1] ⟶ NOW GO TO Q.18

No   [2] ⟶ ANSWER Q.17(b)

69

17   (b) Have any problem(s) ever arisen to your knowledge because the consent of the client or his family has not been sought?

PLEASE TICK ONE BOX ONLY   (✓)

Yes   [1] ⟶ ANSWER Q.17(c)

No   [2] ⟶ NOW GO TO Q.18

Don't know   [9] ⟶ NOW GO TO Q.18

70

17   (c) If possible, describe the type of problem(s) that have arisen.

PLEASE WRITE YOUR ANSWER IN THE BOX BELOW

18 | (a) How is the register kept at present?

PLEASE TICK ONE BOX ONLY (✓)

On a manual system [1] ⟶ NOW GO TO Q.19

On computer [2] ⟶ ⎤
                        ANSWER Q.18
On a manual system and [3] ⟶ (b) and (c)   71
on computer

In some other way [4] ⟶ NOW GO TO Q.19

18 | (b) What type of computer is it?

PLEASE WRITE YOUR ANSWER IN THE BOX BELOW

```
┌─────────────────────────────────────────────────────┐
│                                                       │
│                                                       │
│                                                       │
└─────────────────────────────────────────────────────┘
```

18 | (c) Which of the following package(s)/program(s) does the computer run?

PLEASE TICK ALL BOXES THAT APPLY (✓)

Package(s)/Program(s) which have been written
within your organization (IF POSSIBLE, PLEASE [1]   72
GIVE BRIEF DETAILS)

....

....

....

Package(s)/Program(s) which have been acquired
from another mental handicap register (IF [1]   73
POSSIBLE, PLEASE GIVE BRIEF DETAILS)

....

....

....

Package(s)/Program(s) which have been acquired
from elsewhere - i.e. neither from within your
organization nor from another mental handicap [1]   74
register (IF POSSIBLE, PLEASE GIVE BRIEF DETAILS)

....

....

....

19 | Over the last year, how frequently <u>on average</u> has the register received requests for information <u>per month</u>?

(a) - from Health Service staff and GPs?

PLEASE TICK ONE BOX ONLY   (✓)

6 or more times (per month)   ☐ 1

3 or more times but less than 6 times (per month) ☐ 2

Once or more times but less than 3 times (per month) ☐ 3   6

Occasionally (less than once per month)   ☐ 4

Never   ☐ 5

Don't know   ☐ 9

19 | (b) - from the Social Services staff?

PLEASE TICK ONE BOX ONLY   (✓)

6 or more times (per month)   ☐ 1

3 or more times but less than 6 times (per month) ☐ 2

Once or more times but less than 3 times (per month) ☐ 3   7

Occasionally (less than once per month)   ☐ 4

Never   ☐ 5

Don't know   ☐ 9

19 | (c) - from Education Authority staff?

PLEASE TICK ONE BOX ONLY   (✓)

6 or more times (per month)   ☐ 1

3 or more times but less than 6 times (per month) ☐ 2

Once or more times but less than 3 times (per month) ☐ 3   8

Occasionally (less than once per month)   ☐ 4

Never   ☐ 5

Don't know   ☐ 9

Continued...

19	Continued

(d) – from or on behalf of a joint body?

PLEASE TICK ONE BOX ONLY   (✓)

6 or more times (per month)   ☐ 1

3 or more times but less than 6 times (per month)   ☐ 2

Once or more times but less than 3 times (per month)   ☐ 3

Occasionally (less than once per month)   ☐ 4

Never   ☐ 5

Don't know   ☐ 9

9

19	(e) – from voluntary and private organizations?

PLEASE TICK ONE BOX ONLY   (✓)

6 or more times (per month)   ☐ 1

3 or more times but less than 6 times (per month)   ☐ 2

Once or more times but less than 3 times (per month)   ☐ 3

Occasionally (less than once per month)   ☐ 4

Never   ☐ 5

Don't know   ☐ 9

10

20	(a) Are requests ever made for named information (that is, for names of people on the register or for information on the register about named people)?

PLEASE TICK ONE BOX ONLY (✓)

Yes   ☐ 1 ⟶ ANSWER Q.20 (b), (c), (d) and (e)

No   ☐ 2 ⟶ NOW GO TO Q.21

11

20	(b) Who is allowed to be given named information?	

PLEASE TICK ONE BOX ONLY (✓)

Members of staff of the information-providing
agencies if they have a legitimate interest
in the person or persons concerned [1]

Only senior members of staff of the
information-providing agencies [2]   12

Some other category of people (PLEASE SPECIFY) · [3]

....

....

....

....

20	(c) Must requests for named information be made in writing?	

PLEASE TICK ONE BOX ONLY (✓)

Yes [1]

No [2]   13

Sometimes [3]

20	(d) Before named information can be released, must a doctor or some other senior officer who is not on the staff of the register give his or her consent?	

PLEASE TICK ONE BOX ONLY (✓)

Yes [1]

No [2]   14

Sometimes [3]

20 (e) Describe briefly any advantages or disadvantages of the procedure for requesting named information.

PLEASE WRITE YOUR ANSWER IN THE BOX BELOW

21 (a) Which of the following types of information are stored on the register?

PLEASE TICK ALL BOXES THAT APPLY   (✓)

Basic details (name, address, date of birth, sex) | 1 | 15

Details of services used | 1 | 16

Information about the clients' relatives and/or domestic situation | 1 | 17

Information about the clients' medical condition | 1 | 18

Assessment of clients' abilities and disabilities (eg. scores on Kushlick's Wessex behaviour rating system) | 1 | 19

I.Q. | 1 | 20

Details of welfare benefits | 1 | 21

21	IF YOU HAVE TICKED <u>ALL SEVEN BOXES</u>, <u>OR SIX OF THE SEVEN BOXES</u> IN Q.21(a), ANSWER Q.21(b) and (c), OTHERWISE GO TO Q.22.		

21 (b) Which of the following types of information are requested <u>most often</u>?

TICK <u>TWO ONLY</u> OF THE BOXES BELOW   (✓)

Basic details (name, address, date of birth, sex)	1	22
Details of services used	1	23
Information about the clients' relatives and/or domestic situation	1	24
Information about the clients' medical condition	1	25
Assessment of clients' abilities and disabilities (eg. scores on Kushlick's Wessex behaviour rating system)	1	26
I.Q.	1	27
Details of welfare benefits	1	28

21 (c) Which of the following types of information are requested <u>least often</u>?

TICK <u>TWO ONLY</u> OF THE BOXES BELOW   (✓)

Basic details (name, address, date of birth, sex)	1	29
Details of services used	1	30
Information about the clients' relatives and/or domestic situation	1	31
Information about the clients' medical condition	1	32
Assessment of clients' abilities and disabilities (eg. scores on Kushlick's Wessex behaviour rating system)	1	33
I.Q.	1	34
Details of welfare benefits	1	35

22	In what year was the register first operational? PLEASE WRITE THE YEAR IN THE BOX BELOW	

23   (a) Do you think you know why the register was originally set up?

        PLEASE TICK ONE BOX ONLY   (✓   )

                   Yes   [1] ⟶ ANSWER Q.23(b)

                   No   [2] ⟶ NOW GO TO Q.24

23   (b) Why was the register originally set up?

        PLEASE WRITE YOUR ANSWER IN THE BOX BELOW

24 | What are the uses to which data from the register is <u>now</u> put?

PLEASE TICK ALL BOXES THAT APPLY   (✓)

Planning, monitoring and evaluation of the mental handicap service (IF POSSIBLE, PLEASE INDICATE HOW FREQUENTLY DATA IS USED FOR THIS PURPOSE)   1   41

....

....

Finding potential clients for some service or facility (IF POSSIBLE, PLEASE INDICATE HOW FREQUENTLY DATA IS USED FOR THIS PURPOSE)   1   42

....

....

Providing professionals with data about individual named clients (IF POSSIBLE, PLEASE INDICATE HOW FREQUENTLY DATA IS USED FOR THIS PURPOSE)   1   43

....

....

Facilitating a regular review of clients' needs (IF POSSIBLE, PLEASE INDICATE HOW FREQUENTLY DATA IS USED FOR THIS PURPOSE)   1   44

....

....

Research (IF POSSIBLE, PLEASE INDICATE HOW FREQUENTLY DATA IS USED FOR THIS PURPOSE)   1   45

....

....

Some other use(s) (PLEASE SPECIFY)   1   46

....

....

....

....

25 (a) Does the register make any other useful contribution to the service for mentally handicapped people and their families (i.e. any useful contribution to the service other than through the provision of information)?

PLEASE TICK ONE BOX ONLY (✓)

Yes	1	→ ANSWER Q.25(b)
No	2	→ NOW GO TO Q.26
Don't know	9	→ NOW GO TO Q.26

47

25 (b) What other useful contribution does the register make to the service for mentally handicapped people (i.e. other than through the provision of information)?

PLEASE TICK ALL BOXES THAT APPLY (✓)

The existence of the register increases the general level of cooperation between agencies   1   48

Home visits for the purpose of collecting information for the register give families a valuable opportunity to talk about their problems and to be informed about the service   1   49

The need to provide data for the register leads some service personnel to review their clients more efficiently   1   50

Some other benefit (PLEASE SPECIFY)   1   51

....

....

....

26 (a) Which of the following statements best describes your view of the extent to which data from the register is used?

PLEASE TICK ONE BOX ONLY (✓)

The planners and providers of the service make generally as much use of data from the register as they reasonably can   1 → NOW GO TO Q.27

The planners and providers of the service do <u>not</u> generally make as much use of data from the register as they might   2 → ANSWER Q.26(b)

52

Don't know   9 → NOW GO TO Q.27

26	(b) Why, in your view, do the planners and providers of the service not make as much use of data from the register as they reasonably can?	

PLEASE TICK ALL BOXES THAT APPLY (✓)

Because the planners and providers of the service do not know enough about the register	1	53
Because the register is not located close enough to the planners and providers of the service	1	54
Because staff working on the register do not have enough liaison with the planners and providers of the service	1	55
Because the planners and providers of the service do not themselves know what their information needs are	1	56
Because the provision and planning of services for mentally handicapped people is a low priority in the area	1	57
Because the agency which funds the register has insufficient liaison with the other agencies concerned with mentally handicapped people	1	58
For some other reason(s) (PLEASE SPECIFY)	1	59

....

....

....

....

27	How do the planners and providers of the service know about the register and its possible uses?	

PLEASE TICK ALL BOXES THAT APPLY (✓)

A number of them know about the register because they are involved in supplying information to it	1	60
Information about the register is sometimes distributed to a large number of staff in relevant positions and, as a result, they know more about its possible uses	1	61

Continued

27	Continued		

New staff in relevant positions are routinely informed about the register `[ 1 ]` 62

One or more of the staff of the register are actively involved in the planning and/or administration of the service `[ 1 ]` 63

A number of those now planning and administering the service were involved in setting up the register and so know about it and its uses `[ 1 ]` 64

One or more of the staff of the register make or have made deliberate efforts to inform the planners and providers of the service about the register `[ 1 ]` 65

In some other way(s) (PLEASE SPECIFY) `[ 1 ]` 66

....

....

....

---

28   (a) How accurate has the information on the register generally been found to be for its purposes?

PLEASE TICK ONE BOX ONLY (✓)

Very accurate `[ 1 ]` ⟶ NOW GO TO Q.29

Fairly accurate `[ 2 ]` ⟶ ⎤

Not accurate enough `[ 3 ]` ⟶ ⎦ ANSWER Q.28(b)   67

Don't know `[ 9 ]` ⟶ NOW GO TO Q.29

28   (b) What do you think are the reason(s) why the information is not as accurate as it might be?

PLEASE TICK ALL BOXES THAT APPLY   (✓)

Because some (or all) of it is collected by service personnel and the collection of data for the register is not one of their major priorities `[ 1 ]` 68

Because some (or all) of it is not updated often enough or has not been updated for some time `[ 1 ]` 69

For some other reason(s) (PLEASE SPECIFY) `[ 1 ]` 70

....

....

29 IF YOU WISH TO MAKE ANY OTHER POINTS WHICH YOU THINK WOULD BE
RELEVANT TO OUR STUDY, PLEASE MAKE THEM IN THE BOX BELOW.

THANK YOU FOR COMPLETING THIS QUESTIONNAIRE.

PLEASE SEND IT TO ME IN THE ENCLOSED STAMPED, ADDRESSED ENVELOPE,
TOGETHER WITH A BLANK COPY OF THE FORM STANDARDLY USED FOR
RECORDING DATA ABOUT CLIENTS.

John Cubbon
Research Associate
Department of Health Studies
Sheffield City Polytechnic

36 Collegiate Crescent
Sheffield S10 2BP
Telephone Sheffield 665274 (STD Code 0742)

Department of Health Studies

CASE REGISTERS FOR THE
MENTALLY HANDICAPPED: A
NATIONAL SURVEY & EVALUATION

Director: N A Malin BA MPhil PhD
Research Associate: J E Cubbon MA BPhil

Telephone: Extension 3355

I would be grateful if you could complete the enclosed questionnaire for our project on registers of mentally handicapped people. A stamped, addressed envelope is enclosed.

The Association of Directors of Social Services has approved the project and recommended it to Directors.

The project aims to collect information which will be of value to the mental handicap service:

- It will provide a detailed body of information about the whole range of types of mental handicap registers throughout the country. At the moment it is difficult for those developing registers to find out about a number of the alternative ways of running them.

- The ultimate goal of the project is to assess the advantages and disadvantages of different types of registers. Such an assessment should be helpful to the many Health and Local Authorities in which registers are currently being planned.

You will, in due course, be sent a copy of the report on the findings of the survey.

If your register is still in the process of being set up, please complete as much of the questionnaire as you are able, omitting any questions that are inappropriate.

A handout giving further details about the project and about registers in general is enclosed.

I would be grateful if you would return the questionnaire as soon as you can. If you have any questions at all about the project, or the questionnaire, do not hesitate to contact me.

Yours sincerely

John Cubbon
Research Associate

Serial number   1

Card number   4

---

1. What is the name or title of your job?

PLEASE WRITE YOUR ANSWER IN THE BOX BELOW

---

2. How is your mental handicap register funded?

PLEASE TICK ONE BOX ONLY   (✓)

By the Health Authority | 1 |

By the Local Authority | 2 |

By Joint Funding | 3 |

By some other agency (PLEASE SPECIFY) | 4 |

....

3.(a) How many staff work on the register **full-time**?

PLEASE WRITE YOUR ANSWER IN THE BOX BELOW

7

(b) How many staff work on the register **part-time**?

PLEASE WRITE YOUR ANSWER IN THE BOX BELOW

9

---

4. In what year was information from the register first used?

PLEASE WRITE THE YEAR IN THE BOX BELOW

11 12

5. Is your register still in the process of being set up?

Yes [1]

No [2]

15

6. What is the area covered by your register?

PLEASE TICK ONE BOX ONLY (✓)

The County [1]

The Borough [2]

The Health District [3]

16

The Health District and the Borough/County (where these coincide exactly) [4]

Some other geographical unit (PLEASE SPECIFY) [5]

....

....

7. How many clients are on your register (to the nearest hundred)?

PLEASE WRITE YOUR ANSWER IN THE BOX BELOW

[   ]

17 18
20 2

8. Which of the following provide the register with information about clients?

PLEASE TICK ALL BOXES THAT APPLY (✓)

Community Mental Handicap Team(s) [1] 22

NHS establishments or personnel or records [1] 23

General Practitioners [1] 24

Social Services establishments or personnel or records [1] 25

Education Authority establishments or personnel or records [1] 26

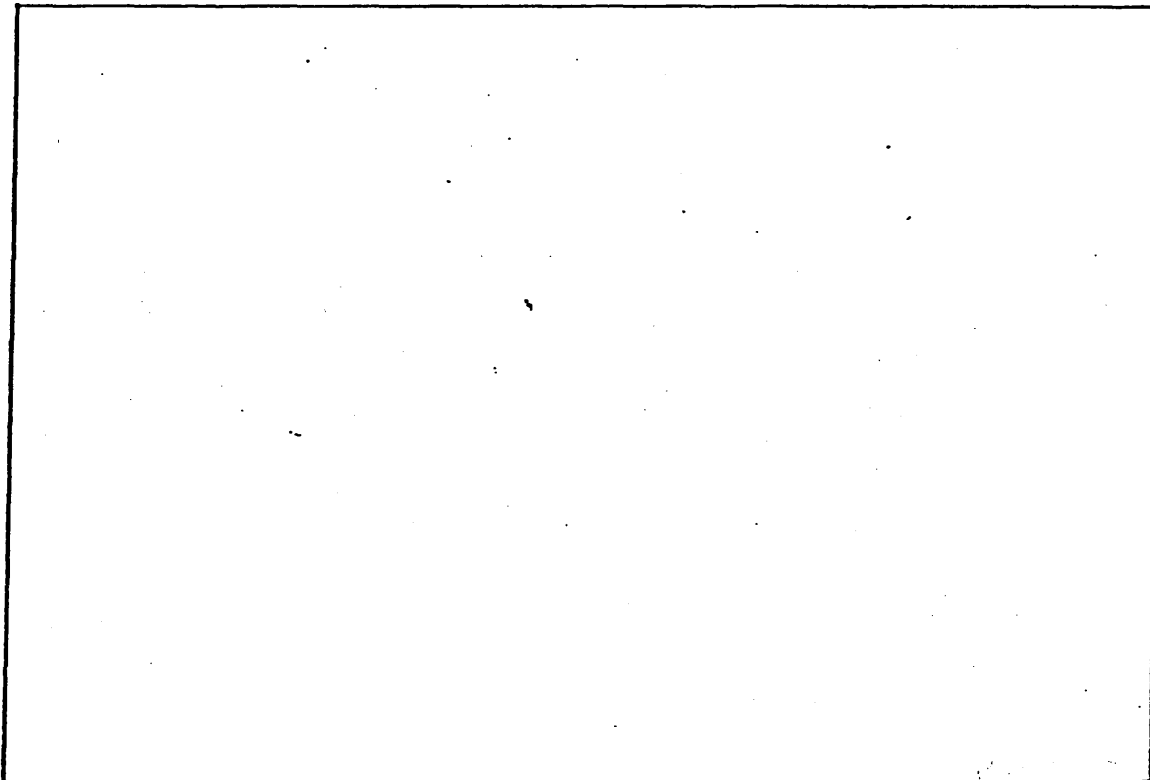Voluntary or private organizations or establishments [1] 27

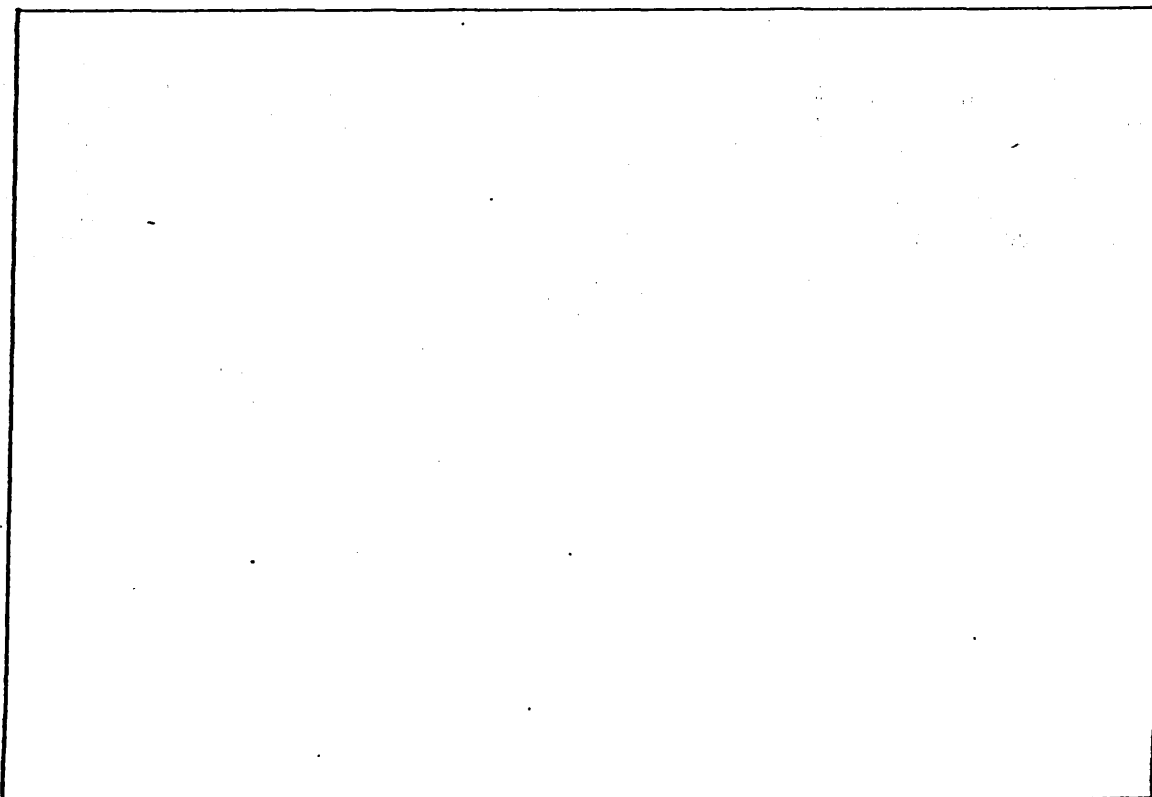Clients themselves or their families [1] 28

9.   How much co-operation have you had from the agencies which provide
     information?

PLEASE WRITE YOUR ANSWER IN THE BOX BELOW

10. How often in general is the information on the register updated?

PLEASE WRITE YOUR ANSWER IN THE BOX BELOW

PLEASE TICK ONE BOX ONLY (✓)

On a manual system [1]

On computer [2]   29

On a manual system and on computer [3]

---

12. Over the last year, how frequently on average has the register received requests for information per month?

(a) – from Health Service staff and GPs?

PLEASE TICK ONE BOX ONLY (✓)

6 or more times (per month) [1]

3 or more times but less than 6 times (per month) [2]

Once or more times but less than 3 times (per month) [3]   30

Occasionally (less than once per month) [4]

Never [5]

Don't know [8]

(b) – from the Social Services staff?

PLEASE TICK ONE BOX ONLY (✓)

6 or more times (per month) [1]

3 or more times but less than 6 times (per month) [2]

Once or more times but less than 3 times (per month) [3]

Occasionally (less than once per month) [4]   31

Never [5]

Don't know [8]

(c) – from Education Authority staff?

PLEASE TICK ONE BOX ONLY (✓)

6 or more times (per month) [1]

3 or more times but less than 6 times (per month) [2]

Once or more times but less than 3 times (per month) [3]

Occasionally (less than once per month) [4]   32

Never [5]

Don't know [8]

(d) – from or on behalf of a Joint Care Planning Team or some other joint body?

PLEASE TICK ONE BOX ONLY   (✓)

6 or more times (per month)   ☐ 1

3 or more times but less than 6 times (per month)   ☐ 2

Once or more times but less than 3 times (per month)   ☐ 3

Occasionally (less than once per month)   ☐ 4   33

Never   ☐ 5

Don't know   ☐ 8

(e) – from voluntary and private organizations?

PLEASE TICK ONE BOX ONLY   (✓)

6 or more times (per month)   ☐ 1

3 or more times but less than 6 times (per month)   ☐ 2

Once or more times but less than 3 times (per month)   ☐ 3

Occasionally (less than once per month)   ☐ 4   34

Never   ☐ 5

Don't know   ☐ 8

13.(a) Which of the following types of information are stored on the register?

PLEASE TICK ALL BOXES THAT APPLY   (✓)

Basic details (name, address, date of birth, sex)   ☐ 1   35

Details of services used   ☐ 1   36

Information about clients' relatives and/or domestic situation   ☐ 1   37

Information about the clients' medical condition   ☐ 1   38

Assessment of clients' abilities and disabilities (eg scores on Kushlick's Wessex behaviour rating system)   ☐ 1   39

I.Q.   ☐ 1   40

Details of welfare benefits   ☐ 1   41

IF YOU HAVE TICKED ALL SEVEN BOXES, OR SIX OF THE SEVEN BOXES IN 13.(a), ANSWER Q.13.(b) AND (c); OTHERWISE GO TO Q.14.

TICK TWO ONLY OF THE BOXES BELOW (✓)

Basic details (name, address, date of birth, sex) | 1 | 42

Details of services used | 1 | 43

Information about the clients' relatives and/or domestic situation | 1 | 44

Information about the clients' medical condition | 1 | 45

Assessment of clients' abilities and disabilities (eg. scores on Kushlick's Wessex behaviour rating system) | 1 | 46

I.Q. | 1 | 47

Details of welfare benefits | 1 | 48

13.(c) Which of the following types of information are requested least often?

TICK TWO ONLY OF THE BOXES BELOW (✓)

Basic details (name, address, date of birth, sex) | 1 | 49

Details of services used | 1 | 50

Information about the clients' relatives and/or domestic situation | 1 | 51

Information about the clients' medical condition | 1 | 52

Assessment of clients' abilities and disabilities (eg. scores on Kushlick's Wessex behaviour rating system) | 1 | 53

I.Q. | 1 | 54

Details of welfare benefits | 1 | 55

14. Is data from the register now being used in any of the following ways?

PLEASE TICK ALL BOXES THAT APPLY (✓)

For finding potential clients for some service or facility | 1 | 56

For providing professionals with data about individual named clients | 1 | 57

For facilitating a regular review of clients' needs | 1 | 58

For research | 1 | 59

For planning, monitoring and evaluation of the mental handicap service | 1 | 60

For some other purpose(s) (PLEASE SPECIFY) | 1 | 61

....

....

15.(a) Which of the following statements best describes your view of the extent to which information from the register is used?

PLEASE TICK ONE BOX ONLY (✓)

The planners and providers of the service make generally as much use of data from the register as they reasonably can
`[ 1 ]` → NOW GO TO Q.16

The planners and providers of the service do <u>not</u> generally make as much use of data from the register as they might
`[ 2 ]` → ANSWER Q.15(b)

62

Information from the register has not yet been used by planners and providers of the service
`[ 3 ]` → NOW GO TO Q.16

Don't know
`[ 8 ]` → NOW GO TO Q.16

15.(b) Why, in your view, do the planners and providers of the service not make as much use of data from the register as they reasonably can?

PLEASE TICK ALL BOXES THAT APPLY (✓)

Because the planners and providers of the service do not know enough about the register
`[ 1 ]` 63

Because the planners and providers of the service are sceptical about the value of the information on the register
`[ 1 ]` 64

Because the register is not located close enough to the planners and providers of the service
`[ 1 ]` 65

Because staff working on the register do not have enough liaison with the planners and providers of the service
`[ 1 ]` 66

Because the planners and providers of the service do not themselves know what their information needs are
`[ 1 ]` 67

Because the provision and planning of services for mentally handicapped people is a low priority in the area
`[ 1 ]` 68

Because the agency which funds the register has insufficient liaison with the other agencies concerned with mentally handicapped people
`[ 1 ]` 69

For some other reason(s) (PLEASE SPECIFY)
`[ 1 ]` 70

....

....
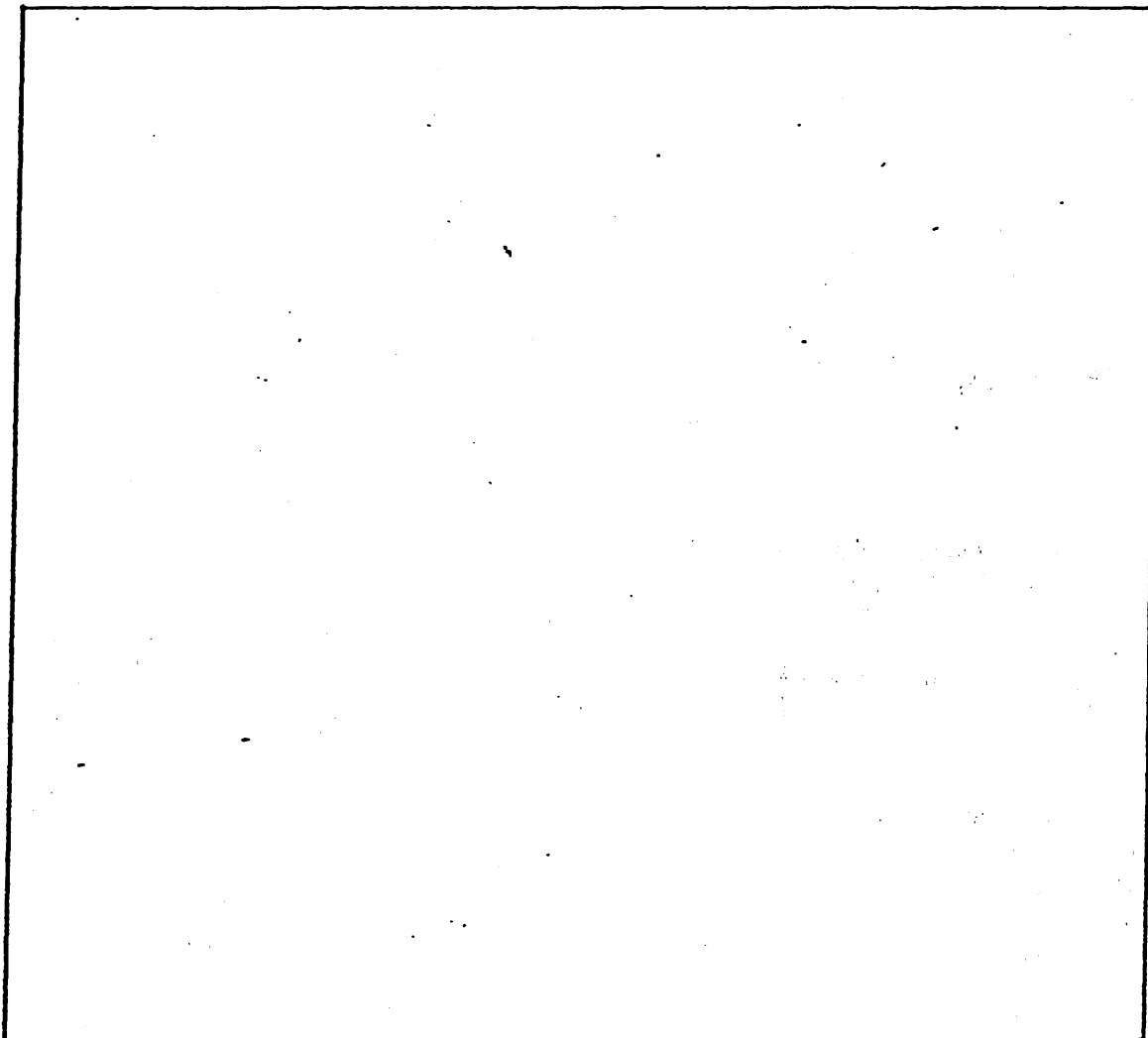
....

16. IF THERE IS ANY WRITTEN INFORMATION ABOUT YOUR REGISTER RELEVANT TO OUR RESEARCH PROJECT, PLEASE ENCLOSE IT WITH THIS QUESTIONNAIRE.

IF YOU WISH TO MAKE ANY OTHER POINTS ABOUT YOUR REGISTER, PLEASE MAKE THEM IN THE BOX BELOW.

MANY THANKS FOR COMPLETING THIS QUESTIONNAIRE.

PLEASE SEND IT TO ME IN THE ENCLOSED STAMPED, ADDRESSED ENVELOPE TOGETHER WITH ANY WRITTEN MATERIAL WHICH YOU CONSIDER RELEVANT.

John Cubbon
Research Associate
Department of Health Studies
Sheffield City Polytechnic

SCHEDULE OF QUESTIONS FOR OPERATORS OF MENTAL HANDICAP REGISTERS

STAFFING

1.1   You wrote on the questionnaire that... staff worked full

        time and... staff part-time on the register. Could you

        tell me what their grades are?

1.2   Could you estimate the number of hours that [each of the

        register staff] spends working on the register?

1.3   Could you describe what [each of the register-staff] does?

ORGANISATION OF DATA COLLECTION

2.1   Could you describe the ways in which information passes from

        grass-roots level to the register?

        ALL AGENCIES? ALL TYPES OF ESTABLISHMENT? ALL TYPES OF

        STAFF?

2.2   INVOLVEMENT OF REGISTER STAFF IN DATA-COLLECTION.

2.3   INVOLVEMENT OF STAFF OUTSIDE THE REGISTER IN DATA-

        COLLECTION?

2.4   Please could I have a blank copy of the form on which

        information about each subject is recorded?

2.4.1   Does your register record scores on Kushlick's Wessex

        Behaviour Rating System?

        IF 'YES' GO TO 2.4.1.1

2.4.1.1 How useful do you find these scores?

COOPERATION

2.5   How much work does data-collection for the register make for

        staff outside? (Is this a significant amount of work?)

2.6   NATURE OF THE CONTACT BETWEEN REGISTER STAFF AND STAFF

        OUTSIDE INVOLVED IN DATA COLLECTION.

3.0　　　　Is the information on the register generally accurate enough

　　　　　for its purposes?

　　　　　IF "NO" GO TO 3.1.

3.1　　　　Why do you think the information on the register is not

　　　　　generally accurate enough for its purposes?

ACCESS TO NAMED INFORMATION

4.0　　　　Is the consent of the subject or his family to registration

　　　　　sought, where possible?

　　　　　IF "YES" GO TO 4.1.

4.1　　　　Why is the consent of the subject or his family sought?

4.2　　　　Before the consent of the subject or his family is sought

　　　　　what are they told about the register?

4.3　　　　How often has consent to registration been refused?

　　　　　IF THERE HAVE BEEN REFUSALS GO TO 4.3.1.

4.3.1　　　Have [refusals to the register] significantly affected the

　　　　　accuracy of the register?

4.4　　　　How is the consent of the subject or his family sought?

4.5　　　　How long does it usually take to seek the consent of

　　　　　[the subject and/or his family]? Do you think this is a

　　　　　significant amount of time?

5.0　　　　Are requests ever made for named information - that is,

　　　　　names of people on the register or information on the

　　　　　register about named people?

　　　　　IF "YES" GO TO 5.1.

5.1　　　　Who is allowed to be given named information?

　　　　　REQUESTS ONLY TO BE MADE BY STAFF ABOVE A CERTAIN LEVEL

　　　　　OF SENIORITY?

5.2　　　　Before named information is released, should by procedure

　　　　　be followed?

　　　　　IF "YES" GO TO 5.2.1.

5.2.1   What procedure [should be followed]?

5.3   Must requests for named information be made in writing?

5.4   Before named information can be released, should the consent
of anyone outside the staff of the register be given?
Whose consent should be given?

5.5   How long usually does it take for a request for named
information to be answered? Why does it take this amount
of time?

IF STAFF OF WELFARE AGENCIES DO NOT HAVE QUICK AND EASY
ACCESS TO NAMED INFORMATION, GO TO 5.6.

5.6   Are staff outside the register at all inconvenienced by the
rules for issuing named information?

WHY WAS THE REGISTER SET UP?

6.0   Do you know why the register was set up?
IF "YES", GO TO 6.1.

6.1   What do you think was the reason or reasons for your
register being set up?

SPECIFIC USES

* 7.1   You indicated on the questionnaire that the register was
used in planning, monitoring and evaluation of the mental
handicap service. Could you give me some examples of this?
How do data from the register come to the attention of
people involved in planning?

* 7.2   You indicated on the questionnaire that the register was
used to provide professionals with data about individual
named clients. What types of information do the
professionals request? And what do they use it for?

*   7.3   You indicated on the questionnaire that the register was

              used to facilitate a regular review of clients' needs.

              Could you describe how it does this?

    7.4   Do you think that there are any types of data held on the

              register which are not really needed?

EXTENT OF USE OF THE REGISTER

*   8.1   You indicated on the questionnaire that the service planners

              and providers make generally as much use of data from the

              register as they reasonably can. Would you like to say a

              bit more about this?

*   8.1.1   Do you think there is any special feature of the register

              which promotes its use by staff outside?

*   8.1.2   Do you think there is any special feature of the service

              for mentally handicapped people in... which promotes use

              of the register by staff outside?

*   8.2   You indicated on the questionnaire that the service planners

              and providers don't generally make as much use of data from

              the register as they might. And you were then asked to say

              why in your view this was so.

*   8.2.1   One of the reasons that you gave was that the service

              planners and providers do not know enough about the register.

              register. Why do you think it is that they don't know enough

              about it? How in your view could [their] knowledge of the

              register be improved so that they would make more use of it?

*   8.2.2   A reason that you gave was that the service planners and

              providers are sceptical about the value of the register.

              Why do you think this is the case?

*   8.2.3   A reason that you gave was that the register is not

              located close enough to the service providers and planners.

              Could you say a bit more about this?

^ 8.2.4   A reason that you gave us was that staff working on the

               register do not have enough liaison with the service

               planners and providers. Why is this?

* 8.2.5   A reason that you gave us was that the service planners

               and providers do not themselves know what their

               information needs are. What makes you think this? How

               could this knowledge of information needs be improved?

* 8.2.6   A reason that you gave was that the provision and planning

               of services for the mentally handicapped people is a low

               priority in the area. What makes you think this?

* 8.2.7   A reason that you gave was that [the agency which funds

               the register] has insufficient liaison with the other

               agencies concerned with mentally handicapped people.

               Why do you think this is the case?

* 8.2.8   EXPLORE ANY OTHER REASONS GIVEN FOR INSUFFICIENT USE

* 8.2.9   Do you think there are any other reasons why the register

               is not used as much as it might be?

* 8.2.10   Is there any group of staff which fails to make use of

               the register more than the rest?

               IF YES GO TO 8.2.10.1

* 8.2.10.1   How do service providers and planners know about the

               register and its possible uses?

* 8.3   How would you like the register to be used?

               IF RESPONDENTS WHO HAD PRAISE FOR THE COOPERATION FROM

               INFORMATION-SUPPLYING AGENCIES AND YET INDICATED THAT

               SERVICE PROVIDERS AND PLANNERS DID NOT MAKE SUFFICIENT

               USE OF THE REGISTER, GO TO 8.4

* 8.4   You gave a favourable account of cooperation from

               information-supply agencies and yet you indicated that

               service planners and providers did not make as much use

               of the register as they might. Why then are people

               outside the register better at providing information

               to the register than requesting it?

FUNDING FOR REGISTERS

* 9.1   You wrote on the questionnaire that your register receives

            Joint Finance. Can you give me details of this? HOW LONG

            FOR? WHAT DOES THE JOINT FINANCE PAY FOR? Will the

            changeover to financing by the Local Authority affect the

            way the register is run? How will it affect it?

* 9.2   Did you register ever receive Joint Finance? When did it

            start? How long did it last? What did it pay for? How

            did the changeover from Joint Finance to funding by the

            Local Authority affect the register?

OUTSIDE ADVICE TAKEN WHILE THE REGISTER WAS SET UP

10.0   Were you involved in planning the register?

            IF YES GO TO 7.1

10.1   Was information about the register taken into consider-

            ation while you register was being planned?

            IF YES GO TO 7.1.1

10.1.1   From which register [did the Authority get information]?

            What sort of contact did you have with them?

            How did you find out about these registers? How useful

            was this information?

10.1.2   Were any registers visited? Who went on visit(s)?

            How useful were they/was it?

10.1.3   Apart from other registers where else did you get advice

            on the setting-up of a register? What was this advice?

MISCELLANEOUS

11.0   How worthwhile has the register been?

12.0   Right, I've come to the end of specific questions I was

            going to ask you. Is there any aspect of the register

            which you feel is important but which hasn't been covered

            yet in our discussion?

Instructions to the interviewer and areas to cover are given in capitals.

Asterisked questions were only asked if the answers on the questionnaire showed that they were appropriate.

The emergence of mental handicap registers

John Cubbon

SUMMARY. An ever-increasing number of registers is being set up. These are essentially planning tools which are more sophisticated than the records generally held by the welfare agencies. Their emergence is symptomatic of a greater emphasis on planning and the need to establish locally-based services. Joint Funding has boosted the formation of registers by financing their establishment and that of a more localised service, and this is aided by the rapidly diminishing price of necessary computer facilities. The introduction of coordinated community services has provided a means of collecting and organising data, as well as constituting another reason for starting registers.

What is a mental handicap register?

In recent years there has been a marked growth in the number of registers of people who are mentally handicapped. The response to a circular we despatched on 2nd August 1983 revealed that 98 of the 318 health authorities and social services departments in England and Wales had registers and that 141 were planning them.

All social services departments and health authorities keep records on their clients or patients who are mentally handicapped; but in general these do not amount to registers. The primary purpose of most mental handicap registers is to provide planning information. Planning for a section of the population of a district can only be effective if there is a full and accurate picture of need. For people with mental handicaps such a picture is only possible if there is a set of records which:

(1) lists as many of the people with mental handicaps as possible in the district;

(2) has up-to-date, basic identifying information about the people listed and the services that they receive;

(3) is of such a form that planning data can be easily extracted from it.

A set of records which meets these conditions can be defined as a "mental handicap register". The conditions can generally be satisfied when health authorities and social services departments combine their data-bases because there are usually some people who are known to one agency but not to the other. If the combined data-base is run efficiently, it will contain regularly updated identifying details and informaton about service use, and statistics for planning will be easy to extract — for example, the number of people in an age-group, the number of people without day care provision, and so on.

The need for registers

Over the last quarter-century there has been increasing emphasis on planning in social welfare (Glennerster, 1981). This has led to the use of more sophisticated and precise planning instruments, such as registers.

Since the 'sixties health and local authorities have made efforts to establish a community-based service for people with mental handicaps. The need to plan the new service and to monitor its operation has led to a recognition of the importance of detailed knowledge about those for whom the service is intended (Cleveland, 1983; Wirral MHAC, 1979). This need has been especially acute in the many authorities with little or no experience of mental handicap. Also, when capital developments are being contemplated it is vital that the facilities planned should meet the needs of the people who will use them.

Official bodies have several times recommended action which would fit in neatly with the establishment of registers; but they have never recommended that registers should be set up in every district.

The root cause of the moves to set up a locally-based service has, of course, been a change in attitudes (Simon, 1981). This has brought about pressure for a new service in two ways: directly, by leading to different attitudes in the planners and providers of services at local level; and, less directly, by being reflected in the recommendations of official bodies which have then been implemented at local level.

Throughout the 'fifties and 'sixties an accumulation of evidence implied that people with mental handicap were not ideally placed in institutions away from the community (Malin, Race, and Jones, 1980, pp 44-66). Since then more and more parents, professionals, administrators, and others have been convinced of the need for change. Though not as radical as some had hoped, the White Paper *Better Services for the Mentally Handicapped* (DHSS, 1971) called for a considerable shift towards care in the community. Its ideology was taken futher in booklets produced by the National Development Group (NDG) and the Development Team for the Mentally Handicapped (DTMH). All these publications have been given close attention at local level.

The White Paper took the view that better information about the numbers of people requiring particular forms of help was needed, and offered estimates on the basis of surveys in a few areas (DHSS, 1971, paras. 21-22). However the Review of the White Paper *Mental Handicap: Progress, Problems and Priorities* (DHSS, 1980) demonstrated that the results of a few surveys could not be applied to the rest of the country. The data from five registers was examined: the average prevalence rate ranged from 3.4 to 2.9 per 1000. The Review concluded that a single national prevalence rate was not appropriate, but its support for registers was only lukewarm. Though health and local authorities were urged to make a joint assessment of needs by looking at the number of people with mental handicap who receive or have received services, it did not specifically recommend that more registers should be set up (DHSS, 1980, pp 28-30). This remains Government policy.

The NDG suggested collection of data on people currently receiving services or requiring them, but it did not view the establishment of new registers, though commendable, as necessary. Instead it recommended a "straightforward list" of people with mental handicaps, as known to each authority, which would give: names, addresses, and brief details of disability; services provided and services required; and which would be equally and freely available to health and local authorities (NDG, 1976, paras. 6-8). Such a list could well meet the three criteria given earlier for a "register".

DTMH Reports have made it quite clear that new services have been planned in some areas on assumptions which are largely out-of-date, or which have never been adequately validated. Moreover, the DTMH may well have recommended the

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setting up of registers in some of the areas that it has visited.

The importance of knowing about as many as possible of the people with mental handicap in the community, many of whom have received either an inadequate service or nothing at all, is now realised. Planning a local service led to a recognition of the need for adequate information about the people for whom the service was intended. Local authorities were to plan, not just for the return of people in hospital for whom they were responsible (whom they knew) but also for people in their areas who in future might need some form of residential accommodation (whom they often did not know). Some respondents to the 1983 circular indicated, of their own accord, that concern about their incomplete knowledge of people with mental handicap within their populations had been an important reason for beginning a register.

Insufficient knowledge is partly the result of inadequate communication between agencies. This has harmful effects at both individual and policy making levels. Sometimes health authorities fail to notify social services departments when children are identified as mentally handicapped. Consultants may not consider it worthwhile to pass on the information. Links between hospital social workers and those in social services are often unsatisfactory. And some social services departments, aware that referrals are not being made, do not seek information from health or education authorities and so have incorrect estimates of numbers (DTMH, 1980, para. 20). Several authorities have felt that registers could contribute to an improvement in the flow of information (Jones, 1979, p. 11; Wirral Mental Handicap Advisory Committee, 1979; Kerry, 1980, p.13).

Why registers have become possible

Registers are essentially joint enterprises, both the products and the tools of collaboration of the agencies involved in mental handicap. As already stated, various statutory devices promoting collaboration between these agencies have facilitated development of community-based services and the emergence of registers.

The most important of these devices is Joint Funding. Within the total allocation of funds to health authorities, a specified amount is earmarked to finance, partly or wholly, the establishment and initial operation of a project which is in the interests of the NHS as well as the local authority, and which can be expected to make a better contribution in terms of total care than if directly applied to health services only (DHSS, 1976, para. 6; DHSS, 1977, para. 6). Generally, projects which meet the criteria for Joint Funding promote a shift of care from hospital to community and are directed towards priority groups. Money received from

health authorities under Joint Funding is a bonus to local authorities; their other sources of income are not reduced (DHSS, 1977).

The incentive for local authorities to use Joint Funding is that it makes extra funds available for schemes they might wish to set up anyway. The incentive for health authorities is perhaps less obvious, since Joint Funding involves them in transferring funds to local authorities. Their Joint Funding allocations, however, cannot be used for any other purpose; and schemes which qualify for Joint Funding generally promote a transfer of people from NHS establishments to the care of local authorities, ultimately reducing the overall expenditure of health authorities. Several respondents to the 1983 circular mentioned that Joint Funding had been used in setting up their registers.

The increased availability of computer facilities is a great advantage, enabling both individual items of data and statistical information to be quickly and easily extracted. This is especially valuable in planning. To find out how many clients could benefit from a particular service, for example, need not be a problem on a computerised register; whereas manual records may involve working laboriously through files or cards.

In the early days, costs of computer hardware and software were considerable so that registers tended to be financed by grants from outside bodies — for example, the DHSS and MRC. Now, registers can be set up and run on microcomputers very much more cheaply, and this is probably why so many agencies are currently introducing registers. Several respondents to the 1983 circular were transferring registers from a manual system to computer, or from one type of computer to another, a reflection of the rate of change in the computing facilities available to local and health authorities.

More comprehensive multidisciplinary community services have needed better information about people with mental handicap locally, and have also provided the means of collecting information more efficiently. Registers are natural concomitants of the community mental handicap teams (CMHT's) which have been set up in many districts over the last few years (Plank, 1982). The general aim of CMHT's is to enhance joint working in the delivery of services. Collaboration among agencies working with people who are mentally handicapped in the population of a given geographical area is always the first step towards the development of a comprehensive mental handicap register. The creation of CMHT's has often been accompanied by the appointment of professionals with new roles, such as specialist social workers and community nurses, who have been well-placed to collect information for registers. CMHT's which endeavour to maintain contact with all the people with mental

handicap in their territory need to know: where they are, their degree of incapacity, and the services they receive (Jones, 1979, p.11). As CMHT members may not meet very often, a central record will do much to integrate their activities. Registers will also be useful if, as the Court Report recommends, CMHT's are to monitor the effectiveness of the service provided (DHSS, 1976, Vol. I, paras 14, 24).

To conclude

There is no doubt that mental handicap registers are in vogue at the moment. Their popularity is revealed by the startlingly large number of authorities planning to set them up. The cheapness of computers, the availability of Joint Finance, and the introduction of coordinated community services provide the means to their establishment. However, it remains to be seen whether registers will continue to proliferate as the purse-strings of health and local authorities are tightened.

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Integrating mental handicap registers with service provision

John Cubbon

SUMMARY. There is growing support for specialist social workers and other CMHT members to have contact with all the people in their area who are mentally handicapped, and for widespread use of regular multidisciplinary reviews. As well as having preventive and other functions, these processes provide the basis for a mental handicap register which can hold all the data needed in planning. If there is contact with the great majority of people with mental handicap in a district or if the users of mental handicap services are regularly reviewed, registers can be set up at almost no extra expense. However, many districts do not yet have the necessary contact or review system. The possibility of integrating registers with service provision should be considered by the many authorities planning to set up registers.

Introduction

Mental handicap registers are mostly used to plan, monitor, and evaluate services. They have transformed the planning process by giving it a more rational, statistical basis. Most have data collection processes which are largely separate from the rest of the service.

A postal survey of English registers, and detailed interviews with register operators in London and within 80 miles of Sheffield, has shown that as a result of recent developments (see Cubbon, 1984), greater integration with the work of service providers is possible.

Basing registers on comprehensive community services

The interviews revealed that there is considerable support for the principle of specialist social workers or other members of community mental handicap teams (CMHT's) having regular contact with every person who is mentally handicapped. Regular visits to families who were not presenting problems were thought to have a preventive function: for example, if circumstances changed so that help might be needed, likely difficulties could be anticipated and steps taken to reduce them. Also, visits enabled everyone to find out about the services available and how they were being developed.

There is also growing support for regular reviews at which all the professionals working with a person who is mentally handicapped meet. Each can find out what goals the others have and how they see the person's problems. His progress can be reviewed and a plan agreed. This may take the form of an Individual Program Plan (IPP) which is a detailed account of an individual's needs and the steps that should be taken to meet them (Blunden, R., 1980; Houts, P. S., Scott, R. A., 1975). The review system ensures that all parts of the service are fully attentive to the needs of clients.

Regular contact with everyone who is mentally handicapped and multidisciplinary reviews of service users are both very expensive; and many authorities probably lack the resources for

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either. But, if comprehensive coverage *is* established, a register can be maintained at almost no extra cost. One of the main distinguishing features of a register is that it aims to be up-to-date and complete. Regular contact and multidisciplinary reviews generate up-to-date information which will be very useful in planning.

Following contact with a client professionals are usually expected to record in case notes the individual's changes of address, circumstances, and use of services. This procedure serves as an *aide-memoire* and also enables others to help the individual effectively if he is referred to them. It has, therefore, an important function, whether or not there is a register. If professionals have contact with all people with mental handicap in a district, a register holding basic and service details can be maintained relatively painlessly: professionals make changes as they normally would in case-notes, and this information is simply transferred to the register.

At multidisciplinary reviews personal and service data will be assembled and decisions taken on individuals' needs. This information is often recorded in note form for future reference — for example, to facilitate assessment of an individual's progress when he is next reviewed. Little extra work is needed to record the information also in a form which would supply statistics for planning.

The great advantage of a register based on contact and multidisciplinary reviews is that the data are already being collected for other purposes and almost no extra effort is required.

Types of data which registers should hold

Contacts and reviews generate all the types of data needed for a register to be an effective planning tool. The postal survey revealed that data most frequently requested from registers were names, addresses, dates of birth, services used, and assessment of abilities. As one experienced register-operator put it, the simpler the information, the more useful it is.

Identifying and service details can be collected in visits by professionals, and perhaps checked at reviews. Addresses provide an invaluable guide to the siting of services. Ages indicate future demand; for example, the number of people approaching school-leaving age indicates how many places are likely to be needed at ATC's.

Measuring need

Information about current use of services can assist planning in a number of ways. If an authority knows the number of people in mental handicap hospitals outside of its area for whom it has responsibility, it can make a start on planning their return. Knowledge of numbers of people not using some service can indicate either whether the service is not really necessary or whether people are unaware of it. Knowing the number of people with mental handicaps living in the community, being cared for by a single person or someone over 60, will assist both in the planning of residential services and in drawing up lists of parents with whom the possibility of children leaving home could be discussed.

A more sensitive measure of need is provided by assessment of individual abilities. The method adopted by most registers is Kushlick's *Wessex Behaviour Rating System*. This is made up

of subscales on incontinence, mobility, behaviour problems, speech, feeding, washing, dressing, reading, and writing. Subjects receive a score of 1, 2, or 3 for each subscale: 1 denotes a high level of disability, 3 none or almost none. Scores are summed to obtain a measure of overall incapacity (Kushlick, Blunden, and Cox, 1973). Perhaps the most significant finding of the interviews was that many register-operators were dissatisfied with the Wessex Scale as a guide in the planning of services. Several interviewees pointed out that people with similar scores could have very different service needs. For example, the same behaviour might be regarded as difficult and disruptive in one situation and unremarkable in another. There is increasing dissatisfaction with the view that a high level of disability, as indicated by the Scale, should be associated with a particular type of day or residential care facility.

A detailed study (Malin, 1980) has shown the importance of group behaviour for the success of group homes. It concludes that people with a wide range of mental handicaps can live in them and that no clear-cut criteria for admission can be given since the right combination of individuals is essential.

Many register operators said that they wished that their registers held information specifically on the services which their clients needed. Such information emerges naturally from reviews. One register, based on reviews, recorded accommodation needs, for example, for "own home with relatives", "minimum support hostel", "fostering", "own independent home", and so on. Another specified need in terms of five alternative settings with different levels of support.

Assessments of service need made at reviews, which might take the form of IPP's, should be formulated in writing in as much detail as necessary. They should be put on the (ideally computerised) register in coded form in less detail, so that statistics useful in planning and monitoring can be calculated. For example, the written record might have "Mr. Jones will arrange one week short-term care every six months", which might be stored on the register simply as "Need for six-monthly short-term care". Assessments of service need are certainly subjective; but if they are made by groups of professionals rather than individuals they are likely to be less idiosyncratic.

Other benefits of integrating registers

Integration of data collection with other processes as advocated in this article has advantages over methods which inhibit the normal flow of the service. For example, register staff who collect data by visiting establishments and professionals must to some extent interrupt the day-to-day work of the service providers. Similarly, staff in the field may consider that the requests for information which some registers send them are unrelated to their normal work.

A CMHT is probably the most obvious vehicle for the operation of a register based on reviews and routine contacts. It needs to have comprehensive coverage of a district's mentally handicapped population. Though this is not a role envisaged for CMHT's by the DTMH (1982), it is strongly favoured by the members of several CMHT's because of its preventive function. A few registers are operated very successfully by specialist mental handicap social workers who are in regular contact with the total mentally handicapped population. This level of coverage by social workers has been supported by the Independent Development Council (1982).

A register maintained by specialist social workers or other CMHT members in their work would probably not be as remote from them as one operated separately so that they may be more inclined to use it. A register might hold data kept elsewhere in greater detail, but it should be possible to extract data from it much more quickly. Even a register in the form of a card-index can be more accessible for some purposes than individuals' case-work files. A register can also be used as an administrative or clerical tool, for example, for facilitating regular reviews.

The prospects for service-based registers

The great barrier to the establishment of registers which are

integrated with the rest of the service is that specialist social workers or other CMHT members need to be in regular contact with all the people in an area who are mentally handicapped. Preferably also, they should be able to give them all regular reviews to assess service needs. Although both these procedures have major benefits in addition to the provision of data for a register, many authorities might consider them too expensive. However, existing systems of review and contact can be built on. Although a register which covers almost all the people in an area will not be accurate enough for epidemiological research, it can still be useful in planning which is, after all, its prime function.

Many authorities are planning registers. Usually they hear about and visit the long-standing registers compiled separately from services. They seldom hear of the recent wave of registers which have grown up naturally at grass-root levels out of a more community-based service. These registers are based on processes which have merits quite apart from the collection of register-data. They can be run cheaply and efficiently; and authorities looking into the possibility of establishing registers should certainly give them consideration.

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Keeping tabs on mental handicap

The benefits of registers in planning services for mentally handicapped people are easy to see but are they being used to best advantage and does everyone understand the need to co-operate? John Cubbon and Nigel Malin describe the findings of their survey

IN THE LAST few years registers of mentally handicapped people have been set up in ever-increasing numbers. They can make the planning of mental handicap services more rational by providing hard, comprehensive data from all agencies, thereby lessening the need for guesswork and the impressions of professionals and others who have only a partial knowledge of the total service.

In a survey conducted by the authors, however, there were indications that the potential of English registers has not always been used fully, often because of organisational failure and ignorance on the part of the planners.

The development of community-based services for mentally handicapped people began officially with the 1971 Government White Paper, 'Better services for the mentally handicapped'[1], which recommended shifting responsibility of care from health to local authorities and from hospital to residential homes and training centres. The use of locally-based registers in planning gained credence. The White Paper proposed a 20-year national plan based on data from three existing registers in Wessex, Newcastle and Camberwell.

During the 1970s the mood of gradual expansion culminated in a large number of plans, 'mainly emanating from health authorities, with a few from local authorities or as a collaborative exercise'[2]. An overall philosophy of service provision emerged, initiated by the Jay Report in 1979[3], stressing the need to regard mentally handicapped people as members of the public, entitled to a lifestyle which was valued and as close as possible to that of non-handicapped people.

Surprising increase in registers

These developments appear to have been accompanied by an interest in local surveys of need. Government advice has not remained consistently in favour of setting up registers and the 1980 DHSS[4] review of the earlier White Paper stated that the cost involved in setting up a register and its use should be seriously reconsidered. (This was reiterated by the National Development Group for the Mentally Handicapped.)

The rise in the number of registers since 1974 is, therefore, at first sight surprising, for

'Planning is still largely undertaken on the assumption that a group of people with mental handicap have identical needs which can be met in identical ways, and that they wish to spend all their time with others like themselves'

this is precisely the period in which the money available to health and local authorities has been dwindling. The reason given for setting up a mental handicap register is often the need for a radical change in the service to one that is community based. Part of the reason must also be cheaper computers. It is now possible to operate a register holding substantial information on anything up to 2,000 mentally handicapped people on a microcomputer[5] costing less than £10,000.

Paradox of priority in DHSS policy

However, much of the increase in the rate of introducing registers can be attributed to joint finance[6,7], hence the importance of using a locally based register for service provision. Health authorities, social service departments, education departments and voluntary organisations all have a stake in providing services for mentally handicapped people. But if a coordinated and planned response is required then there is a case for basing registers on whole areas.

Collaboration between health and local authorities has been well-examined by Glennerster[8] who claims that there is a paradox in DHSS policy of giving priority to groups such as mentally handicapped people while at the same time promoting organisational cohesiveness through central strategy[9,10,11].

The 1973 White Paper on collaboration between NHS and local government[12] produced recommendations that formed the basis of new joint machinery introduced in 1976-77 which led to joint care planning teams. Subsequently the Care in the Community document[13] sponsored the extension of joint financing, the shift of responsibility for care from health to local authorities through direct lump sum payments on an individual basis, and the overall movement towards coordinated agency action in meeting the needs of priority groups. All of this has added momentum to the setting up of the registers.

Eighteen months ago the authors began a study of mental handicap registers in England and Wales, financed by the Economic and Social Research Council, which aimed to identify the nature and function of registers and establish their relevance to planning. The

first part of the fieldwork has been a postal survey of the English ones, to which 95 per cent responded.

Our survey has shown that the rate at which registers are being set up has never been higher. In 1977 two registers became operational; in 1979, three; in 1981, seven; and in 1983, ten. Of the 59 registers now in existence, 34 were still being set up. Of the registers now operational, 20 (34 per cent) are funded by the local authority; 16 (27 per cent) receive joint funding; 12 (20 per cent) are funded by the health authority; and 11 (19 per cent) are funded in some other way. Those receiving joint finance were all set up after 1980. The high proportion of registers funded by the local authority may also reflect the availability of joint finance.

Most of the registers covered areas which coincided with the boundaries of single health authorities or social service departments; 24 (41 per cent) are maintained by a single member of staff working part-time; only 8 registers (14 per cent) have staff working on them full time. Statistics of use in planning are obviously more quickly and easily available if registers are computerised, yet 26 (44 per cent) were held manually.

Several respondents had plans or hopes for the computerisation of their registers. Though computers have been seen as increasing the danger of information coming into unauthorised hands, some computerised registers can be made to give specified groups of people access only to particular parts of what is stored[14].

Registers vary in the amount of data that they hold on each client. All the registers held basic details such as name, address, date of birth and sex; 92 per cent held details of services used; 86 per cent information about relatives and/or domestic situation; 66 per cent medical condition; 54 per cent an assessment of clients' abilities and disabilities; 22 per cent IQ and welfare benefits. This data needs continual updating to be effective for service providers. Most registers are revised at least once a year and there has been general agreement on an annual update as an absolute minimum[15]. '

Basic information wanted most

The simpler the information, the more useful it appeared to be. The most frequent inquiries were for basic details, details of services used — both of which are cheap and easy to collect — and assessments of abilities and disabilities. Medical condition, IQ and welfare benefits were least frequently requested. To maintain a comprehensive register of adults alone, information is likely to be needed from health authorities, social service departments, and ideally also private and voluntary organisations. Cooperation from a number of agencies and a broad mix of professionals is, therefore, essential.

What emerged clearly from the survey was that register staff should positively encourage staff outside to provide information if they are to be sources of information. It is important for register staff to inform these colleagues of the purposes, potential benefits and the rules governing access to the register's

information. Personal contact is crucial. As one planning document put it; 'nothing could be worse than to have staff complete updating forms and never meet or hear from the staff who manage the system.'

Staff should also be able to appreciate their role in the service developments which result from the register they help to maintain. A multi-agency steering group was found to be useful in building up rapport between information suppliers and the register.

Most registers enjoyed a high level of co-operation. Of the 49 registers to which more than one agency contributed information, 29 (59 per cent) were wholly positive about the cooperation that they received. If criticisms were made, they tended to be only of a paticular group. GPs were singled out most frequently for their reluctance in providing information, perhaps because they are not specialists in mental handicap and so do not regard it as a high priority. A number of registers found it difficult to maintain satisfactory data on the under-fives, often because paediatricians were reluctant to give small children definite diagnoses of mental handicap. Several registers therefore, have, not attempted to hold data on the pre-school population.

'The reason most frequently given by planners and service providers for lack of use of registers was ignorance about them and what they could be used for'

The use to which registers are being put is of singular importance yet difficult to trace through a postal survey. It is clear nevertheless that registers are not on the whole used as they might be and this appears to be a symptom of the deficiencies of joint care planning. Service planners and providers are not hostile to registers and do not feel that the information they supply is unhelpful, even if they do not always exploit them to the full. Twenty-four register operators considered that service providers and planners generally made as much use of the register as they reasonably could, while 18 felt that they did not. The reason most frequently given for lack of use was ignorance by service providers and planners about the register and what they could use it for.

There were 51 registers (86 per cent) used for planning, monitoring and evaluation of the mental handicap service; 44 (75 per cent) for finding potential clients for some service or facility; 38 (64 per cent) for providing professionals with data about individually named clients; 26 (44 per cent) for research; 25 (42 per cent) for facilitating a regular review of clients' needs; and 9 (15 per cent) had some other purpose.

Even if it was not mentioned, concern about the privacy and confidentiality of named information on registers may well have lurked behind comments about inadequate cooperation between register operators and

users. Some registers require requests for named information to be made available to people or a body outside the register, such as a joint care planning team. This causes delay for bona fide professionals needing such information. A number of registers sought the consent of clients or their parents to registration, informing them about the register. There were also variations in the range of professional staff to whom registers would release information, particularly without the prior and specific consent of the client.

Many local authorities appear to support the continued existence of a register and it is clear that many are in the process of being set up. However planning is still largely undertaken on the assumption that a group of people with mental handicap will have identical needs which can be met in identical ways. This can lead to a further erroneous assumption that people with mental handicap wish to spend all their time with others like themselves.

If a register is to be effective in helping to enhance the quality of their lives it needs to promote planning according to individual needs. It cannot be overstressed that the quality of information gathered by the register and the relationship between register operators and service providers are vital.

The postal survey has shown registers to vary immensely in their types of data, their sources, the areas they cover, the frequency with which they are updated, their method of data-collection, the number of staff working on them, and the way in which they store data. This variety cannot be just a reflection of the different requirements of different districts. Some of it is because of lack of detailed comparison of the various types of organisation of registers. This survey is being followed by detailed interviews of register operators in the hope that the overall findings will go some way to the development of a well-grounded consensus on alternative ways of running a register. □

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